

A Brief Parent Guide on Autism Spectrum Disorders (ASD):

Information for Parents of School-Age Children



Introduction

If you are the parent or caregiver of a school-age child who has been diagnosed with autism spectrum disorder (ASD), this booklet is written for you.

Receiving a diagnosis of autism spectrum disorder can be an overwhelming experience. You may have received other diagnoses before the ASD diagnosis was made, or this may be the first diagnosis given to your child. Either way, an ASD diagnosis can explain some of the differences you have observed during your child's development and can also provide a direction for appropriate interventions at home, in school, and in the community.

Included in this booklet are questions that parents frequently ask when their school-age child receives an ASD diagnosis, and brief answers containing links to resources with more detailed information.

What is Autism Spectrum Disorder (ASD)?

Autism spectrum disorder (ASD) refers to a developmental disability that involves communication, social interaction and behavioral difficulties. The terminology has recently changed, so ASD now includes the previous diagnoses of Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

Children with an ASD diagnosis show difficulties in two main areas:

- social communication and social interaction
- restricted interests and/or repetitive behaviors

Many different symptoms can manifest within each of these areas. Therefore, two children with the same diagnosis can have different abilities and behave in very different ways.

The range of ASD symptoms is broad. Within the language and communication area, some children are nonverbal, some speak in single words or short phrases, while others have excellent verbal skills. Children's socialization styles may differ as well. Some children have limited social interest and tend to spend much of their time alone, while others are interested in being social but have difficulty doing so successfully. Children can also have a wide range of interests and repetitive behaviors. Some children have interests in unusual items, such as elevators or street signs, or collecting unusual objects like pencil erasers. Children may have interests that are unusual in their intensity and that may or may not be age appropriate. For example, a child may know detailed facts about a particular topic or may be interested in only one toy that is played with exclusively and/or repetitively. Children may also do repetitive movements with their hands (e.g., hand flapping) or complex mannerisms with their entire body (i.e., jumping while flapping). In addition, difficulties with transitions or changes in routine and unusual responses to sensory experiences are common in children with ASD.

How common are autism spectrum disorders?

The most recent estimates indicate that 1 out of every 36 children in the United States is diagnosed with ASD. Boys are diagnosed about 4 times more frequently than girls. These prevalence rates suggest that ASD occurs more commonly than childhood cancer, juvenile diabetes, and pediatric AIDS combined. (www.cdc.gov/ncbddd/autism/data.html)

Scientists do not currently have an explanation for the increase in the diagnosis, although we do know that public awareness has increased. Further, clinicians, researchers, teachers, and family members are recognizing the broad spectrum of symptoms present in this disorder. The previous notion that children with ASD do not interact or talk is outdated and has been replaced by a broader and more inclusive understanding of the disorder. Consequently, a greater number of children are now identified as having ASD. Clinicians also have new assessment tools that help them understand a child's communication, social interaction abilities, and interests. Finally, although there is no single explanation for this increase in prevalence, scientists are exploring the potential role of environmental factors.

How did my child go so long without a diagnosis?

Individuals with ASD are diagnosed at all ages, even in adulthood. Sometimes parents notice difficulties with their child's development but are told that their child "will grow out of it" or that it is "just a phase." In other instances, a child will receive multiple diagnoses that focus on individual symptoms before receiving a diagnosis of ASD that encompasses all aspects of the child's behaviors.

Common initial diagnoses include sensory integration disorder, developmental delay, speech-language disorder, attention deficit-hyperactivity disorder (ADHD), and obsessive-compulsive disorder (OCD).

Although children with ASD are sometimes not diagnosed until they reach school-age and even adolescence, symptoms may have been present early in a child's development. Often, one of the first signs of developmental difficulties is delayed language or a loss of language. However, many children with ASD, especially those previously diagnosed with Asperger's Disorder, do not have delayed language development. Parents often report concerns that their child had a difficult time starting preschool and playing cooperatively with other children, as well as managing the transitions between activities at school. Behavior and attention problems in preschool are commonly recalled, as are difficulties with fine motor skills, such as coloring inside the lines and using scissors. Toilet training may have also been difficult. Looking back, parents may recall that their child did not play like other children. Their child may have used toys or objects in a repetitive way without imagination or pretend play. Sometimes parents report that their child's

preschool teacher had to make particular accommodations to help improve behavior and social interaction. With these accommodations, their child functioned well and concerns were not noticed until their child was in an environment without these particular supports.

Children may have received interventions to help improve skills in specific areas (e.g., speech-language services, occupational therapy), but the overall reason for their difficulties may not be identified until much later by someone who is familiar with ASD and makes a referral to an appropriate provider. As parents, educational professionals, medical providers, and therapists become more familiar with the characteristics of ASD, children can be identified at much younger ages so interventions can begin sooner rather than later.

What other behaviors are common in children with autism spectrum disorders?

Children who are diagnosed with ASD show difficulties in two main areas: social communication and social interaction, and restricted interests and/or repetitive behaviors. This second area includes sensory interests (e.g., seeking out textures to feel, smelling objects that are not typically smelled) and sensory aversions (e.g., covering ears in response to loud noises such as a vacuum cleaner, blender, or toilet flushing; refusing to wear certain types of clothing). Children also tend to show motor difficulties with some gross motor skills (e.g., running, skipping, catching a ball) and with some fine motor skills (e.g., handwriting, buttoning a shirt, using eating utensils). Many children with ASD also have attention and learning difficulties that interfere with performance in the classroom and prevent them from functioning at their highest potential. It is not uncommon for children to have received a diagnosis of attention deficit-hyperactivity disorder (ADHD) prior to their ASD diagnosis.

Is there a genetic test for autism spectrum disorders?

No genetic test is currently available to determine if your child has an ASD. Many research studies are looking into the genetics of ASD, but no single gene or group of genes has been identified as causing ASD. However, some genetic disorders (such as Fragile X syndrome) are associated with a diagnosis of ASD. Talking with your medical provider can help determine what genetic testing, if any, should be completed to rule out an associated genetic condition. If a specific syndrome is found, this information can help you plan for medical interventions and make future family planning decisions.

Are there medical problems that go along with an ASD diagnosis?

Children who have a diagnosis of ASD should be evaluated by a physician who has expertise in the medical management of autism spectrum disorder. It is not uncommon for children with ASD to experience medical problems, such as sleeping difficulties, GI symptoms (e.g., constipation, reflux, and diarrhea), feeding issues, or seizures. Often, treating these symptoms can result in improvements in behavior because the child is feeling better and is more likely to pay attention to school instruction or therapeutic interventions.

Does my child need medication?

No pill can “cure” autism. Rather, medications for children with ASD target specific symptoms, such as aggression, attention difficulties, obsessive-compulsive behaviors, anxiety, or depression. Not all children with ASD need medication. However, many children have benefited from the use of medications to manage behavioral and psychological difficulties. Finding a professional with whom you can talk about the benefits and risks of medication for your child will be helpful. Children with ASD do not always respond in a typical manner to medications, so having your child evaluated by a medical doctor who understands this diagnosis is important.

My child also has significant attention problems. Is a separate diagnosis of Attention Deficit-Hyperactivity Disorder (ADHD) needed?

Attention problems are common in children with ASD, so a separate diagnosis of ADHD is not required. However, since many children receive this diagnosis before they receive a diagnosis of autism spectrum disorder, ADHD often remains in children’s medical files and educational plans. Further, prescribing physicians may use this diagnosis to describe the symptoms for which they are treating your child.

My child also has emotional problems. What should I do?

A large number of children with ASD experience emotional difficulties such as anxiety, depression, anger, and mood swings. Often, these symptoms increase in intensity when children are under stress or overwhelmed in a particular environment. Sources of stress can include being frustrated in a classroom due to an increased amount of verbal instruction, excessive noise, or a change in routine. Stress also increases due to difficulties with social interactions and understanding the often unspoken and complex social banter that exists among peers. Emotional symptoms may arise from inadequate social

skills, being bullied, being teased, or recognizing that they are “different” than peers. Children with ASD tend to be socially naïve and emotionally immature, and they may struggle to interpret and comprehend the complex social world of their peers. Children and adolescents may also experience symptoms of depression or anxiety when they realize that they have problems adjusting their social behaviors to “fit in.”

Behavioral techniques can help children understand, anticipate, and cope with emotional symptoms. In some cases, psychological intervention with both the child and family is useful to develop a plan with specific intervention strategies that build on the child’s strengths and promote self-esteem. Intervention strategies can be incorporated into the home environment, school setting, and/or extra-curricular activities and can include peers and adults to help implement the interventions. Additionally, you may want to speak with your child’s medical provider to determine if medication is appropriate.

My child has difficulty with motor skills. What should I do?

While motor difficulties are not required for a diagnosis, it is common for children with ASD to have delays in both gross and fine motor skills. Difficulties in these skills often appear in everyday activities, such as holding utensils, getting dressed, brushing teeth, tying shoes, running smoothly, and riding a bicycle. To improve skills in these areas, children frequently benefit from physical and occupational therapies that are designed to strengthen muscles and improve daily living activities. Children with ASD can greatly benefit from occupational and physical therapies but may also have persistent difficulties despite consistent intervention.

Why do I have to remind my child each day how to do familiar things?

Parents of children with ASD often report that they tell their child how to complete certain activities each day, and that their child has difficulty completing the tasks without prompting. It is important to remember that children with ASD, even those who have excellent language abilities, can have a difficult time processing and retaining large amounts of verbal information.

In order to help children learn and retain how to complete multi-step processes, parents can use a series of pictures, often referred to as visual supports, to represent each step of the instructions. Visual supports help children by translating

verbal directions into a sequence of pictures that children can refer to each time they complete an activity rather than relying on a large amount of fleeting words. Visual supports also make communication more concrete. For example, if you say, “Clean your room,” your child might not understand what to do or remember what steps are involved. Instead, place a series of pictures on the wall that indicate what to do to clean the room—pictures of a bed that has been made, clothes hanging neatly in the closet, and toys in their appropriate place. If your child can read, written visual supports may be more appropriate than pictures. Visual supports can be used in a variety of contexts, tailored to each child’s developmental level.

What are common interventions for children with ASD?

One of the most important aspects of an intervention program is that it is tailored to meet your child’s and family’s individual needs. Much more important than the name of the program(s) are how the environment is structured and what educational strategies are implemented to meet your child’s and your family’s goals.

Many times, several providers work with a child who has ASD, including speech-language pathologists, occupational therapists, physical therapists, and behavioral therapists. These services can be provided in a child’s school after an evaluation is completed to determine if the child is eligible for the specific service(s). Families also may choose to pursue these services independently with private practitioners in the community. Maintaining close contact with your child’s providers so that similar strategies can be used in all environments (e.g., home, school, therapy) will help your child generalize the skills being learned to multiple settings. Your child may not need services from all of the providers listed below, but their roles are briefly described along with links to their professional organization websites, in case you would like additional information.

Speech-language pathologists (SLPs) are trained in the assessment, treatment, and prevention of communication disorders. Typically, they assess and treat difficulties in language understanding and expression, as well as problems with speech, such as articulation and fluency. Since communication is an area of significant difficulty for children with autism spectrum disorder, SLPs are often crucial members of the intervention team. In addition to helping with *functional*

communication skills and addressing speech difficulties, SLPs can help with the *pragmatic* (i.e., social) aspects of language. Children often benefit from learning appropriate conversation starters and endings, as well as strategies to help them hold a conversation on a variety of topics. For more information, see the American Speech and Hearing Association website at www.asha.org.

Occupational Therapists (OTs) typically focus on helping children develop fine motor skills (e.g., handwriting, buttoning, hooking, closing zippers), process information from their senses, and carry out daily living activities (e.g., eating, dressing, grooming). Difficulties with fine motor skills and sensory issues can impact a child's behavior and functioning in the classroom environment. Children can experience increased frustration with handwriting, even on short assignments. Or, they may become agitated by too much sensory input or be inattentive as a result of too little sensory input. Interventions designed by an occupational therapist specially trained in strategies to address sensory issues can help manage and improve a child's functioning due to these difficulties. For more information, see the American Occupational Therapy website at www.aota.org.

Physical Therapists (PTs) are trained to treat problems with movements and posture. In contrast to OTs, they tend to focus on developing gross motor skills (i.e., movements that involve the muscles of the body, arms and legs). PTs can help children with ASD who have difficulties with coordination, balance, or motor planning move about their environment and participate more effectively in play and recreational activities. For more information, see the American Physical Therapy Association website at: www.apta.org.

Behavior Therapists vary in their training backgrounds. Some will have certification through the Behavior Analyst Certification Board (BACB) and will have the designation of being a Board Certified Behavior Analyst (BCBA). Whether you are trying to locate a behavior therapist through the school system or a private organization, it is important to find out their educational background and whether or not they have experience working with children with ASD.

Behavior therapists likely will implement a therapy called Applied Behavior Analysis (ABA). Applied behavior analysis is an organized approach that teaches children new skills with positive reinforcement and rewards, while also decreasing

unwanted behaviors. ABA includes many approaches, but they all work on the same basic behavioral principles. For school-age children, many of the behavioral principles focus on improving social skills, managing unexpected transitions, and implementing reinforcement systems to target specific behavioral problems at home, in school, and in settings where they play and interact with other people.

Your child's behavior therapist should be aware of your child's Individual Education Program (IEP) goals and keep records to track the progress being made. This therapist can assist in determining future intervention goals based on ongoing assessments of your child's progress. For more information about ABA and other treatment approaches, see the Behavior Analyst Certification Board website at www.bacb.com.

What is adaptive behavior?

Adaptive behavior is the set of skills that helps each person function in everyday life. These skills can include an individual's way of communicating, ability to make and maintain social relationships (e.g., initiating interactions with others, taking turns, sharing), personal hygiene (e.g., bathing and getting dressed independently), ability to complete domestic activities (e.g., helping with chores and cooking, putting personal belongings away, understanding money and time), coping strategies (e.g., managing transitions) and motor abilities (e.g., riding a bicycle, throwing and catching a ball). Learning to function in everyday life is an important part of gaining independence. Delays in a child's adaptive functioning can help provide valuable information about potential areas for intervention.

It is important to note that adaptive behavior is not the same thing as intelligence. Scores on an adaptive behavior measure can be quite different from scores on an intelligence test. It is not uncommon to see a child who has a diagnosis of ASD with average to above average scores on an intelligence test, but scores in the impaired range on a measure of adaptive behavior. This discrepancy indicates that a child who is bright and has the ability to function at an age-appropriate level in problem-solving can actually be behind in skills that are required for daily living and gaining independence.

Why is my child, who was previously an excellent student, starting to have difficulties in school?

A child may begin having difficulties in school for many

reasons. Your child may have a learning disability. The school can assess your child to determine if a learning disability (e.g., reading disorder) is preventing your child from succeeding academically. Another common reason that children with ASD start having difficulties is that school work becomes more focused on abstract concepts rather than concrete information in more advanced grades. As children progress in elementary school, they are expected to read and learn increasingly complex information. Further, they are asked questions that include providing information that is inferred rather than stated in the reading. For example, questions like “What is the main idea?” or “What will probably happen next?” are difficult for children with ASD because the answers are not factual, but are based on comprehension of the material on a more abstract level. The same is true for mathematical skills. Children with ASD often do well with math facts, but struggle with word problems or higher level mathematic concepts such as algebra.

These difficulties may seem counterintuitive to parents since many children with ASD have a vast wealth of knowledge on certain academic topics, such as history or astronomy. However, this kind of knowledge may be based on memorized facts rather than a conceptual understanding of the material.

What is an IEP and how can it help my child in school?

An IEP is an Individualized Education Program for children 3 years of age and older. An IEP provides your child individualized intervention services through the public education system. Your child’s school will determine eligibility for an IEP. This decision is based on eligibility guidelines put forth by the Tennessee Department of Education, which are outlined in a document found at: sites.ed.gov/idea/regs/b/d/300.324

Parents are an important part of the IEP process. You will be invited to a meeting to talk about your child and to help develop the IEP. The IEP will focus on your child’s educational needs and will outline the supports or services needed, how frequently these services will be provided, and how progress will be measured. Often children with ASD benefit from special education services including speech, occupational, and physical therapies, as well as classroom accommodations such as help with transitions and modifications to school work. In Tennessee, STEP (Support and Training for Exceptional Parents) is a statewide, family-to-family program that supports families by providing free information, advocacy, training, and

support services to parents of children eligible to receive special education services. This includes children with ASD from infancy through age 22 years. Services are free of charge to parents. For more information, contact STEP at **1-800-280-STEP** or tnstep.info.

Will my child grow out of the ASD diagnosis?

A diagnosis of ASD means that behaviors consistent with this diagnosis were present early in development and will continue to be present throughout a person’s life. However, with intervention, symptoms can improve over time. There have been reports of children losing their diagnosis, but these cases are the exception rather than the norm. In the event that a child does lose the diagnosis, it is not uncommon for the problems previously experienced to persist, just in a less impairing manner.

How do I tell my child about the ASD diagnosis?

How you tell your child about the ASD diagnosis is a personal decision. There is no single right way to give your child this information, but it is important to talk to your child about the diagnosis. As some children with ASD get older, they may become aware that they are different from their peers. Recognizing these differences and understanding their diagnosis may help children understand why they have difficulties in some areas but have strengths in others. Most important, when you talk to your child about the diagnosis, remember to present the information at the appropriate developmental level, so that it is understood, and provide the opportunity for your child to ask questions. Books written for parents and children about this topic may be helpful. The Autism Society of North Carolina has an excellent bookstore with titles that address this topic (autismbookstore.com/).

What resources are available to learn more about my child’s diagnosis?

Many online resources provide information related to ASD. It is important to be a careful consumer and obtain information from reliable sources, some of which are listed below. Be wary of websites or treatments that promise a cure or seem too good to be true. In Tennessee, Tennessee Disability Pathfinder, a statewide helpline with multilingual staff, keeps an updated list of autism-related resources. See TNPathfinder.org or call **1-800-640-4636** to find resources in your county or region.

Pathfinder provides information about parent support resources, such as the local chapters of the Autism Society of America (ASA) www.autism-society.org, which provides information, support, and advocacy for the autism community:

Autism Tennessee

www.autismtn.org, 615-385-2077
support@autismtn.org

Autism Resources of the Mid-South

www.autismresourcesmidsouth.org, 901-509-3027
autismresourcesmidsouth@gmail.com

Autism Society of East Tennessee

www.asaetc.org, 865-247-5082
info@asaetc.org

Another resource is Autism Speaks (www.autismspeaks.org/), which has information about diagnosis, treatment, and community resources, as well as recent updates from the scientific community.

What else should I do?

Develop your own personal team of allies for support. Parenting is often challenging, and we usually do not receive adequate preparation even for raising a child who has typical development. When you have a child with a developmental disability like an ASD, parenting becomes even more complicated. Assembling a group of people you can trust and rely upon is very important. You may want to develop a longstanding relationship with a professional (e.g., medical doctor, psychologist, social worker, therapist) who can monitor your child's development over time and answer your questions as they arise.

You will be better able to meet your child's needs if you take care of yourself. Find parent support groups. Spend enjoyable time with your other children or family members. Seek support in your faith community. If you are feeling so sad or overwhelmed that you feel hopeless or paralyzed, seek help from a counselor or therapist.

Talking with other parents who have children with ASD can be invaluable. A helpful resource with a well-organized website is Autism Tennessee autismtn.org. It provides a wealth of information about bimonthly autism orientations, monthly workshops, conferences, local support groups, as well as links

to resources organized by specific topics: ABA/educational programs, advocacy, behavior resources, occupational therapy, speech therapy, and parent training. It also has the largest autism-specific lending library in Tennessee. Additionally, the site links to the online bookstore of the Autism Society of North Carolina, which has the largest nonprofit ASD-specific selection of books. Autism Tennessee can be contacted by phone at **615-385-2077**.

What can I expect for the future?

Even with a new diagnosis of ASD, you may already have questions about your child's future. Will my child be able to go to college, hold a job, or have a family? These questions are normal but can be anxiety-provoking because there are no ready answers. If possible, try not to look too far ahead right now. Instead, focus on meeting your child's current needs and finding joy in your family's interactions. It is encouraging that we live in a time when energy and resources are being devoted to better understanding and treating ASD. Our hope is that new discoveries will result in more effective treatments that will help your child live a happy, productive life.

Vanderbilt University Medical Center (VUMC) Resources

The Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders—TRIAD—provides *services* to children and families; provides exemplary *training* to parents, service providers, and future professionals; and conducts state-of-the-art *research* on understanding and treating ASD.

Vanderbilt University is a member of the **Autism Treatment Network (ATN)**, a network of 14 centers in North America supported by **Autism Speaks**. The ATN is dedicated to improving medical care for children and adolescents with ASD by offering comprehensive diagnosis, treatment, care and counseling.

For questions about diagnostic, medical, early intervention, educational, and behavioral resources at VUMC and in the community:

Vanderbilt Autism Resource Line

triad.vumc.org/autismline
Toll free: 1-877-273-8862 or local: 615-322-7565
Email: autismresources@vumc.org

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