

A Brief Parent Guide on Autism:

Information for Parents of Toddlers and Preschoolers



Introduction

If you are the parent or caregiver of a young child in Tennessee who has recently received a diagnosis of an autism spectrum disorder (ASD), this booklet is written for you.

You may have had concerns about your child's development for a long time but have just received an "official" diagnosis of ASD. Even if you have been suspecting ASD, receiving the diagnosis can feel overwhelming. You have to adjust emotionally to the diagnosis in terms of what this means for you and your family, and at the same time you have to make plans for appropriate interventions.

Since there is an incredible amount of information about ASD to sort through from multiple sources (the Internet, books, teachers, other parents, etc.), we hope this booklet will be a useful place to start. Included are questions that are frequently asked by parents when their child receives an ASD diagnosis, and brief answers that also contain links to resources with more detailed information.

What is an autism spectrum disorder?

ASD is a complex brain-based disorder that affects multiple areas of development, including social interaction, verbal and nonverbal communication, play, behavior and interests. Its symptoms show up early in life, sometimes in infancy, but generally before 3 years of age. (See: www.ninds.nih.gov/disorders/autism/autism.htm for more information.)

Why are different names used for autism spectrum disorder?

In the past there have been a variety of names used to describe subcategories of autism that were thought to fall under the larger category of "autism spectrum disorders" or "pervasive developmental disorders." You may have heard terms such as PDD-NOS (which stands for Pervasive Developmental Disorder-Not Otherwise Specified) or Asperger's Disorder, in addition to autism. However, because research has shown that it is often difficult for clinicians to accurately draw a line between autism and PDD-NOS in very young children, the diagnostic terms have recently changed.

To decrease confusion, the newest edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) only uses the term “autism spectrum disorder” rather than including specific subcategories. Whether your current diagnostician uses the term autism, autism spectrum disorder, or PDD-NOS, the types of interventions your child needs will be the same.

What causes autism spectrum disorder?

A lot of research is being conducted right now to try to answer this question. In a minority of individuals, ASD is a sign of an underlying genetic condition, such as Fragile X. However, in most cases the cause is unknown. The current understanding is that ASD is caused by a combination of genetic and environmental risk factors. At this time there is no clear evidence that ASD is caused by something that the parents did or did not do before or during pregnancy or while taking care of their infant or toddler.

Do vaccines cause autism spectrum disorder?

There has been a lot of public concern and media attention about a possible link between vaccines and ASD. Multiple scientific studies have now looked at this issue, and the evidence indicates that vaccines are not associated with ASD. We also know that there are serious health risks connected with failing to get vaccinated. See www.cdc.gov/ncbddd/autism/topics.html for more information. Talk to your healthcare provider if you have additional questions.

How common is autism spectrum disorder?

ASD is considered to be the fastest growing developmental disability diagnosis. The Centers for Disease Control and Prevention report that 1 in 68 children in the United States has autism spectrum disorder and that boys are much more likely to be affected than girls. (See: www.cdc.gov/ncbddd/autism/facts.html for more information.)

How is autism spectrum disorder diagnosed?

The diagnosis of ASD is based on a child’s behaviors. Currently, there is no medical test (such as a blood test, x-ray, or MRI) that can make a diagnosis of ASD. Doctors may order genetic testing to look for a genetic cause, and they may recommend other tests or studies to help determine if conditions (such as seizures) are also present.

When professionals perform an evaluation to see if a child has ASD, they look for specific kinds of difficulties in two main areas: social communication and interaction, and unusual behaviors and interests. However, each child is unique, so your child may not show all the characteristics listed below.

Social Communication and Interaction: Young children with ASD often have difficulty with the give-and-take of social interactions. Compared to children who are developing more typically, they may be less likely to use eye contact to communicate with caregivers, to turn when their name is called, to enjoy and participate in games like peek-a-boo or pat-a-cake, or to approach other children to play. They may enjoy being held by their parents or engaging in active play (e.g., chase or tickle games) but show less social interest and responsiveness than you would usually see in young children without developmental concerns.

Children with ASD are often slower to use single words and phrases than expected. They are also less likely to use common gestures, such as pointing to make requests or to direct a caregiver’s attention to interesting sights or sounds. Some children may develop language at the expected times but show loss of language skills around 18 – 24 months. This loss of skills may include a decrease in social interest, as well as a loss of the words or phrases they had previously used. Children who do develop language may ask for things they want but have difficulty carrying on simple conversations.

Behaviors and Interests: Young children with ASD often show a more narrow range of play interests than their peers and may demonstrate more repetitive behaviors. For example, they may focus on lining up or spinning objects rather than pretending to feed a doll or teddy bear. They may also seem preoccupied with certain objects or insist on following particular routines. In addition, they may repeat specific movements, such as flapping their hands, rocking, or running back and forth. They also may show unusual patterns of speaking, such as repeating or echoing phrases they hear people say in person or on television or videos. Finally, they may show differences in processing information they take in from their senses. That is, they may be over-sensitive or under-sensitive to things they hear, see, touch, taste, or smell. For example, a child with ASD might not turn when his name is called, but may become very distressed at certain common sounds, such as a hair dryer.

Timing: In addition to demonstrating developmental differences in the two areas described above, children with ASD often show these different patterns early in life.

Are there other behaviors or features that go along with autism spectrum disorder?

A number of behaviors go along with autism spectrum disorder, but these features are not required to make the diagnosis. For example, it is common for children with ASD to demonstrate a high activity level. They may have a short attention span for non-preferred activities but be able to focus on objects that they like for long periods of time. They may also be picky eaters and/or have difficulty sleeping.

Do all children with autism spectrum disorder have significant developmental delays?

No, there is a very wide range of abilities in cognitive or thinking skills among children with ASD. Some children with ASD are above average or even gifted. Other children have significant delays in all areas of development. Although the diagnosis of ASD does not depend on your child's cognitive skills, it is helpful to have information about this area in order to better understand your child's strengths and needs and to plan interventions.

Should I tell other people my child has ASD?

This is a very personal decision. In order to receive the early intervention or school services your child needs, you will need to share the diagnostic reports that mention ASD with those professionals. It will also be very helpful for your Primary Care Professional and other therapists to have this information, since it will help them in planning appropriate interventions.

It is up to you whether you want to share the diagnosis with relatives and friends. If they have spent a lot of time with your child, it is likely that they have noticed some developmental differences. However, they may have misinterpreted autism-related behaviors as your child being shy or spoiled. Sharing the diagnosis may help them better understand why your child is having difficulties interacting and communicating with others. It may also increase their availability as a support to you in the future.

Where should I start to find help?

If your child is under **3 years of age**, contact Tennessee's Early Intervention System (TEIS). You can reach them at 1-800-852-7157 or get more information about their services at <http://tinyurl.com/tngov-teis>. TEIS is a program that is administered through Tennessee's Department of Education, Division of Special Education, Office of Early Childhood. Its purpose is to help families who have children with developmental delays or disabilities (such as ASD) find supports and services. There are nine TEIS districts within the state of Tennessee.

Once your child is referred to TEIS, a service coordinator from your district will contact you to set up a visit to explain how eligibility is determined and how the system works. They can meet you at your home or another convenient location (such as the public library). It is important to know that if you decide to participate in TEIS, a special plan called an Individualized Family Service Plan (IFSP) will be developed with you. This will spell out your goals for your child and the strategies designed to meet them. As your child approaches his or her third birthday, TEIS will assist you with the transition to school services.

The eligibility evaluation for TEIS and service coordination will be at no cost to you. If a service (e.g., speech-language therapy) needs to be paid for, TEIS must, by law, be the payor of last resort. This means TEIS must use your family's insurance or health coverage to pay for IFSP services. If you do not have insurance, TEIS will work with you to find supports and services and will help pay for them.

If your child is **over 3 years of age**, contact your local school system. Call the school that your child is zoned for or call the Special Education office at your local Board of Education to get the process started. The school may arrange for some additional evaluations (for example, a speech-language evaluation or occupational therapy evaluation) and may ask for your permission to get previous reports (for example, from the clinician who made the ASD diagnosis).

After determining that your child is eligible for special education services through the school system, an IEP or Individual Education Plan will be developed. You are an important part of this process. You will be invited to an M-team (multidisciplinary team) meeting to talk about your child and help develop the

IEP. The IEP will focus on your child's educational needs and will outline what supports or services he/she will receive, how frequently these will be provided, and how progress will be measured.

Regardless of your child's age, there is also an internet community and statewide helpline called Tennessee Disability Pathfinder that keeps an updated list of autism-related resources and provides more information about ASD and steps to services. See familypathfinder.org or call: 1-800-640-4636 to find resources in your specific area of Tennessee. This program provides information about parent support resources, such as the local chapters of the Autism Society of America (ASA) that provide information, support, and advocacy for the autism community:

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

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

Vanderbilt Autism Resource Line

Web: triad.vanderbilt.edu

Toll free: 1-877-273-8862 or Local: 615-322-7565

autismresources@vanderbilt.edu

Middle TN:

Autism Tennessee

Web: www.autismtn.org

Phone: 615-385-2077

Email: admin@autismtn.org

West TN:

Autism Resources of the Mid-South

Web: autismresourcesmidsouth.org

Phone: 901-509-3027

Email: autismresourcesmidsouth@gmail.com

East TN:

Autism Society of East Tennessee

Web: www.asaetc.org

Phone: 865-247-5082

Email: info@asaetc.org

You may want to request the “First 100 Days Kit” available through Autism Speaks. This toolkit assists families of children under 5 years of age in getting the important information they need for the first few months after receiving an ASD diagnosis. In addition to information about ASD, it includes advice about how to deal with the diagnosis and descriptions of the wide range of treatment approaches. The kit also includes a variety of useful forms for keeping track of contacts and treatments, as well as a glossary of terms. The First 100 Days Kit can be accessed at www.autismspeaks.org/family-services/tool-kits.

How do I find out about my child's educational rights?

For a national perspective, you may want to read about the Individuals with Disabilities Education Act (IDEA). This is a federal law that was reauthorized in 2004 (and renamed the Individuals with Disabilities Education Improvement Act) and ensures services to children with disabilities throughout the United States. IDEA governs how states and public agencies provide early intervention, special education, and related services (like speech-language therapy) to eligible infants, toddlers, children, and youth with disabilities.

Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B. See idea.ed.gov/ or The Early Childhood Technical Assistance (ECTA) Center ectacenter.org for more information.

In Tennessee, Support and Training for Exceptional Parents (STEP) is a statewide family-to-family program that is designed to support families by providing free information, advocacy training, and support services to parents of children eligible to receive special education services under IDEA. This includes children with ASD from infancy through age 21 years. There is no charge for services to parents. For more information, contact STEP at 1-800-280-STEP or www.tnstep.org.

What areas should we focus on in our intervention plan?

The IFSP or IEP should address the areas that are challenging for your child. With ASD, this often means helping your child develop practical communication skills, improve social interest and interactions with children and adults, develop play skills and imagination, decrease problem behaviors, and promote overall learning and thinking skills. Since transitions are often difficult for children with ASD, the IFSP or IEP may also include strategies to help your child smoothly manage his or her daily schedule.

Even though children with ASD share certain features, your child will have unique strengths and needs. Consequently, no two intervention plans should be identical. As the names suggest, the IFSP or IEP should be “individualized” and designed specifically for your child.

In addition to teachers, what other specialists should be on our intervention team?

This depends on your child’s unique developmental pattern and needs. Some of the specialists who are often very helpful in working with children with ASD include speech-language pathologists, occupational therapists, physical therapists, and behavior practitioners. You may not need all these specialists on your team, but their roles will be briefly described here, along with links to their professional organization websites, in case you would like more information.

Speech-language pathologists (SLPs) are trained in the assessment, treatment, and prevention of communication disorders. They typically assess and treat difficulties in language understanding and expression and also problems with speech (articulation and fluency). Since communicating with words and gestures is typically hard for young children with ASD, speech-language pathologists are often crucial members of the intervention team. In addition to helping to develop practical communication skills and addressing speech difficulties, some SLPs also have training and experience in treating eating disorders. This is very useful for children with ASD who may be picky eaters or have difficulty tolerating certain food tastes or textures. For more information see the American Speech and Hearing Association website at: www.asha.org.

Occupational therapists (OTs) typically focus on helping people develop fine motor skills (movements involving the smaller muscles of the arms, hands and face), process information from their senses, and carry out daily living activities, such as eating, dressing, and grooming. For young children with ASD, OTs are often helpful in building their play skills, learning self-care skills, and coping with their sensory processing differences. For more information see the American Occupational Therapy Association website at: www.aota.org.

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

Behavior practitioners vary in their training backgrounds. Some will have certification through the Behavior Analyst Certification Board (BACB). Whether you are trying to locate a behavior practitioners through the early intervention or school system or are looking to hire one privately, it is important to find out about their educational background and work experiences with children with ASD.

Behavior practitioners will likely use an approach based in the principles of what is called **Applied Behavior Analysis (ABA)**. While the name sounds intimidating, it is basically an organized approach that looks at what affects someone’s behavior and ability to learn and uses that information to teach new skills. There are a number of specific types of interventions that fall under the category of ABA (discrete trial teaching, pivotal response training, incidental/naturalistic teaching, etc.), but they all use the same basic behavior principles and may include things like visual supports and rewards.

The goals of interventions based in ABA are to increase positive behaviors, to teach new skills, to decrease undesired behaviors, and to help children to use these new skills at home, school, and other settings where they play and interact with other people. Your behavior practitioner should be aware of your child’s IFSP or IEP goals and should keep records to track the progress being made. For more information about

ABA and other treatment approaches, see the “Treating Autism” section of the “First 100 Days Kit” which is available at www.autismspeaks.org/family-services/tool-kits/100-day-kit or the Behavior Analyst Certification Board at www.BACB.com.

Interventions based in ABA are currently the interventions that have the most research support for children with ASD. For more information about what is considered evidence-based practice for children with ASD, see the National Autism Center, National Standards Project, 2015, at www.nationalautismcenter.org/national-standards-project/, and The National Professional Development Center on Autism Spectrum Disorders Evidence-Based Practice Report, 2014, at autismprdc.fpg.unc.edu/sites/autismprdc.fpg.unc.edu/files/2014-EBP-Report.pdf.

What are the characteristics of effective interventions for young children with ASD?

This question was carefully investigated by the National Research Council at the request of the U.S. Department of Education’s Office of Special Education Programs. The multidisciplinary committee that studied this question agreed on the following:

Effective interventions start when ASD is suspected, involve active engagement with the child for at least 25 hours per week, include one-on-one and small group teaching, incorporate parent training, have a low student to teacher ratio in classroom settings, and regularly assess the child’s progress.

As you are developing your child’s IFSP or IEP, these are good principles to keep in mind. See the National Research Council’s (2001) *Educating Children with Autism* at www.nap.edu/openbook.php?isbn=0309072697 for more details.

Should I use alternative or less mainstream treatments?

When you start searching for autism-related treatments, you will find ones that have strong evidence of their effectiveness, such as the behavioral interventions and therapies mentioned above, and you will also find information about a wide array of alternative treatments. As you try to decide whether to use alternative treatments, trust your judgment and be a careful consumer. Be very wary of treatments that promise

a cure or seem too good to be true. Unfortunately, there are people willing to take advantage of anxious parents to make a profit, so be cautious. For more information see the American Academy of Pediatrics website at www.aap.org.

Does my child need to see medical subspecialists?

Children who have a diagnosis of ASD should be evaluated by a physician with expertise in the evaluation and management of autism spectrum disorder.

It is not rare for children with ASD to also have medical problems such as GI disturbances (constipation, reflux, diarrhea), sleep difficulties, feeding issues, or sometimes seizures. While there is no cure for autism, treating conditions that go along with ASD may increase your child’s comfort. When children feel better, they may be more receptive to learning, and consequently they may receive more benefit from educational and therapeutic interventions.

About 15% of children with ASD also have an identifiable syndrome (for example, Fragile X syndrome). Your Primary Care Professional can help refer you to a geneticist or other specialist who can perform the appropriate medical tests. If a specific syndrome is identified, this will give you information to better understand your child and to help make family planning decisions.

Does my child need medication?

There is no medicine that will cure ASD, but there are medicines that can treat some of the symptoms. For example, some children benefit from medication for sleep problems, anxiety, hyperactivity, self-injurious behavior, and mood swings. If you consider medication, talk with your physician about possible side effects and whether the medicine is appropriate for young children. For more information, see the American Academy of Pediatrics website at www.aap.org.

Are my younger (or future) children at risk for autism spectrum disorder?

We know that having one child with ASD does increase the risk for later-born children. Studies have shown that families who have one child with ASD have about a 15-20% chance of having a second child with ASD. This risk is higher if there are two or more children in the family who have the diagnosis. A specific recurrence risk can be provided if your child is diag-

nosed with a genetic syndrome that is associated with autism.

You will want to work with your Primary Care Professional (PCP) to be sure that your younger children get regular developmental and autism-specific screenings during well-child visits. If any concerns arise, your PCP can assist with making referrals for appropriate evaluations and interventions.

What else should I do?

Develop your own personal team of allies for support. Parenting is often very challenging, and we usually don't receive adequate preparation even for typical development. When you are faced with a developmental disability like ASD, parenting can become even more complicated. Assembling a group of people you can trust and rely upon is very important.

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 children or family members. Seek respite care. Ask for assistance from your faith community. If you are feeling so sad or overwhelmed that you feel hopeless or paralyzed, seek out the help of a counselor or therapist.

Talking with other parents who have children with ASD can be invaluable. One very helpful resource that has a well-organized website is Autism Tennessee. See www.autismtn.org. They provide a wealth of information about bimonthly autism orientations, monthly workshop schedules, 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. They also have the largest autism-specific lending library in Tennessee. They can be contacted by phone at 615-385-2077 or 866-508-4987. There is also an online social network specifically for parents of children with ASD that can be found at www.myautismteam.com.

What can I expect for the future?

Even though you have just recently received a diagnosis of ASD, you may already be worrying about what the future will hold for your child. Will he or she be able to go to college, hold a job, or have a family? Asking these questions is very 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 where lots of 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.

This publication was authored by Evon Batey Lee, Ph.D., Associate Professor of Pediatrics at Vanderbilt University, who serves as Associate Director of the Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) Training Program and Training Director of the University Center for Excellence in Developmental Disabilities (UCEDD). It was edited, designed, and produced by the Dissemination and Graphics staff of the Vanderbilt Kennedy Center UCEDD. We are grateful for review and suggestions by many, including Whitney Loring, Psy.D., and other faculty of the Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) and by Autism Tennessee.

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