

AUTISM SPECTRUM DISORDER

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Introduction

Autism Spectrum Disorder (ASD) is a life-long developmental disability that is typically diagnosed during childhood. ASD is categorized as a spectrum because there is a great range of abilities and traits found in youth diagnosed with this disorder. Some youth exhibit mild symptoms and others have much more severe symptoms. Many can also be characterized as having scatter skills, in which individuals are strong in certain areas and weaker in others.

ASD is marked by two main characteristics: difficulty in relating to others and a fixed set of interests or repetitive behaviors (Kennedy & American Psychiatric Association [APA], 2015). Youth with ASD also tend to have other communication and social challenges, such as responding inappropriately in conversations, misreading nonverbal interactions, and having difficulty building friendships appropriate to their age (APA, 2013a). Additionally, youth diagnosed with ASD may be dependent on routines and highly sensitive to changes in their environments.

In 2013, the American Psychiatric Association released the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Significant changes were made to the criteria and categories of ASD. The *DSM-5* redefined ASD as a single disorder and made other changes to the diagnostic classification of ASD. These changes are discussed in detail later in this section.

Because ASD is a developmental disability, youth diagnosed with ASD require a combination and sequence of interventions and supports. These interventions are individually planned and coordinated and are of lifelong or extended duration. Such a combination of services enables individuals with disabilities to be more active, productive, and independent.

Some youth with ASD may also have diagnosable mental health disorders. Unfortunately, it is frequently assumed that behaviors associated with co-occurring mental health disorders are related to the ASD diagnosis. This assumption can leave mental health issues untreated and exacerbate symptoms.

At its November 9, 2011, meeting, the Commission on Youth recommended that the *Collection's* section on ASD be revised to include discussion of co-occurring mental health disorders and to clarify that ASD is a neurodevelopmental disorder, not a mental health disorder. Accordingly, this revised section includes additional information about ASD, as well as co-occurring mental health disorders.

Recent Changes from the DSM-IV-TR to the DSM-5

Prior to the May 2013 publication of the *DSM-5*, disorders classified on the autism spectrum were recognized as distinct subtypes. These subtypes included: autistic disorder, Asperger's disorder, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS) (APA, 2000). With the publication of the *DSM-5*, all autism-related disorders were merged into the umbrella diagnosis of ASD (APA, 2013b).

The *DSM-5* reduced the *DSM-IV-TR's* three autism domains into two. Restrictive and repetitive behaviors and interests remain one domain, but social deficits and communication deficits have been combined into the second domain (Anderson, 2013). Several social/communication criteria were also merged and streamlined, and language delay was removed as a criteria. The strict requirement for onset before three years of age was changed to onset in the early developmental period (Volkmar et al., 2014). Moreover, because youth with ASD are so diverse in their symptoms and abilities, severity levels were assigned to each domain. Finally, youth with the social/communication deficits of ASD but with no issues with restricted and repetitive behaviors may receive a new diagnosis called social communication disorder (Anderson). The new criteria allow for a history of symptoms that may not be present currently, recognizing that through intervention or normal development some children with ASD no longer present some symptoms later in life.

Another change made to the *DSM-5* is that criteria for ASD and attention-deficit/hyperactivity disorder (ADHD) were modified to make it possible for youth to be diagnosed with both disorders (Anderson, 2013). This acknowledges the fact that many children are diagnosed with both ASD and ADHD, even though the *DSM-IV-TR* specifically stated that a diagnosis of ADHD could not be made in someone with ASD.

Concern has been expressed that some individuals previously given one of the *DSM-IV-TR* diagnoses may no longer meet *DSM-5* criteria for ASD, which may cause them to lose support services. However, the *DSM-5* definition includes the following statement:

Individuals with a well-established *DSM-IV* diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. (APA, 2013b)

The *DSM-5* is a manual for assessment and diagnosis of mental health disorders and does not include information for treatment of any disorder. In the future, more evidence supporting treatments of disorders with *DSM-5* classifications will be available as clinical studies utilizing *DSM-5* criteria are conducted. As a result, this *Collection* will reference studies that utilize *DSM-IV* diagnostic criteria to explain treatments.

Prevalence

According to current estimates, ASD is more prevalent in the pediatric population than Down syndrome, cerebral palsy, cystic fibrosis, muscular dystrophy, leukemia, pediatric aids, or juvenile diabetes (Autism Speaks, 2012; Talk About Curing Autism [TACA], 2015). To understand the scope of ASD in the United States, the Children's Health Act of 2000 authorized the Centers for Disease Control (CDC) to create the Autism and Developmental Disabilities Monitoring (ADDM) Network. ADDM Network. The CDC has been tracking ASD for over a decade through the Network.

Unless otherwise cited, information in the remainder of this section is taken from the CDC (Christensen, Baio, Braun et al., 2016). To estimate the prevalence of ASD, in 2012, the ADDM Network examined data obtained from 11 sites located in Arkansas, Arizona, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, South Carolina, Utah, and Wisconsin. The CDC determined that age eight was a reasonable index age to monitor peak prevalence because previous work has shown that, by this age, most children with ASD have been identified for services. These 11 communities were selected because of consistent population comprised over 8.5 percent of the U.S. population of eight-year-olds in 2012. After evaluating the data, the CDC found that overall estimated ASD prevalence in eight-year-old children for the 2012 surveillance year was 14.6 per 1,000 (1 in 68). Findings from the report include the following statistics:

- The percentage of children identified with ASD ranged widely across geographic area. For example, in the areas where the ADDM Network reviewed both health and special education records, the percentage of children who were identified with ASD ranged from a low of 1 in 81 (or 1.2 percent) in areas of South Carolina to a high of 1 in 41 (or 2.5 percent) in areas of New Jersey.
- ASD is almost 4.5 times more common among boys (1 in 42) than among girls (1 in 189).
- Caucasian children were more likely to be identified with ASD than African American or Hispanic children. African American children were more likely to be identified with ASD than Hispanic children.
- Among children identified with ASD who had IQ scores available, about a third also had intellectual disability.
- 87 percent of children later diagnosed with ASD had a documented developmental concern by age three, but less than half (43 percent) of those children received clinical developmental evaluations by age three.

Prior to this study, the ADDM Network estimated the following prevalence rates:

- 1 in 68 children in 2010
- 1 in 88 children in 2008
- 1 in 110 children in 2006
- 1 in 150 children in 2002 (data collected in 2000 and 2002) (Johns Hopkins Bloomberg School of Public Health, 2016).

It is not known whether the increase in prevalence of ASD indicates an upward trend in the actual incidence of the disorder or whether it reflects changes in identification and diagnosis. The CDC has noted that increasing awareness of ASD and improvements in the way children are identified, diagnosed, and served in their local communities have likely resulted in the increase in prevalence. In addition, ASD prevalence was significantly higher in ADDM Network sites that had access to education reporting sources, as compared to sites relying only on health sources for case identification (CDC, 2012). It is also worth noting that the surveillance areas are not representative of the United States as a whole. According to the *DSM-5*, increasing prevalence rates may also be related to expanded *DSM-IV* diagnostic criteria and

associated study methodology. The *DSM-5* estimates that one percent of children in the US have ASD (APA, 2013b).

Causes and Risk Factors

ASD affects youth of all racial, ethnic, and social groups. Although the causes of ASD are not yet known, it has been established that ASD is not caused by any psychological factors (National Information Center for Children and Youth with Disabilities [NICHCY], 2001). Much evidence points to a genetic basis for the disorders (Volkmar et al., 2014; Volkmar, Westphal, Gupta, & Wiesner, 2008). The number of areas affected by ASD suggests that a diverse and widely distributed set of neural systems must be affected.

The high recurrence risk for ASD in siblings, and the even higher concordance for ASD in identical twins, has provided strong support for the importance of genetic factors. Epidemiological findings reveal that ASD has heritability estimates ranging from 37 to 90 percent (APA, 2013b). As stated previously, ASD is seen more commonly in boys than girls (ratio of 4:1) and biological siblings of an affected child run a higher risk of having the disorder (APA). When evaluating siblings, when one identical twin has ASD, there is a 36 to 95 percent likelihood that the other identical twin has ASD. When one non-identical twin has ASD, there is a zero to 31 percent chance that the other twin has ASD (CDC, 2013). In non-twin siblings, when one child has ASD, there is a two to 18 percent chance that a second child will have ASD (CDC). Additionally, about 10 percent of children with ASD also have other genetic and chromosomal disorders such as Down syndrome, fragile X syndrome, or tuberous sclerosis, thus potentially linking ASD and certain genetic or chromosomal differences (CDC).

A recent study of ASD established a link between the neurotransmitter gamma-aminobutyric acid (GABA) and various symptoms of ASD. GABA inhibits brain cells from firing in response to stimuli from the outside environment (Robertson et al., 2015). The study found that, during a visual test, the brains of youth diagnosed with ASD reacted differently as compared to the brains of youth without an ASD diagnosis. This discovery offers valuable insight about ASD and the role that neurotransmitters may play.

In the recent years, there has also been a focus on searching for environmental causal factors, including immunizations, heavy metals, infectious agents, and pharmacological agents (Volkmar et al., 2008). The *DSM-5* states that a variety of nonspecific risk factors, such as advanced parental age, low birth weight, or fetal exposure to valproate (an anticonvulsant and mood stabilizer used to treat seizures and bipolar disorder and to help prevent migraine headaches), may contribute to the risk of ASD (APA, 2013b). Pre- and perinatal maternal infections and birth complications associated with ASD have also been reported with some consistency.

There has also been a focus on a possible association between childhood immunizations and ASD (Newschaffer & Curran, 2003). However, numerous studies show that vaccines do not play any role in the etiology of ASD (CDC, 2015). This is described in more detail in the Vaccines and Autism section of the *Collection*.

Studies have been conducted to identify environmental factors that may combine with or increase genetic susceptibility to ASD. Possible risk factors identified to date include:

- Deficiency in folic acid intake before conception (*American Journal of Clinical Nutrition*, Schmidt, et al. as cited by Glicksman, 2012).
- Mother's exposure to pesticides (*Environmental Health Perspective*, Shelton, et al., as cited by Glicksman, 2012).
- Mother's exposure to air pollution (*Environmental Health Perspective*, Volk, et al., as cited by Glicksman, 2012).
- Obesity in the mother (*Pediatrics*, Krakowiak, et al., as cited by Glicksman, 2012).

Diagnostic Criteria

Although the *DSM-IV* delineated categories of ASD, the *DSM-5* eliminates these categories in favor of a single diagnosis along with specifiers. A requirement for diagnosis is that the youth must meet all three behavioral criteria in the domain entitled “Social Communication & Social Interaction” and at least two of the four criteria in the domain entitled “Restrictive, Repetitive Behavior, Interests, Activities,” which are outlined in Table 1. These symptoms must be present from early childhood and limit or impair everyday functioning. However, the revised criteria allow for a history of symptoms that may not be present currently, recognizing that, because of intervention or normal development, some children with ASD no longer present some symptoms later in life. Table 1 outlines the *DSM-5* diagnostic criteria for ASD.

Table 1
DSM-5 Diagnostic Criteria for ASD

Social Communication & Social Interaction

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

Restricted, Repetitive Behavior, Interests, Activities

- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g. simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 2. Insistence on sameness, excessive adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

For A and B, current severity must also be specified. Severity is based on social communication impairments and restricted, repetitive patterns of behavior and is based on three levels defined in the DSM-5. See Table 2: Severity Levels of ASD by Domain.

Continued on next page

Table 1 (continued)
DSM-5 Diagnostic Criteria for ASD

Other Criteria

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Diagnosis should specify if:

- With or without intellectual impairment;
- With or without structural language impairment;
- Associated with a known medical/genetic condition or environmental’ factor;
- Associated with another neurodevelopmental, mental, or behavioral disorder;
- Age at first concern;
- With or without loss of established skills; and
- Severity.

Source: APA, 2013b.

The *DSM-5* also lists three levels of severity in each of the two key domains (“social communication” and “restrictive, repetitive behavior”). Severity specifiers describe separate symptoms in each of the two domains (APA, 2013b). These severity levels are outlined in Table 2.

Autism Spectrum Disorder and Co-occurring Mental Health Disorders

Recent studies have shown that mental health disorders are common and frequently multiple in children and adolescents with ASD (Ousley & Cermak, 2014; Simonoff et al., 2008). Accurate, reliable diagnosis of co-occurring mental health disorders is critical. When a youth’s symptoms can be attributed to the mental health disorder, more targeted intervention is possible (Leyfer et al., 2006).

A study that examined the adjusted odds of youth with ASD being diagnosed with a co-occurring mental health disorder found that the likelihood rose significantly with each additional year of life and as ASD severity increased. This study also revealed that potentially treatable co-occurring disorders were likely to be under diagnosed (Rosenberg, Kaufman, Law, & Law, 2011).

Table 2
Severity Levels for ASD

Severity	Social Communication	Restricted, Repetitive Behaviors
Level 3 “Requiring very substantial support”	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, if they do, makes unusual approaches to meet needs and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors that markedly interfere with functioning in all spheres. Great distress/ difficulty changing focus or action.
Level 2 “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.
Level 1 “Requiring support”	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses 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: APA, 2013b.

According to the *DSM-5*, approximately 70 percent of individuals with ASD may have one comorbid mental disorder, and 40 percent may have two or more comorbid disorders (APA, 2013b). ASD frequently coexists with intellectual impairment and structural language disorder (i.e., an inability to comprehend and construct sentences with proper grammar) (APA). In addition, using standardized assessments, researchers have found that one-third or more of individuals with ASD also meet criteria for formal ADHD diagnosis, and that the most common ADHD subtypes are the predominantly inattentive type and the combined type (Ousley & Cermak, 2014). As noted previously, when criteria for both ADHD and ASD are met, both diagnoses should be given. Youth who are nonverbal or have language deficits and experience changes in sleep or eating and increases in challenging behaviors should also be evaluated for anxiety or depression.

Unless otherwise cited, the information in the remainder of this section is taken from Volkmar et al. (2014). In most epidemiologically based samples of persons with ASD, approximately 50 percent exhibit severe or profound intellectual disability, 35 percent exhibit mild to moderate intellectual disability, and the remaining have IQs in the normal range. A range of behavioral difficulties can also be observed in youth with ASD, including hyperactivity, obsessive-compulsive behaviors, self-injury, aggression, stereotypies (repetitive or ritualistic movements, postures, or utterances), tics, and affective symptoms. The issue of whether these qualify as additional disorders is complex. Case reports and case series have also suggested possible associations with bipolar disorders, tics, and Tourette's syndrome. Medical conditions also commonly associated with ASD include epilepsy, sleep problems, and constipation (APA). Avoidant-restrictive food intake disorder is also a fairly frequent presenting feature of ASD and extreme and limited food preferences may also be present (APA, 2013b).

ASD also can co-exist with developmental coordination disorder, anxiety disorders, depressive disorders, and other comorbid disorders (APA, 2013b). Anxiety symptoms are one of the top treatment concerns of parents and clinicians. Parents report a high level of anxiety symptoms experienced in relation to their child's inability to accept changes in daily routines, to transition from one activity to another, to accept redirection from perseverative behaviors, or to tolerate environmental stimuli such as particular sounds. Parents also report the presence of anxiety symptoms that seem unrelated to core ASD symptoms, including specific fears, social phobia, and obsessive-compulsive behaviors.

Successful early intervention for those diagnosed with ASD includes the identification of co-occurring mental health symptoms in the toddler years (Matson, 2010). Research in this area has shown that toddlers diagnosed with ASD have more symptoms related to tantrum/conduct behavior, inattention/impulsivity, avoidance behavior, anxiety/repetitive behavior, and eating/sleep problems when compared with their same-aged peers without an ASD diagnosis who were also developing atypically. In older children diagnosed with ASD, findings have been similar.

Co-occurring mental health disorders in youth with ASD can be difficult to diagnose. This is because communication with the child or adolescent may be impaired; almost half of youth diagnosed with ASD are functionally nonverbal (Leyfer et al., 2006). Moreover, youth with ASD may also have a cognitive difficulty, which makes it difficult for them to describe their mental state. Thus, it is challenging to ascertain whether the youth's difficulties originate from the core features of their ASD or from the attributes of a co-occurring mental health disorder (Leyfer et al.). Accordingly, it may be prudent to incorporate an assessment for a co-occurring mental health disorders upon diagnosis of an ASD (Simonoff et al., 2008).

Identification and treatment of co-occurring mental health disorders in youth with ASD can result in better outcomes versus only addressing the youth's ASD symptoms (Leyfer et al., 2006). Please refer to the appropriate sections of the *Collection* for additional information on evidence-based and promising practices for the co-occurring mental health disorders discussed in this section.

Early Warning Signs

Though ASD is often not diagnosed until the age of three, some children begin to show signs of developmental delay much earlier. Early identification of these signs is critical to assist in early diagnosis and intervention.

The list below contains the early warning signs published by the American Academy of Pediatrics (AAP, 2006) to aid parents and professionals with early identification and, consequently, early intervention. These are:

- Not turning when the parent says the child's name;
- Not turning to look when the parent points and says, "look at..." and not pointing themselves to show parents an interesting object or event;
- Lack of back and forth babbling;
- Smiling late; and
- Failure to make eye contact with people.

According to the AAP (2006), the following signs warrant immediate attention:

- No babbling, pointing, or other gestures by 12 months;
- No single words by 16 months;
- No two-word phrases by 24 months; and
- Regression or loss of language or social skills at any age.

It is important to understand that there is variability in the age at which children may present the features essential for this diagnosis. As noted previously, preschool children with ASD typically present with marked lack of interest in others, failures in empathy, absent or severely delayed speech and communication, marked resistance to change, restricted interests, and stereotyped movements (Volkmar et al., 2014). Common parental concerns include a child's lack of language, inconsistencies in responsiveness, or concern that the child might be deaf. In children with ASD, social and communication skills usually increase by school age; however, problems dealing with change and transitions, and various self-stimulatory behaviors (sometimes including self-injury), also may become more prominent during this time (Volkmar et al.). In adolescence, a small number of individuals with ASD make marked developmental gains; however, another subgroup may behaviorally deteriorate (e.g., tantrums, self-injury, or aggression). Earlier detection and provision of services improves long-term prognosis, thus making early diagnosis particularly important.

Screening and Assessment

Multiple professional societies in the medical and child developmental fields have published specific practice parameters for the assessment and screening of ASD. There is some disagreement among these societies whether universal screening should be conducted.

The American Academy of Family Physicians has concluded that the current evidence is insufficient to assess the balance of benefits and harms of screening for ASD in children for whom no concerns of ASD have been raised by their parents or clinical provider (American Academy of Family Physicians, as cited by the U.S. Preventive Services Task Force, 2016). Moreover, the United Kingdom National Screening Committee does not recommend systematic population screening, citing concerns about the stability of ASD diagnosis at a young age, lack of data on positive predictive value, and weakness of the evidence for the efficacy of treatment (United Kingdom National Screening Committee, as cited by the U.S. Preventive Services Task Force).

The American Academy of Neurology and the Child Neurology Society recommends that routine developmental surveillance be performed on all children to identify those at risk for any type of atypical development, followed by screening specifically for ASD using a validated screening instrument (Filipek et al., as cited by the U.S. Preventive Services Task Force, 2016). The American Academy of Child and Adolescent Psychiatry (AACAP) also recommends that both the developmental assessment of young children and the psychiatric assessment of all children should routinely include questions about ASD symptomatology (Volkmar, et al., as cited by the U.S. Preventive Services Task Force), and that such practices should be clinical standards (Volkmar et al., 2014). Screening should include inquiries about the core symptoms of ASD, including social relatedness and repetitive or unusual behaviors. Screening is applicable to young children and to infants, when the diagnosis may first be considered. In some

instances, screening may be relevant to older children, for example, those who are more intellectually able and whose social disability is therefore more likely to be detected later. The AACAP further recommends that if screening indicates significant ASD symptomatology, a thorough diagnostic evaluation should be performed to determine the presence of ASD (Volkmar et al.).

The American Academy of Pediatrics’ Bright Futures Guidelines recommends universal screening for ASD in all children at ages 18 and 24 months in addition to developmental surveillance and monitoring (Committee on Practice and Ambulatory Medicine; Bright Futures Periodicity Schedule Workgroup, 2015). The Guidelines reflect the belief that, in order for screening to be effective, it must be applied to all children, not only those with symptoms. Screening should follow the American Academy of Pediatrics (AAP) 2007 Statement “Identification and Evaluation of Children with Autism Spectrum Disorders” (Committee on Practice and Ambulatory Medicine; Bright Futures Periodicity Schedule Workgroup). The Bright Futures Guidelines assert that that all children be screened for developmental delays and disabilities during regular well-child doctor visits at 9, 18, and 24 or 30 months. Additional screening might be needed if a child is at high risk for developmental problems because of preterm birth or low birth weight (Johnson et al., 2007).

In addition, all children should be screened specifically for ASD during regular well-child doctor visits at 18 and 24 months. Additional screening might be needed if a child is at high risk for ASD (e.g., having a sibling with ASD) or if symptoms are present (Johnson et al., 2007).

The AAP has outlined two levels of screening (Johnson et al., 2007). Level 1 screening is developmental surveillance that should be performed on all children. It involves identifying children at-risk for any type of developmental disability. If the Level 1 screening raises any cause for concern, the child should then be referred to the next level of screening (New York State Department of Health Bureau of Early Intervention, 2013). Table 3 presents the available evidence-based Level 1 screening measures.

**Table 3
Level 1 Screening Instruments**

Screening Tool	Age	Format (# of Items)
Checklist for Autism in Toddlers (CHAT)	18–24+ months	Parent interview or questionnaire and interactive (parent: 9; clinician: 5)
CHAT, Denver Modifications	18–24+ months	Parent interview or questionnaire and interactive (parent: 9; clinician: 5)
Checklist for Autism in Toddlers-23 (CHAT-23)	16–86 months (all had mental ages of 18–24 months)	Parent interview or questionnaire and interactive (parent: 23, clinician: 5)
Childhood Asperger Syndrome Test (CAST)	4–11 years	Questionnaire completed by parent (37)
Modified Checklist for Autism in Toddlers (M-CHAT)	16–48 months	Questionnaire completed by parent (23)
Pervasive Developmental Disorders Screening Test-II, Primary Care Screener (PDDST-II PCS)	18–48 months	Questionnaire completed by parent (22)

Source: Johnson et al., 2007.

Level 2 screening of children is for those children already identified to be at risk for a developmental disorder and involves both a diagnostic evaluation and more in-depth investigation (Johnson et al, 2007). At this level, a distinction is made between ASD and other developmental disabilities and includes evaluation by ASD specialists. The goal is to determine the best means of intervention based on the child's profile of strengths and weaknesses (New York State Department of Health Bureau of Early Intervention, 2013; Siegel et al., 1998). Table 4 presents the available evidence-based Level 2 screeners/diagnostic tools for ASD.

Table 4
Level 2 Screening Instruments

Screening Tool	Age	Format (# of Items)
Asperger Syndrome Diagnostic Scale (ASDS)	5–18 years	Questionnaire completed by parent, teacher, or clinician (50)
Autism Behavior Checklist (ABC)	≥18 months	Behavioral checklist completed by interviewer (57)
Autism Quotient (AQ)–Adolescent Version	11–16 years	Questionnaire completed by parent (50)
Autism Spectrum Screening Questionnaire (ASSQ)	6–17 years	Questionnaire completed by parent (27)
Childhood Autism Rating Scale (CARS)	>2 years	Behavioral checklist completed by trained interviewer/ observer (15)
Gilliam Asperger's Disorder Scale (GADS)	3–22 years	Questionnaire completed by parent, teacher, or clinician (32)
Gilliam Autism Rating Scale–2nd Edition (GARS-2)	3–22 years	Questionnaire completed by parent or teacher (42)
Krug Asperger's Disorder Index (KADI)	6–21 years	Questionnaire completed by parent or clinician (32)
Pervasive Developmental Disorders Screening Test-II, Developmental Clinic Screener (PDDST-II, DCS)	18–48 months	Questionnaire completed by parent (14)
Pervasive Developmental Disorders Screening Test-II, Autism Clinic Severity Screener (PDDST-II, ACSC)	18–48 months	Questionnaire completed by parent (12)
Screening Tool for Autism in Two-Year-Olds (STAT)	24–36 months	Interactive, requires specific training (12)

Source: Johnson et al., 2007.

Once a child has been recognized during the screening process as being at risk for ASD, a detailed assessment should be completed to establish a diagnosis. There are several considerations important to the assessment process.

- A developmental perspective must be maintained. Since ASD is characterized by an unevenness in development that varies over the lifespan (Ozonoff, Goodlin-Jones, & Solomon, 2005), studying a child within a developmental framework provides a benchmark for understanding the severity or characteristics of delays and deviances.
- Evaluating a child with ASD should include obtaining information from multiple sources and contexts, as symptoms of ASD may be dependent on characteristics of the environment (Ozonoff, Goodlin-Jones, & Solomon). Measures of parent report, teacher report, and child observation across settings; cognitive and adaptive behavior assessments; and clinical judgments may all factor into a comprehensive assessment of ASD (Filipek et al., 1999).
- Assessments of ASD must be multidisciplinary whenever possible. They should incorporate findings from professionals in the fields of psychology, psychiatry, neurology, pediatrics, speech, and language (Ozonoff, Goodlin-Jones, & Solomon).

There are three major diagnostic challenges in the comprehensive assessment of a child with a suspected ASD. These are:

1. Determining the child's overall level of functioning;
2. Making the categorical diagnosis of ASD; and
3. Determining the extent of the search for an associated etiology (Johnson et al., 2007).

As discussed, the evaluation should include information from multiple sources because the child's performance may vary among settings and caregivers. In order to accomplish these three goals, a comprehensive evaluation should include the following components:

1. Health, developmental, and behavioral histories that include at least a three-generation family pedigree and a review of systems
2. A comprehensive physical examination
3. Developmental and/or psychometric evaluations (depending on age/skill level) to determine the child's overall level of functioning and whether a discrepancy between motor-adaptive problem-solving and social communication skills is evident
4. The determination of the presence of a categorical *DSM-5* diagnosis, preferably with standardized tools that operationalize the *DSM-5* criteria
5. Assessment of the parents' knowledge of ASD, their coping skills, and available resources and supports
6. If the child has clinical features that are characteristic of a specific genetic or neurologic disorder that can be easily confirmed by a specific laboratory test, then the clinician may want to proceed with a laboratory investigation to search for a known etiology or coexisting condition guided by information obtained (Johnson et al., 2007)

The AACAP Practice Parameter, which was revised in 2014 and replaces those released in 1999, offers the following recommendations as clinical standards when assessing youth for ASD:

- Recommendation 1. The developmental assessment of young children and the psychiatric assessment of all children should routinely include questions about ASD symptomatology.
- Recommendation 2. If the screening indicates significant ASD symptomatology, a thorough diagnostic evaluation should be performed to determine the presence of ASD.
- Recommendation 3. Clinicians should coordinate an appropriate multidisciplinary assessment of children with ASD (Volkmar, et al., 2014).

Various instruments for the assessment of ASD have been developed and are outlined in Table 5. The AACAP Practice Parameter asserts that all of these instruments vary in their usefulness for usual clinical

practice and that these instruments may need to be revised to provide evidence of validity for *DSM-5* ASD criteria. (Volkmar et al., 2014).

Table 5
Summary of Selected Assessment Instruments
for Autism Spectrum Disorder

Scale	Uses	Age Range	Method of Administration
Autism Behavior Checklist (ABC)	screening	children	parent rated
Childhood Autism Rating Scale (CARS)	screening	children	clinician rated
Checklist for Autism in Toddlers (M-CHAT)	screening	toddlers	parent rated
Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler (CSBS-DP-IT) Checklist	screening	toddlers	parent rated
Autism Screening Questionnaire (ASQ)	screening	child/adult	parent rated
Autism Quotient (AQ)	screening	child/adult	self or parent rated
Childhood Autism Screening Test (CAST)	screening	4–11 years	parent rated
Asperger Syndrome Diagnostic Scale (ASDS)	screening	5–18 years	parent or teacher rated
Gilliam Asperger's Disorder Scale (GADS)	screening	3–22 years	parent or teacher rated
Asperger Syndrome Diagnostic Interview (ASDI)	screening	child/adult	interview + clinician rated
Social Responsiveness Scales (SRS)	screening	4–18 years	parent or teacher rated
Autism Diagnostic Interview–Revised (ADI)	diagnostic	child/adult	interview + clinician rated
Diagnostic Interview for Social and Communication Disorders (DISCO)	diagnostic	child/adult	interview + clinician rated
Autism Diagnostic Observation Schedule (ADOS)	diagnostic	child/adult	semi-structured interactive session

Source: Volkmar et al., 2014.

General Principals for Intervention

Serving a child with ASD is determined by the child's individual needs. A combination of three principles can improve outcomes for youth with ASD, lessen challenging behavior, and provide the child with maximum independence. These are highlighted in the paragraphs that follow.

Early Intervention

Evidence from various diagnosis and intervention research suggests that early detection of ASD is key to improving developmental outcomes (Brasic, 2015; Goin-Kochel & Myers, 2005; Dawson & Osterling, 1997). Early detection leads to early intervention, and for youth with ASD, participation in specialized intervention programs can optimize long-term outcomes (Volkmar et al., 2014). Some young children with ASD who receive early intervention have shown significant improvements in cognitive, social, and language functioning as compared to older children who undergo the same interventions (Rogers, 1998).

Evidence has shown that both younger age and more intervention hours positively affect developmental rates (Volkmar et al., 2014). Studies conducted on one specific research-proven intervention for very young children with ASD found that children aged 18 to 30 months participating in the treatment program significantly improved their IQs, social interaction, and language abilities (Pediatrics, Dawson, et al., as cited by Glicksman, 2012). Additional studies have underscored that it may be the earliness of the intervention, rather than the method itself, that leads to positive outcomes (Glicksman).

Educational Intervention

Early diagnosis and appropriate educational programs are important for youth with ASD. The appropriate goals for educational services for children with ASD are the same as those for other children. Part B of the Individuals with Disabilities Education Act (IDEA) (Public Law 94-142, Public Law 99-457, and Public Law 102-119) requires that children with a disability receive a free and appropriate education (FAPE). Children with ASD may have behavioral and communication challenges that interfere with learning. Therefore, they may benefit from an Individualized Education Program (IEP), as provided for under IDEA. The Autism Society of America recommends that IEPs are structured so that they can be carried out both at home and school (2002). Children with a disability from birth through the age three are also eligible for early intervention services under Part C of IDEA. In Virginia, parents with children between ages two and three can choose for their child to stay in Part C, early intervention services, or transition to Part B services.

Infant/toddler services under Part C of IDEA can be home-based, center-based, or a combination. The nature of the services is determined based on an assessment of the child and the family's priorities. The services provided in response to this plan may include the identification of appropriate assistive technology, intervention for sensory impairments, family counseling, parent training, health services, language services, health intervention, occupational therapy, physical therapy, case management, and transportation to services (Biasini et al., 1999).

In Virginia, the Virginia Department of Behavioral Health and Developmental Services (VDBHDS) is the lead agency that administers Part C of IDEA. Virginia's statewide early intervention system is called the Infant & Toddler Connection of Virginia. In Virginia, children from birth to age three are eligible for Part C early intervention services:

- If they have a 25-percent developmental delay in one or more areas of development;
- If they have atypical development; or
- If they are diagnosed with a physical or mental condition that has a high probability of resulting in a developmental delay (Virginia Board for People with Disabilities, 2014).

As noted previously, parents in Virginia with children between ages two and three can choose that their child to remain in Part C so that they can continue receiving early intervention services. However, once the child reaches the age of three, special education programs established by Part B of IDEA are available for the child and family (NICHCY, 2009). The services provided through IDEA to school-aged children are most often provided in home-based, center-based, or naturally occurring environments. An IEP is developed based on team evaluation and parental input. This plan describes the objectives for improving the child's skills and may include family or parent-focused activities. These services must also be provided in the least restrictive setting possible, but must provide for a continuum of placements that includes instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions. Some students with ASD who receive special education services need accommodations or modifications to their educational program in order to participate in the general curriculum and to be successful in school.

Section 504 of the Rehabilitation Act of 1973, as amended, prohibits discrimination based on a physical or mental impairment that substantially limits a major life activity (Virginia Department of Education,

n.d.; Missouri Autism Guidelines Initiative [MAGI], 2012). Section 504 prohibits discrimination on the basis of handicap in any program or activity receiving federal financial assistance. A qualified child under Section 504 applies to a broader population than the definition of a child with a disability under IDEA. A qualified child under Section 504 is any person who meets one or more of the following criteria:

- Has a physical or mental impairment that substantially limits one or more major life activities
- Has a record of such an impairment
- Is regarded as having such an impairment (Virginia Department of Education)

Under Section 504, it is frequently necessary to provide accommodations or modifications to the setting or education program to allow an eligible student to access education without discrimination. In this context, the term accommodation refers to teaching supports and services that a student may require to access the curriculum (MAGI, 2012).

Family-centered Approach

Family involvement is a critical element of a child's educational program. A multi-disciplinary and family-focused approach, in which the service providers and the parents work in a collaborative manner to develop appropriate interventions for the child, is considered the most effective method of service delivery for children with ASD and their families (Volkmar et al., 2014; Volkmar et al., 1999). A family-centered approach employs the expertise of the family regarding the strengths and needs of the child.

For very young children, issues of diagnosis and identification of appropriate treatment programs will often be most the most important factors (Volkmar et al., 2014). For school-age children, psychopharmacologic and behavioral issues may become more prominent, whereas for adolescents, transition from middle/secondary education to postsecondary education and employment, along with planning for independence, is important (Volkmar et al., 2014). As part of this long-term engagement, parents and siblings of children with ASD will need support.

About Evidence-based Practices

There are two important resources that detail evidence-based practices and resources for children and adolescents diagnosed with ASD. Both of these initiatives were undertaken to provide information to clinicians, family members, and others because treatments for ASD are diverse and interventions with no scientific evidence were being recommended for children and adolescents with ASD (England, 2015). These two resources are discussed in the following paragraphs.

In 2008, the National Professional Development Center on Autism Spectrum Disorders (NPDC) conducted an extensive review of the autism intervention literature published between 1997 and 2007 and identified evidence-based practices for children and youth with ASD. The project utilized strict criteria relating to evidence-based practices. In 2014, the NPDC released findings from a follow-up review of studies from 1990-2011 and identified 27 practices that meet the criteria for evidence-based practice (Wong et al., 2013). The NPDC is currently developing online modules for each of the 27 identified practices.

In addition, the National Standards Project has published two reports that detail evidence-based interventions for ASD based on behavioral and educational studies. The National Autism Center first launched the project in 2005 to address the need for evidence-based practice guidelines for ASD. The National Standards Project has had the support and guidance of an expert panel composed of nationally recognized scholars, researchers, and other leaders representing diverse fields of study. Phase 1 of the National Standards Project was published in 2009. The second phase of the National Standards Project was launched in 2011 in order to provide up-to-date information on the effectiveness of a broad range of interventions for ASD (National Autism Center, 2015). The Phase 2 findings were published in 2015 and

identified 14 interventions for children and adolescents that have sufficient evidence of effectiveness. Between Phase 1 and Phase 2, several interventions were moved from the “What Seems to Work” category to the “What Works” category.

Analysis of both resources conducted by the California Autism Professional Training and Information Network (CAPTAIN) has noted very little difference between the reviews conducted by these two initiatives (England, 2014). The NPDC lists interventions separately, whereas the National Standards Project discusses treatments as intervention strategies, or classes, that are clustered into packages (England). There is considerable overlap between the NPDC and the National Standards Project, with a majority of the interventions being included in both resources. The consistent theme that emerges from both projects is the importance of selecting interventions that are sufficient in their intensity and that are individualized to meet the needs of the child and the family.

What Works – Evidence-based Practices

The treatments outlined in the following paragraphs are taken from the National Autism Center’s National Standards Project (2015).

Behavioral Interventions

The researchers found that behavioral interventions were classified as the most effective for children and adolescents with ASD (Arick, 2015). The behavioral intervention category is comprised of interventions described as antecedent interventions and consequent interventions. Antecedent interventions involve the modification of situational events that may precede the occurrence of a target behavior. These alterations are made to increase the likelihood of success or reduce the likelihood of problems occurring. Consequent interventions involve making changes to the environment following the occurrence of a targeted behavior. Many of the consequent interventions are designed to reduce challenging behavior and teach functional alternative skills through the application of basic principles of behavior change.

Discrete Trial Teaching or Training (DTT)

DTT is a behavioral intervention that focuses on the principles of operant learning to intervene with children with ASD. In DTT, children learn appropriate responses to the presence of specific words and environmental stimuli. DTT may also be called the ABC model, whereby every trial or task given to the child to perform consists of an antecedent (directive or request to the child to perform an action), behavior (response from child), and consequence (reaction from therapist). Teaching trials are repeated many times, initially in rapid succession, until the child performs a response readily, without adult-delivered prompts (Green, 1996). A pause to separate trials from each other, called the inter-trial interval, is essential. Data is kept on multiple trials, and the child moves on to additional tasks as the old ones are mastered. The child’s responses are recorded and evaluated according to specific, objective definitions and criteria. Timing and pacing of teaching sessions, practice opportunities, and consequences delivery are designed precisely for each child’s learning pace and style to help ensure success (Green). To maximize those successes, emerging skills are practiced and reinforced in many less-structured situations. For some high-functioning children with ASD, certain skills can be taught entirely in relatively unstructured environments from the outset (Green). However, to ensure that these “naturalistic” practices occur frequently, the practice opportunities have to be arranged carefully and reinforcers given consistently. The overall emphasis is on teaching the child how to learn in a traditional environment and how to act on that environment in ways such that there are consistently positive outcomes for the child, their family, and others (Green; Lovaas, 1987; Lovaas & Smith, 1989).

Cognitive Behavioral Intervention Package

Cognitive behavioral therapy has long been an evidence-based intervention for individuals diagnosed with anxiety disorders and depressive disorders (i.e., without ASD). There are manualized cognitive behavioral intervention programs that have been modified for youth and adolescents with ASD. These modifications can take different forms but usually involve making adjustments to materials (e.g., adding visual cues, role-play) or the structure of sessions. There are also cognitive behavioral intervention programs developed and individualized for specific purposes (e.g., to address anger management). Cognitive behavioral interventions often include several commonly used strategies that include:

- An educational component describing feelings/emotions, physical responses to emotions, and prevalence of individuals with similar challenges.
- A cognitive restructuring component in which the therapist assists the individual to modify cognitive distortions such as “all-or-nothing” thinking or “catastrophizing.”
- Development of scale to identify anxiety or distress. Some scales take the form of a thermometer, a ladder, or “volume control.”
- Homework assignments. Individuals are expected to work on skills in the home, school, and community setting. There may be a specific assignment that requires some type of recording of behavior or observations.
- Parent sessions. Cognitive behavioral interventions often take place for 45 minutes to one hour per week for a specified number of weeks (e.g., 16 weeks). During that time, there are often “parent sessions” in which the parents and therapist meet to discuss progress and strategies to support the individual with ASD.

Some of the manualized cognitive behavioral intervention packages modified in studies reviewed in the NSP2 included The Coping Cat Program and Exploring Feelings.

Comprehensive Behavioral Treatment for Young Children (CBTYC)

CBTYC programs involve intensive early behavioral interventions that target a range of essential skills that are associated with ASD (e.g., communication, social, and pre-academic/academic skills, etc.). These interventions are often described as applied behavior analysis (ABA), early intensive behavioral intervention (EIBI), or behavioral inclusive programs.

Applied Behavior Analysis (ABA)

In his mental health report for children, the U.S. Surgeon General recognized applied behavior analysis (ABA) as the intervention of choice for ASD (Rosenwasser & Axelrod, 2001). ABA, also called behavioral intervention or behavioral treatment, has consistently been recognized as one of the most well-researched and effective intervention techniques for children—especially young children—with ASD (Lovaas, 1987; Dawson & Osterling, 1997; Rogers, 1998; Smith, Groen, & Wynn, 2004). According to Green (1996), ABA can be used effectively to produce comprehensive and lasting improvements in many important skill areas for most children with ASD, regardless of their age. ABA, however, is most beneficial when intervention starts before three years of age (Dawson & Osterling; Lovaas & Smith, 2003) and the child undergoes intensive behavior therapy at least 15 hours a week (Dawson & Osterling).

Language Training (Production)

Language training (production) targets the ability of the individual with ASD to communicate verbally (i.e., functional use of spoken words). Language training (production) has recently been moved from the “What Seems to Work” to the “What Works” category. It makes use of various strategies to elicit verbal

communication from individuals with ASD and begins with appropriate assessment and identification of developmentally appropriate targets. Individualized programs often include strategies such as:

- Modeling verbalizations for the individual with ASD to imitate;
- Various prompting procedures including verbal, visual, and gestural prompts;
- Cue-Pause-Point;
- Using music as part of language training; and
- Reinforcement for display of targeted verbal response.

Modeling

The goal of modeling is to correctly demonstrate a target behavior to encourage imitation. Children can learn a great deal from observing the behavior of parents, siblings, peers, and teachers, but they often need to be taught which behaviors should be imitated. There are two types of modeling: live and video modeling. Live modeling occurs when a person demonstrates the target behavior in the presence of the child. Video modeling occurs when the target behavior is pre-recorded. Video modeling can be a great option for children and adolescents who have an affinity for television shows and movies, or who have an interest in seeing themselves on a monitor. Some children and adolescents may enjoy assisting in the production of the video.

Naturalistic Teaching Strategies (NTS)

NTS are a compilation of strategies that are used to teach children skills in their home, school, and community. The basic concepts include using materials in the environment and naturally occurring activities as opportunities to increase adaptive skills. These strategies are primarily child-directed.

Parent Training Package

The parent training package category is an addition to the interventions discussed in the Phase 1 report. Parent training package focuses on the elements of the interventions used in studies in which parents acted as therapists or received training to implement various strategies. This intervention acknowledges the critical role that parents and caregivers play in providing a therapeutic environment for their family members with ASD.

Peer Training Package

Difficulty interacting appropriately with peers is a commonly reported characteristic of ASD, and children with ASD often rely on adults for prompting and guidance. Peer training packages facilitate skill growth for children with ASD by training peers on how to initiate and respond during social interactions with the child with ASD. These programs have been used in school and community settings.

Learning Experience: An Alternative Program (LEAP)

LEAP is a peer-based educational program that embraces the educational and therapeutic value of peer-mediated interventions (Kohler et al., 2005). According to Campbell et al. (2008), LEAP provides classroom instruction, parent education (as needed), and the provision of speech and occupational therapy and other services within the classroom. The range of activities varies from quiet to active, from small group to larger group, and from child- versus teacher-directed. LEAP instruction is data-driven, individualized, and focused on generalizing learning skills through saturation of learning opportunities throughout the day. Family involvement is highly encouraged in this model and entails providing classroom support and instruction. In addition, families are asked to participate in curriculum development for the teaching of core behavioral principles that increase desirable behaviors and decrease maladaptive behaviors. Peers are also actively involved in the curriculum as intervention agents. According to Campbell et al., through the use of the LEAP

curriculum, children with ASD have shown decreases in ASD symptoms and long-term improvements in educational, cognitive, developmental, and social domains (Hoyson, Jamieson, & Strain, 1984; Strain & Hoyson, 2000).

Pivotal Response Training (PRT)

PRT focuses on targeting pivotal behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues. Key to the delivery of PRT is parent involvement and implementation in the natural environment such as the home, community, and school setting. The development of PRT in part has resulted from findings from the DTT literature (Campbell et al., 2008). PRT is based on the theory that, if improvements in functioning can be achieved in the areas that are most disabling to children (i.e., pivotal areas), then effects should extend to other areas (Campbell et al.). Pivotal areas of intervention in PRT include teaching children to respond to multiple environmental cues and increasing motivation, capacity for self-management, and self-initiations. PRT has gained increasing evidence-based support in recent years (Campbell et al.; Sherer & Schreibman, 2005) and is now considered one of the more effective and proven interventions for children with ASD.

Schedules

Schedules can be used for children with ASD to increase their independence and allow them to plan for upcoming activities. A schedule simply identifies the activities that must be completed during a given time period and the order in which these activities should be completed. Children with ASD may better handle transitions when they can predict what will happen next. This can be accomplished through the use of schedules. Schedules can be used anywhere — at home, in classrooms, during doctors' visits, or on community outings. Schedules also can be used for any activity — including leisure time, social interaction, self-care, and housekeeping tasks. It is important for children and adolescents to possess prerequisite skills of picture identification (when using pictures) or reading (when using words/phrases) when considering use of schedules.

Scripting

Scripting occurs when a youth with ASD is provided guidance as to how to use language to initiate or respond in certain situations. These interventions involve developing an oral and/or written script about a specific skill or situation that serves as a model for the child. Scripts are usually practiced repeatedly before the skill is used in the actual situation. Scripting has recently been established as an effective treatment (What Works).

Self-Management

Self-management strategies have been widely used to promote independence with tasks in which adult supervision is not needed, accepted, or expected. The process can involve teaching youth with ASD to evaluate and record their performance while completing an activity. Self-management is also used to help these individuals monitor social behaviors and disruptive behaviors. These strategies involve teaching individuals to gain access to preferred items/activities for a job well done.

Social Skills Package

Social skills refer to a wide range of abilities, such as making eye contact appropriately, using gestures, reciprocating information, and initiating or ending an interaction. The challenges individuals with ASD face regarding social skills vary greatly. The general goal of any social skills package intervention is to provide individuals with the skills necessary to participate meaningfully in social environments.

Story-based Intervention

Story-based interventions identify a target behavior and involve a written description of the situations under which specific behaviors are expected to occur. Most stories aim to increase perspective taking skills and are written from an “I” or “some people” perspective. The most well-known story-based intervention is Social Stories.

What Seems to Work

As outlined in the National Standards Project, emerging interventions (What Seems to Work) are those interventions for which one or more studies suggest they may produce favorable outcomes but additional high quality studies are needed to consistently show these interventions are effective (National Autism Center, 2015). The National Standards Project identified 18 such treatments. Based on the available evidence, these treatments should be considered by a decision-making team if treatments classified as effective (What Works) are unsuccessful in producing positive outcomes.

As outlined by the National Standards Project, research findings have shown that the following practices have emerging support (What Seems to Work) for treating ASD.

Augmentative and Alternative Communication Devices

Augmentative and alternative communication is any form of communication that individuals use if they are unable or unwilling to use standard forms of communication such as speech (Research Autism, 2015). Augmentative communication systems are designed to complement and/or enhance standard means of communication. Examples include, but are not restricted to, pictures, photographs, symbols, communication books, and computers or other electronic devices (National Autism Center, 2009).

Developmental Relationship-based Treatment

These treatments involve a combination of procedures that are based on developmental theory and emphasize the importance of building social relationships. These treatments may be delivered in a variety of settings (e.g., home, classroom, community). All of the studies falling into this category met the strict criteria of (a) targeting the defining symptoms of ASD, (b) having treatment manuals available, (c) providing treatment with a high degree of intensity, and (d) measuring the overall effectiveness of the program (National Autism Center, 2009). These treatment programs may be referred to by other names such as floor time, DIR (differential, individual differences, relationship-based), or relationship development intervention (RDI). Floor time has become a popular intervention among parents, but it continues to lack scientific evidence (Lindgren & Doobay, 2011). Accordingly, floor time is listed in the Unproven Practice section.

Exercise

These interventions involve an increase in physical exertion as a means of reducing problems behaviors or increasing appropriate behavior (National Autism Center, 2009).

Exposure Package

These interventions require that the individual with ASD increasingly face anxiety-provoking situations. At the same time the use of maladaptive strategies used in the past is prevented (National Autism Center, 2009). Exposure treatment involves exposing youth to the non-dangerous situations that they fear, with a focus on having them learn that their anxiety will decrease over time.

Functional Communication Training (FCT)

FCT is a behavioral method that replaces disruptive or inappropriate behavior with more appropriate and effective communication (Lindgren & Doobay, 2011). After the communicative functions of disruptive behaviors are determined through functional behavioral analysis, socially appropriate behaviors are taught as replacements for problem behaviors. FCT has been shown to significantly reduce problem behavior and to increase communication and social interaction. This intervention is very effective with young children with limited cognitive and language skills, but it can be used with individuals of all ages. When delivered through weekly training sessions with parents and their children, FCT can be a very effective and efficient intervention strategy for reducing problem behavior and increasing communication and social behavior (Lindgren & Doobay).

Imitation-based Intervention

These interventions rely on adults imitating the actions of a child (National Autism Center, 2009).

Initiation Training

These interventions involve directly teaching individuals with ASD to initiate interactions with their peers (National Autism Center, 2009).

Language Training (Production & Understanding)

These interventions have as their primary goals to increase both speech production and understanding of communicative acts. Examples include total communication training, position object training, position self-training, and language programming strategies (National Autism Center, 2009).

Massage Therapy

This intervention involves the provision of deep tissue stimulation (National Autism Center, 2009).

Multi-component Package

These interventions involve a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations. These treatments do not better fit one of the other treatment packages discussed in this section nor are they associated with specific treatment programs (National Autism Center, 2009).

Music Therapy

These interventions seek to teach individual skills or goals through music. A targeted skill (e.g., counting, learning colors, taking turns, etc.) is first presented through song or rhythmic cuing and music is eventually faded (National Autism Center, 2009).

Picture Exchange Communication System

This treatment involves the application of a specific augmentative and alternative communication system based on behavioral principles that are designed to teach functional communication to children with limited verbal and/or communication skills (National Autism Center, 2009).

Reductive Package

These interventions rely on strategies designed to reduce problem behaviors without increasing alternative appropriate behaviors. Examples include water mist, behavior chain interruption (without attempting to increase an appropriate behavior), protective equipment, and ammonia (National Autism Center, 2009).

Sign Instruction

These interventions involve the direct teaching of sign language as a means of communicating with other individuals in the environment (National Autism Center, 2009).

Social Communication Intervention

These psychosocial interventions involve targeting some combination of social communication impairments (such as pragmatic communication skills, or the inability to successfully read social situations). These treatments may also be referred to as social pragmatic interventions (National Autism Center, 2009).

Structured Teaching

This intervention involves a combination of procedures that rely heavily on the physical organization of setting, predictable schedules, and individualized use of teaching methods. These procedures assume that that modifications can make thinking, learning, and understanding easier for people with ASD if they are adapted to individual learning styles of autism and individual learning characteristics. All of the studies falling into this category met the strict criteria of (a) targeting the defining symptoms of ASD, (b) having treatment manuals, (c) providing treatment with a high degree of intensity, and (d) measuring the overall effectiveness of the program (e.g., conducting studies that measure subcomponents of the program). These treatment programs may also be referred to as TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children) (National Autism Center, 2009).

Technology-based Intervention

These interventions require the presentation of instructional materials using the medium of computers or related technologies. Examples include Alpha Program, Delta Messages, the Emotion Trainer Computer Program, or use of a pager, a robot, or a PDA (Personal Digital Assistant) or other hand-held mobile device. The theories behind technology-based treatments may vary but they are unique in their use of technology (National Autism Center, 2009).

Theory of Mind Training

This training is designed to teach individuals with ASD to recognize and identify mental states in oneself or in others and to be able to take the perspective of another person in order to predict their actions (National Autism Center, 2009).

Pharmacological Interventions

Although pharmacological interventions cannot cure ASD, they may be considered for challenges such as aggression, self-injurious behavior, repetitive behaviors, sleep disturbance, anxiety, hyperactivity, inattention, destructive behavior, or other maladaptive behaviors (Myers, Johnson & the Council on Children with Disabilities, 2007). Pharmacologic interventions may increase the ability of youth with ASD to benefit from educational and other interventions and to remain in a less restrictive environment through the management of severe and challenging behaviors (Volkmar et al., 2014). After treatable medical causes and environmental factors have been ruled out, medication may be considered when behavioral symptoms cause significant impairment in functioning. It is important to note that these drugs do not alter or improve core ASD characteristics.

Antipsychotics (e.g., risperidone), selective serotonin reuptake inhibitors (SSRIs), and stimulants have been tested in different clinical studies with some proven benefits (Lindgren & Doobay, 2011). Antipsychotics such as risperidone and aripiprazole have been approved by the Food and Drug Administration for the treatment of irritability, consisting primarily of physical aggression and severe

tantrum behavior, associated with ASD (Volkmar et al., 2014). As noted in the updated AACAP Practice Parameter, the combination of medication with parent training is moderately more efficacious than medication alone for decreasing serious behavioral disturbances, and modestly more efficacious for adaptive functioning (Volkmar et al.). However, evidence also supports significant adverse effects of these medications (McPheeters et al., 2011). More rigorous, controlled studies are called for to establish the evidence-base of intervention efficacy (Myers, Johnson, & the Council on Children with Disabilities, 2007). Youth with ASD may be nonverbal, so treatment response is often judged by caregiver report and observation of specific behaviors (Volkmar et al.).

A recent study revealed that almost one in ten youth treated with antipsychotic medications were diagnosed with ASD and/or intellectual disability, and one in six youth with ASD received antipsychotics (Part et al., 2016). The study noted that both proportions increased in later years. This study also reiterated that the side effects of antipsychotics could be quite problematic, especially in children and adolescents. The researchers stated that clinicians should carefully assess the benefits and the risks prior to starting youth with ASD or intellectual disability on an antipsychotic, and that they should attempt to maximize non-pharmacologic interventions for comorbid disorders. Based on the study results and the known adverse effects of antipsychotics, the authors concluded that clinicians should consider using psychosocial interventions that are proven to be effective for behavioral dysregulation such as irritability and aggression before prescribing antipsychotics to adolescents with ASD or intellectual disability. The authors further stressed that, because outcomes of antipsychotic use in youth with ASD and/or intellectual disability require further study, it is imperative to regularly monitor both their efficacy and tolerability (Part et al.).

Unproven Practices

The following are complementary and alternative intervention approaches for which there is conflicting data on their effectiveness (National Autism Center, 2015).

- Animal-assisted therapy
- Auditory Integration Training
- Concept mapping
- DIR/Floor time
- Gluten-free and/or casein-free diet
- Facilitated communication
- Movement-based intervention
- Sensory integration
- Shock therapy
- Social-behavioral learning strategy (e.g., SODA)
- Social cognition/social thinking intervention program
- Holding therapy (Ennis-Cole, Durodoye, & Harris, 2013)

Table 6
Summary of Interventions for ASD

What Works	
Behavioral interventions	Includes antecedent interventions and consequent interventions.
Discrete trial teaching or training (DTT)	A type of behavioral intervention that uses operant learning techniques to change behavior. Also known as the ABC model (action request, behavior, consequence).
Cognitive behavioral intervention package	CBT modified for ASD youth
Comprehensive behavioral treatment for young children (CBTYC)	Also known as applied behavior analysis (ABA), early intensive behavioral intervention (EIBI), and behavioral inclusive programs.
Language training (production)	Targets the ability to communicate verbally
Modeling	Involves demonstrating a target behavior to encourage imitation
Naturalistic teaching strategies (NTS)	Child-directed strategies that use naturally occurring activities to increase adaptive skills
Parent training package	Involves training parents to act as therapists
Peer training package	Involves training peers on how to behavior during social interactions with a youth with ASD
Learning experience: An alternative program (LEAP)	A type of peer training program for peers, teachers, parents, and others
Pivotal response training (PRI)	Involves targeting pivotal behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues
Schedules	Used to increase independence in youth with ASD
Scripting	Providing scripted language to be used as a model in specific situations
Self-management	Strategies that involve teaching youth to track performance while completing an activity
Social skills package	Aims to provide youth with the skills (such as making eye contact appropriately) necessary to participate in social environments
Story-based intervention	Use stories to increase perspective taking skills

Table 6 (continued)
Summary of Interventions for ASD

What Seems to Work	
Augmentative and alternative communication devices	Communication systems designed to complement speech (pictures, symbols, etc.)
Developmental relationship-based treatment	Programs that emphasize the importance of building social relationships by using the principals of developmental theory
Exercise	Uses physical exertion to regulate behavior
Exposure package	Requires youth to face anxiety-provoking situations
Functional communication training (fct)	Behavioral method that replaces disruptive or inappropriate behavior with more appropriate and effective communication
Imitation-based intervention	Relies on adults imitating the actions of a child
Initiation training	Involves directly teaching individuals with ASD to initiate interactions with their peers
Language training (production and understanding)	Aims to increase both speech production and understanding of communicative acts.
Massage therapy	Involves the provision of deep tissue stimulation
Multi-component package	Involves a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations.
Music therapy	Aims to teach individual skills or goals through music
Picture exchange communication system	Involves the application of a specific augmentative and alternative communication system for youth with limited communication skills
Reductive package	Relies on strategies designed to reduce problem behaviors without increasing alternative appropriate behaviors
Sign instruction	Teaches sign language as a means of communicating
Social communication intervention	Targets some combination of social communication impairments
Structured teaching	Relies heavily on the physical organization of setting, predictable schedules, and individualized use of teaching methods
Technology-based intervention	Presents instructional materials using the medium of computers or related technologies
Theory of mind training	Aims to teach youth to recognize and identify the mental states of others

Table 6 (continued)
Summary of Interventions for ASD

Not Adequately Tested
<ul style="list-style-type: none">• Animal-assisted therapy (e.g., hippotherapy: the use of horseback riding as a therapeutic or rehabilitative treatment)• Auditory integration training• Concept mapping• DIR/Floor time• Gluten-free and/or casein-free diet• Facilitated communication• Movement-based intervention• Sensory integration• Shock therapy• Social-behavioral learning strategy (e.g., SODA)• Social cognition/social thinking Intervention program• Holding therapy

Vaccines and Autism

Concern has been expressed during the past decade about vaccines and their role in the development of ASD. It was theorized that a link might exist between ASD and the use of thimerosal, a mercury-based preservative once used in the measles-mumps-rubella (MMR) vaccine (National Institute of Mental Health [NIMH], 2007). Although mercury is no longer used in childhood vaccines in the United States, some parents expressed concerns about vaccinations (NIMH). In May 2004, the Institute of Medicine (IOM) released a report that stated that thimerosal had no causal relationship with the development of ASD (NIMH).

In 2008, in response to persisting public concerns, the CDC commenced a study on thimerosal and ASD using data obtained from managed care organizations in the U.S. to determine whether exposure to thimerosal in infancy was related to ASD. The study's goal was to provide the best available scientific information about whether there is a causal association between exposure to thimerosal and the development of ASD. Study findings showed that prenatal and infant exposure to vaccines containing thimerosal did not increase risk for ASD (Price et al., 2010). Researchers also noted that these results applied to both boys and girls. The outcome noted by the CDC was that thimerosal-containing immunizations did not increase the risk of any of the ASD outcomes (Price et al.). The recommended vaccination course for all children continues to be two doses of MMR vaccine (CDC, 2007).

Under the National Childhood Vaccine Injury Act of 1986, Congress established the National Vaccine Injury Compensation Program (VICP) to provide compensation to people injured by vaccines (Institute of Medicine [IOM], 2011). The Health Resources and Services Administration (HRSA) asked the IOM to review a list of adverse events associated with eight of the 12 vaccines covered by VICP and to evaluate the scientific evidence about the event. The vaccines were those recommended by the CDC for routine administration in children and included the MMR vaccine (IOM). An analysis of more than 1,000 research articles concluded that few health problems were caused by, or clearly associated with, these vaccines (IOM). The report also asserted there was no link between immunizations and serious conditions that have raised concerns, including Type 1 diabetes and ASD (IOM). The data were inadequate to reach conclusions about other suggested adverse effects.

A 2013 CDC study added to the research asserting vaccines do not cause ASD. The study examined the number of antigens (substances in vaccines that cause the body's immune system to produce disease-fighting antibodies) from vaccines during the first two years of life. The results showed that the total amount of antigen from vaccines received was the same between children with ASD and those that did not have ASD (DeStefano, Price, & Weintraub, 2013).

A study published in 2015 also found that receipt of the MMR vaccine was not associated with increased risk of ASD, regardless of whether older siblings had ASD (Marshall et al., 2015). Study participants included children continuously enrolled in a health plan from birth to at least five years of age from 2001 to 2012 who also had an older sibling continuously enrolled for at least six months between 1997 and 2012. These findings indicate no harmful association between MMR vaccine receipt and ASD, even among children already at higher risk for ASD (Marshall et al.).

Activities in Virginia

In recent years, Virginia has responded to rising concerns about the Commonwealth's ability to provide high quality services to children diagnosed with ASD. In 2006, the Virginia Department of Behavioral Health and Developmental Services (VDBHDS), formerly the Department of Mental Health, Mental Retardation and Substance Abuse Services, convened a workgroup to assess how to best provide a coordinated response to educating and treating individuals with ASD. In 2007 the workgroup developed recommendations to address services and supports, including one to establish a central agency for ASD.

In 2007, the Joint Commission on Health Care (JCHC) convened the Workgroup Regarding the Commonwealth's Ability to Serve Children and Adults with Autistic Spectrum Disorder (ASD). The workgroup's objective was to recommend a primary agency for developing, coordinating, and overseeing autism services. This agency, as envisioned, would serve as the primary entity to oversee the provision of services for individuals diagnosed with ASD. The JCHC recommended having the Secretary of Health and Human Resources develop a plan to identify the state agency to be responsible for serving individuals with ASD and whether that agency should serve individuals with only ASD or with all developmental disabilities.

In 2008 the Virginia General Assembly passed House Joint Resolution 105, which directed the Joint Legislative Audit Review Commission (JLARC) to examine services available to Virginians with ASD. JLARC compared Virginia services to those provided in other states, assessed the availability of ASD training for public safety personnel, and identified best practices and ways to improve delivery of services to Virginians. Findings from this comprehensive review can be accessed on the JLARC website (Virginia Joint Legislative Audit and Review Commission, 2009).

One recommendation from the JLARC study was:

The Department of Behavioral Health and Developmental Services should create a detailed action plan reflecting the input of relevant stakeholders and the evaluation of options conducted by other State agencies, which specifies how the department will address the issues contained in this report and build a more effective system of care for Virginians with developmental disabilities, including autism spectrum disorders.

The status of the resulting plan can be accessed on the Department's website (Virginia Department of Behavioral Health and Developmental Services, 2013).

In 2011, legislation was passed requiring health insurance plans in businesses employing at least 50 people to offer coverage for ASD for 2 to 6 year olds (House Bill 2467/Senate Bill 1062). The Governor amended this legislation to license board certified behavior analysts (BCBAs). The legislation, however, did not authorize the Virginia Board of Medicine to promulgate regulations to govern the licensure. In

2012, legislation (House Bill 1106) was passed to require the Board of Medicine to license behavior and assistant behavior analysts. The bill also required the Board to convene a workgroup relating to the licensure and practice of applied behavior analysis and contained an emergency clause that requires the Board to promulgate emergency regulations within 280 days of enactment.

Additional legislation was passed by the 2012 General Assembly with the goal of improving delivery of school-based services to youth with ASD (House Bill 325). This legislation required school divisions to ensure that aides assigned to work with a teacher who has primary oversight of students with ASD receive training in student behavior management within 60 days of assignment to such responsibility. School boards may also provide such training to other employees, including transportation employees. The Virginia Board of Education must provide training standards that school divisions may use to fulfill the training requirement. An enactment clause was added requiring the Virginia Board of Education, in consultation with Virginia Commonwealth University, to develop online training that school divisions may use to fulfill the requirements of this legislation. Such training must be made available to local school divisions free of charge.

In 2014, the General Assembly enacted legislation (House Bill 926) that established the Advisory Board on Behavior Analysis to advise the Virginia Board of Medicine on issues related to licensure of behavior analysts and assistant behavior analysts. In addition, the legislation provided for several exceptions to the licensure requirements. In 2015, the General Assembly enacted legislation (House Bill 1940) requiring health insurers, health care subscription plans, and health maintenance organizations to provide coverage for the diagnosis and treatment of ASD in individuals from ages two years through 10 years. The legislation does not apply to policies, contracts, or plans issued in the individual market or the small group market, which effective January 1, 2016, includes employers with no more than 100 employees.

In 2011, the Virginia General Assembly created the Virginia Autism Advisory Council (Senate Bill 1269). The Virginia Autism Council is the legislative body charged with promoting coordination of services and resources among agencies involved in the delivery of services to Virginians with autism spectrum disorders (ASDs) and increasing public awareness of such services and resources. The Council is to submit an annual report with progress updates and recommendations to the Governor and the General Assembly. The Council had a sunset provision, meaning that the statutory language creating the Council would expire July 1, 2016; however, legislation was enacted during the 2016 General Assembly Session (Senate Bill 225) that extended the sunset provision for the Council to July 1, 2018. The Council adopted a work plan in 2014 that tasked the Council with formulating potential strategies for lowering Virginia's current Medicaid waiver waiting lists and evaluating the adequacy of the Commonwealth's current employment support programs and efforts for students with ASD. The Council adopted a recommendation to continue assessing the issue of uniform application of dyslexic and ASD support across the Commonwealth. The Council invited parents of children with ASD and dyslexia from various regions in the Commonwealth to testify before the Council regarding their satisfaction and experiences with the services being provided in their area. The Council included in its work plan the issue of proper diagnosis (Virginia Autism Advisory Council, 2015).

In Virginia, individuals with ASD may be eligible to receive services from Virginia's Home and Community-based Medicaid Waivers program. Medicaid waivers provide funding for services that allow individuals with developmental disabilities, including those with ASD, to live in their homes/communities rather than reside and receive services in an institution.

In 2013, Virginia's Medicaid agency, the Department of Medical Assistance Services, and Virginia's Department of Behavioral Health and Developmental Services (Virginia's agency with operational authority for Virginia's waivers) undertook a study of three of Virginia's six existing Medicaid waivers (Virginia Department of Medical Assistance Services [VDMAS] & Virginia Department of Behavioral Health and Developmental Services [VDBHDS], 2015). The study reviewed Virginia's Intellectual

Disability (ID) Waiver, the Individual and Family Developmental Disability (DD) Supports Waiver, and the Day Support (DS) Waiver. Currently, Virginia's ID, DD, and DS Waivers distinguish eligibility separately between those with intellectual disability and those with a developmental disability. However, developmental disability is an umbrella term that includes individuals with intellectual disability. Accordingly, these three waivers are in the process of being revised to better serve individuals with a diagnosis of intellectual disability or a developmental disability. Under the current system, an individual with a diagnosis of ASD, but no specific diagnosis noting an intellectual disability, would only be eligible to receive services under the DD Waiver. In the new plan, the three waivers will be open to all eligible individuals, creating a unified system for individuals to access waiver services (VDMAS & VDBHDS).

The following are the waivers proposed to replace the existing ID/DD waivers:

- The current Day Support Waiver will become the “Building Independence” Waiver and provide supports for adults able to live independently in the community, with other support and or housing subsidies as needed.
- The current Developmental Disabilities Waiver will become the “Family and Individual Supports” Waiver and provide supports for individuals living with their families, friends, or in their own homes, including supports for those with some medical or behavioral needs. It will be available to children and adults.
- The current Intellectual Disability Waiver will become the “Community Living” Waiver and provide up to and including 24/7 services and supports for individuals with exceptional medical and/or behavioral support needs through licensed services. This waiver will include residential supports and a full array of medical, behavioral, and nonmedical supports. It will be available to adults and some children (e.g., those who require out-of-home residential supports) (VDMAS & VDBHDS, 2015).

The new waivers are to be implemented in two phases. The redesigned waivers include new services. They will have a nondiagnosis specific eligibility. Eligibility will be assessed based on a newly revised instrument (the VIDES) and level of need will be determined through use of the nationally validated Supports Intensity Scale (SIS). SIS scores will be used to determine provider reimbursement according to tiers for certain services. In addition, the Commonwealth will transition to a single statewide waiting list based on priority of need. Currently the DD Waiver waiting list is chronological and the ID waiver waiting list is based on local prioritization.

Another Virginia Medicaid Waiver also serves individuals with ASD. The Elderly or Disabled with Consumer Direction (EDCD) Waiver provides services that help individuals live in their own home or community instead of a nursing home. It is available to individuals 65 years of age and older, and to individuals of any age who have a disability. Individuals who depend on another person for supports and have medical or nursing needs may be eligible for the EDCD Waiver (Virginia Department for the Aging and Rehabilitative Services, 2008).

Cultural Considerations

Cultural differences for youth diagnosed with ASD exist in norms for social interaction, nonverbal communication, and relationships. Cultural and socioeconomic factors may also have an impact upon the individual's age at diagnosis (APA, 2013b). As discussed in the preceding section on prevalence, the most recent data on ASD prevalence was gathered in 2012 through the active surveillance system, Autism and Developmental Disabilities Monitoring Network (ADMM). The surveillance found that Caucasian children were more likely to be identified with ASD than African American or Hispanic children, and that African American children were more likely to be identified with ASD than Hispanic children. In order to receive early intervention, an accurate diagnosis is essential, which means the signs of developmental delay must be recognized and explored as soon as possible. Minority families may view developmental

delays as temporary and even normal (Ennis-Cole, Durodoye, & Harris, 2013). As a result, they may not identify subtle but meaningful warning signs for ASD (lack of pointing, lack of imitation, lack of eye contact, and lack of socially appropriated behavior) (Ennis-Cole, Durodoye, & Harris).

Traditional cultural perspectives may also influence treatment recommendations. Parent with information about interventions and practices that have strong research support are in a better position to select interventions that may be helpful for their children.

Overview for Families

The information discussed in this section is derived from the American Academy of Child and Adolescent Psychiatry Facts for Families Guide to Autism (2013).

Most infants and young children are very social creatures who want contact with others and need that contact to thrive and grow. They smile, cuddle, laugh, and respond eagerly to games like peek-a-boo or hide-and-seek. Occasionally, however, a child does not interact in this expected manner. Instead, the child seems to exist in his or her own world, a place characterized by repetitive routines, odd and peculiar behaviors, problems in communication, and a total lack of social awareness or interest in others. These are characteristics of a developmental disorder called Autism Spectrum Disorder (ASD).

ASD is usually identified by the time a child is 30 months old. It is often discovered when parents become concerned that their child may be deaf, is not yet talking, resists cuddling, and/or avoids interaction with others. Some of the early signs and symptoms that suggest a young child may need further evaluation for ASD include:

- No smiling by six months of age
- No back-and-forth sharing of sounds, smiles, or facial expressions by nine months
- No babbling, pointing, reaching, or waving by 12 months
- No single words by 16 months
- No two word phrases by 24 months
- Regression in development
- Any loss of speech, babbling, or social skills

A preschool age child with ASD is generally withdrawn, aloof, and fails to respond to other people. Many of these children will not even make eye contact. They may also engage in odd or ritualistic behaviors like rocking, hand flapping, or an obsessive need to maintain order. Many children with ASD do not speak at all. Those who do may speak in rhyme, have echolalia (repeating another person's words like an echo), refer to themselves as a "he" or "she," or use peculiar language.

The severity of ASD varies widely, from mild to severe. Some children are very bright and do well in school, although they have problems with school adjustment. They may be able to live independently when they grow up. Other children have significantly more challenges. Intellectual disability may or may not be a concurrent diagnosis.

The cause of ASD remains unknown. Children with ASD need a comprehensive evaluation and specialized behavioral and educational programs. Typically, a multi-disciplinary team diagnoses ASD. Such a team may include a developmental pediatrician, a neurologist, a neuropsychologist, and perhaps at times a psychiatrist. These providers can help families design and implement an appropriate treatment plan, which usually includes educational components.

Although there is no cure for ASD, appropriate specialized treatment provided early in life can have a positive impact on children's development and help them to achieve the best possible outcomes.

Conclusion

Each child and adolescent with ASD is unique, with differing strengths and needs. New evidence and information on ASD is being published almost daily. Early identification and intervention are key elements influencing long term outcomes for children and youth with an ASD diagnosis. Multi-disciplinary evaluations and child- and family-centered service planning are critical to assisting the child in improving communication and social skills, achieving educational and employment goals, and becoming as independent as possible.

Resources and Organizations

American Academy of Pediatrics

<http://www.aap.org>

Autism Focused Intervention Resources and Modules (AFIRM)

An extension of the National Professional Development Center (NPDC)

<http://afirm.fpg.unc.edu/selecting-ebp>

Asperger Syndrome Education Network (ASPEN)

<http://www.aspennj.org>

Association of University Centers on Disabilities

<http://www.aucd.org>

Autism and PDD Support Network

<http://www.autism-pdd.net>

Autism Research Institute (ARI)

4182 Adams Avenue

San Diego, CA 92116

<https://www.autism.com/index.asp>

Autism Society of America

7910 Woodmont Avenue, Suite 300

Bethesda, MD 20814-3067

<http://www.autism-society.org/>

Autism Speaks

2 Park Avenue, 11th Floor

New York, NY 10016

<http://www.autismspeaks.org>

Autism Spectrum Connection

<http://www.aspergersyndrome.org/>

Centers for Disease Control and Prevention

Autism Spectrum Disorder (ASD)

<http://www.cdc.gov/ncbddd/autism/index.html>

Center for Parent Information and Resources

<http://www.parentcenterhub.org/>

Individuals with Disabilities Education Act (IDEA)

<https://sites.ed.gov/idea/>

Interagency Autism Coordinating Committee

<https://iacc.hhs.gov/>

National Autism Center

<http://www.nationalautismcenter.org>

National Alliance for Autism Research

99 Wall Street, Research Park

Princeton, NJ 08540

National Institute of Child Health and Human Development

<https://www.nichd.nih.gov/Pages/index.aspx>

National Institute of Mental Health (NIMH)

6001 Executive Blvd., Rm. 8184, MSC 9663

Bethesda, MD 20892-9663

<https://www.nimh.nih.gov/index.shtml>

National Institute on Deafness and Other Communication Disorders

31 Center Drive, MSC 2320

Bethesda, MD 20892-2320

<http://www.nidcd.nih.gov>

National Network for Immunization Information

<https://www.immunizationinfo.net/>

National Professional Development Center

<http://autismpdc.fpg.unc.edu/>

U.S. Autism & Asperger Association

<http://www.usautism.org>

U.S. Department of Education

U.S. Office of Special Education and
Rehabilitative Services

400 Maryland Ave., S.W.

Washington, DC 20202-7100

**U.S. Department of Health and Human
Services**

The Interagency Autism Coordinating
Committee (IACC)

<https://iacc.hhs.gov/>

Wrights Law

<http://www.wrightslaw.com/>

Virginia Resources and Organizations

Autism Outreach, Inc.

<http://autismoutreach.org/>

Autism Society of America

Central Virginia Chapter

P.O. Box 29364

Richmond, VA 23242-0364

<http://ascv.org>

Commonwealth Autism

4108 E. Parham Road

Henrico, VA 23228

<http://www.autismva.org/>

Infant & Toddler Connection of Virginia

1220 Bank Street, 9th Floor

P.O. Box 1797

Richmond, VA 23219-1797

<http://www.infantva.org/>

**Parent Educational Advocacy Training
Center (PEATC)**

6320 Augusta Drive, Suite 1200

Springfield, VA 22150

<http://www.peatc.org/>

Partnership for People with Disabilities

<https://partnership.vcu.edu/>

The Radford University Autism Center

Department of Communication Sciences &
Disorders

P.O. Box 6961

Radford, VA 24142

[http://www.radford.edu/content/wchs/home/
cosd.html/autism.html](http://www.radford.edu/content/wchs/home/cosd.html/autism.html)

Virginia Autism Advisory Council

<http://www.autismtrainingva.org/>

Virginia Autism Project

<http://www.virginiaautismproject.com/>

Virginia Autism Resource Center

Richmond Office: 4100 Price Club Blvd.

Midlothian, VA 23112

Winchester Office: P.O. Box 2500

Winchester, VA 22604

<http://www.varc.org/>

Virginia Board for People with Disabilities

<https://www.vaboard.org/>

**Virginia Commonwealth University Autism
Center for Excellence (VCU-ACE)**

1314 West Main Street

Richmond, VA 23284

[http://www.vcuautismcenter.org/projects/dia
gnosis.cfm](http://www.vcuautismcenter.org/projects/diagnosis.cfm)

**Virginia Department for Aging and
Rehabilitative Services**

8004 Franklin Farms Drive

Henrico, VA 23229-5019

<https://vadars.org/>

**Virginia Department of Behavioral Health
and Developmental Services**

Office of Developmental Services

P.O. Box 1797

Richmond, VA 23219

[http://www.dbhds.virginia.gov/development
al-services](http://www.dbhds.virginia.gov/developmental-services)

Virginia Department of Education

Office of Special Education and Student Services

P.O. Box 2120

Richmond, VA 23218-2120

http://www.doe.virginia.gov/about/spec_ed_and_stu_svs/index.shtml

Publications:

Autism Spectrum Disorders

http://www.doe.virginia.gov/special_ed/disabilities/autism/index.shtml

Autism Spectrum Disorders and the Transition to Adulthood

http://www.doe.virginia.gov/special_ed/disabilities/autism/technical_asst_documents/autism_transition.pdf

Guidelines for Educating Students with Autism Spectrum Disorders

http://www.doe.virginia.gov/special_ed/disabilities/autism/technical_asst_documents/autism_guidelines.pdf

Models of Best Practice in the Education of Students with Autism Spectrum Disorders

http://www.doe.virginia.gov/special_ed/disabilities/autism/technical_asst_documents/autism_models_of_best_practice.pdf

Virginia Department of Health

Child & Adolescent Health, Division of Child & Adolescent Health

109 Governor Street, 8th Floor

Richmond, VA 23219

<http://www.vdh.virginia.gov>

Virginia Department of Medical Assistance Service

600 East Broad Street

Richmond, VA 23219

<http://www.dmas.virginia.gov/>

Virginia Institute of Autism

1414 Westwood Road

Charlottesville, VA 22903-5149

<http://www.viaschool.org>

Virginia Tech Autism Clinic

3110 Prices Fork Road

Blacksburg, VA 24061

<http://www.psyc.vt.edu/outreach/autism>

Virginia's Training/Technical Assistance Centers (TTAC)

<http://ttaonline.org/>

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