

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 autism or PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified). Even if you have been suspecting an 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 autism 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 autism?

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

What is the difference between autism and PDD-NOS?

It is often difficult for clinicians to draw a line between autism and PDD-NOS in very young children. In general, a diagnosis of autism (or autistic disorder) is used when children show atypical development before 3 years of age in social interaction, verbal and nonverbal communication, and behavior and interests.

PDD-NOS is used when the social difficulties are present and the child has impaired development in either the communication area OR the behavior and interests area. In reality, clinicians may give the diagnosis of PDD-NOS when the child shows features of autism but functions at the milder end of the spectrum.

Because this is a difficult and confusing issue, clinicians who work with very young children now frequently use the term “autism spectrum disorders” to include both autism and PDD-NOS. To avoid this confusion, it is likely that the next edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) will only use 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 you need will be the same.

What causes autism?

A lot of research is being conducted right now to try to answer this question. In a minority of individuals, autism 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 autism is caused by a combination of gene and environmental factors. At this time there is no evidence that autism 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?

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

How common is autism?

Autism is considered to be the fastest growing developmental disability diagnosis. The Centers for Disease Control and Prevention report that 1 in 110 children in the United States has an autism spectrum disorder and that boys are much more likely to be affected than girls. (See: <http://www.cdc.gov/> for more information.)

How is autism diagnosed?

The diagnosis of autism is based on a child's behaviors. Currently, there is no medical test (e.g., blood test, x-ray, MRI) that can make a diagnosis of autism. 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 evaluate a child to see if the child has autism or a related diagnosis, they look for difficulties in three areas: social interaction, communication, and unusual interests/behaviors.

Social Interaction: Young children with autism have difficulty with the give-and-take of social interactions. Compared to children who are developing more typically, they may be less likely to sustain eye contact with caregivers, to turn when their name is called, to enjoy 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.

Communication: Children with autism 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 regression or 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 show unusual patterns of speaking, such as repeating or echoing phrases they hear people say or that they hear on television or videos. They may ask for things they want but have great difficulty carrying on simple conversations.

Behavior and Interests: Young children with autism often show a more narrow range of play interests than their peers and 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.

Timing: In addition to demonstrating developmental differences in the three areas described above, children with autism must show these different patterns before 3 years of age.

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

A number of behaviors go along with autism spectrum disorders, 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. 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 an ASD might not turn when his name is called, but can hear a key turning in a lock in another room.

Do all children with autism have significant developmental delays?

No, there is a very wide range of abilities in cognitive or thinking skills among children on the autism spectrum. Some children with autism are above average or even gifted. Other children have significant delays in all areas of development. Although the diagnosis of autism 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.

Besides autism and PDD-NOS, are there other conditions that fall under the umbrella category of “autism spectrum disorders?”

There are five conditions that fall under “autism spectrum disorders” (sometimes also called “pervasive developmental disorders”) listed in the formal diagnostic classification system (*Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition).

- (1) Autistic Disorder
- (2) Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- (3) Asperger Disorder
- (4) Rett Syndrome
- (5) Childhood Disintegrative Disorder

Asperger disorder is often not identified until children are older and in school. Children with this disorder generally learn to speak at the typical times and have average intelligence. However, they have difficulties with social interactions, such as making friends, and have strong interests. Boys are much more likely than girls to have Asperger disorder.

Rett syndrome is a very rare condition that primarily affects girls. They develop normally until around 6 to 18 months of age and then start to lose language and social skills. They also show a decrease in using their hands for practical, everyday activities (such as playing with toys and using a spoon to feed themselves). Children with Rett syndrome often have repetitive movements (such as rubbing or clapping their hands). A specific gene has been identified as causing Rett syndrome.

Childhood Disintegrative Disorder (CDD) is even less common than Rett syndrome. Children with CDD develop typically for the first few years of life. Then sometime between 2 and 10 years of age, they lose language, social, play and motor skills. Their intellectual skills may eventually fall in the severe range of intellectual disability (previously called mental retardation), and they may develop seizures.

Should I tell other people my child has an 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 autism or PDD-NOS. 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://www.TN.Gov/education/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 autism) find supports and services. There are nine TEIS districts in 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 IFSP (Individualized Family Service Plan) 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 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 the Tennessee Disability Pathfinder that keeps an updated list of autism-related resources. See <http://kc.vanderbilt.edu/tnpathfinder/> 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:

Autism Society of East Tennessee:

Web: www.asaetc.org
Phone: (865) 247-5082
Email: asaetc@gmail.com

Autism Society of Middle Tennessee:

Web: www.tnautism.org
Phone: (615) 385-2077
(866) 508-4987
Email: asmt@tnautism.org

Autism Society of the Mid-South

Web: www.autismsocietymidsouth.org
Phone: (901) 542-2767
Email: autismsocietymidsouth@yahoo.com

You may want to request the "First 100 Days Kit" available through Autism Speaks. This tool kit assists families of children under 5 years of age in getting the important information they need for the first few months after receiving an autism diagnosis. In addition to information about autism, 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 <http://www.autismspeaks.org/>.

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 <http://idea.ed.gov/> or the National Early Childhood Technical Assistance Center (NECTAC) <http://www.nectac.org/default.asp> for more information.

In Tennessee, STEP (Support and Training for Exceptional Parents) 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 22 years. There is no charge for services to parents. For more information, contact STEP at 1-800-280-STEP or <http://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 ASDs, 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 ASDs, the IFSP or IEP may also include strategies to help your child smoothly manage his or her daily schedule.

Even though children with ASDs 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 ASDs include speech-language pathologists, occupational therapists, physical therapists, and behavior therapists. 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 ASDs 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 ASDs, 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 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 ASDs 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 therapists vary in their training backgrounds. Some will have certification through the Behavior Analyst Certification Board (BACB). Whether you are trying to locate a behavior therapist 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 ASDs.

Behavior therapists will likely implement a therapy called **Applied Behavior Analysis (ABA)**. While the name sounds intimidating, it is basically an organized approach to behavior change where you increase positive behaviors or teach new skills by rewarding the behaviors you want to develop. There are a number of specific types of ABA (discrete trial training, pivotal response training, incidental teaching, etc.), but they all work on the same basic behavior principles.

The goals of 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 therapist 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 <http://www.autismspeaks.org/> or the Behavior Analyst Certification Board at www.BACB.com.

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 <http://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 <http://www.aap.org/> and the National Autism Center, National Standards Project, 2009 at <http://www.nationalautismcenter.org/nsp/>.

Does my child need to see medical subspecialists?

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

It is not rare for children with ASDs 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 ASDs may increase your child's comfort. When children feel better, they may be more receptive to learning, and consequently they may benefit more from educational and therapeutic interventions.

About 15% of children with ASDs 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. See the American Academy of Pediatrics website at <http://www.aap.org/healthtopics/autism.cfm> for more information.

Does my child need medication?

There is no medicine that will cure autism, 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?

We know that having one child with autism does increase the risk for later-born children. Studies have shown that families who have one child with autism have about a 15-20% chance of having a second child with autism. 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 diagnosed 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 an ASD, parenting becomes 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 other 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 an ASD can be invaluable. One very helpful resource that has a well-organized website is the Autism Society of Middle Tennessee (ASMT). See www.tnautism.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.

What can I expect for the future?

Even though you have just recently received a diagnosis of an 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 ASDs. Our hope is that new discoveries will result in more effective treatments that will help your child live a happy, productive life.

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This publication was made possible by Grant No. T73MC00050 from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS.

Printed June 2011. Cover photos from istockphoto.com ©KEVIN RUSS and ©GABRIEL BOONE



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