

AUTISM SPECTRUM DISORDER: FACT SHEET FOR PARENTS

What is autism spectrum disorder (ASD)? Autism spectrum disorder is a developmental, or learning and thinking, disorder. It is caused by a problem with how the brain functions that affects social-emotional, communication, and behavior skills. These brain differences can cause problems such as repetitive behaviors and communication difficulties. The child with ASD has struggles with social communication and social interactions that cannot be explained by developmental *delays*; the child has obsessive and repetitive patterns of behavior, interests, and activities, and may also have unusual reactions to sensations.

How is autism spectrum disorder diagnosed? Professionals with experience diagnosing ASD interview parents about their child's social, communication, and play behaviors, their language skills, and observe the child for behavioral symptoms. They compare the child's symptoms to a list developed by the American Psychiatric Association. They consider whether the child's behavior is unusual for the child's developmental age, or if the symptoms suggest another developmental condition. The symptoms must begin in early childhood and must disrupt the child's day-to-day functioning. If the child has enough symptoms, the child is diagnosed with autism spectrum disorder. The word "spectrum" means that the symptoms of ASD can vary from mild to more severe.

What causes autism spectrum disorder? What we *do* know: parents do not cause autism! ASD is a neurodevelopmental disorder, something that occurs in the early formation of the brain. We also know that early diagnosis and early treatment are very important. ASD comes in many forms with more than one cause. More than 1% or 1 in 88 children in the U.S. have ASD. Research shows that there are many genes that can cause the brain differences in the brain, but the way genes work to cause ASD is still not understood. Researchers are still investigating other possible causes, such as environmental and other triggers. A visit with a geneticist may be helpful in determining if your child's ASD has a specific genetic cause.

Will it get better? All children with ASD improve their social, language and behavioral skills with intensive teaching, beginning with early intervention. Most children with ASD, even those whose symptoms improve greatly, will have some life-long differences in behavior and social communication. Remember that each child is unique and that all children with ASD are different in their needs and symptoms.

What are the treatments for ASD? Developmental and behavioral interventions are the mainstay of treatment. For children with severe delays in communication and social interaction, the treatment focus is primarily on improving simple behaviors, like pointing toward or looking at an object, and vocalizing to communicate. A therapist often gives small rewards to the child. This treatment is most effective when parents learn and use the same techniques with their child. For children who have mild symptoms, there are other interventions that help teach the child language and social skills. Treatment or educational programming is best when it is led by an individual or team with experience in ASD.

What can I do as a parent to help my child? Keep doing all the good things you've done as a parent. Ask to be taught some of the intervention techniques so you can do them with your child. Learn as much as you can about your child's diagnosis so that you can be an informed member of your child's team. Ask for respite services so you get a break and can have the energy to be a parent and also a special teacher for your child. Reach out to other families to share strategies and resources.

Are there medications that can help? At this time, there are no medications that can cure ASD. As children with ASD grow and develop they may also have symptoms of anxiety or depression. Some children may have self-injurious behaviors, repetitive behaviors and interests, or distractibility, impulsivity and hyperactivity (ADHD). Sometimes a pediatrician or child psychiatrist can reduce these symptoms with medications.

What can my child's primary care provider do to help? Your pediatrician or primary care provider (your “medical home”) can help you:

- to monitor for medical issues which may occur more frequently in children with ASD
- to coordinate medical care and appointments for your child
- to make decisions about treatment options and make referrals if there are significant behavioral challenges, anxiety, or mood concerns
- to prescribe treatments that are now covered under insurance in Vermont
- to participate in your child’s team meetings
- to advocate for your needs as a family in caring for your child

Should our child be seen in Child Development Clinic again? We may make a specific plan with you at your child’s CDC appointment to return for an update or re-evaluation. We also remain available at any time for your concerns or questions; you may request a follow-up visit as well. When children have an established diagnosis and a good treatment program there is often less need to follow up with the CDC team.

Who else can help me? Your child’s early intervention, early education or special-education team at your child’s school, as well as service providers from your community developmental service agency can help. Meeting regularly with your child’s team can be very helpful. Other parents of children with ASD, and parent advocacy groups such as the Vermont Family Network, can provide lots of practical ideas and support to families. More information and resources, including information about how to access ASD insurance coverage for VT children, and links to national organizations can be found at www.vermontfamilynetwork.org/i-need-help-with/developmental-disabilities/autism/.

We also recommend the following books and reliable internet sites:

- The Autism Speaks 100 Day Kit was created specifically for newly diagnosed families to help them make the best possible use of the 100 days following the diagnosis of an ASD: www.autismspeaks.org/docs/family_services_docs/100_day_kit.pdf
- The National Professional Development Center website has information on 24 evidence-based interventions for teaching children with ASD’s: <http://autismpdc.fpg.unc.edu/content/briefs>
- The Center for Disease Control and Prevention ASD fact sheet: http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/autismfactsheet.pdf
- *Sound Advice on Autism*, a collection of interviews through the American Academy of Pediatrics (AAP) for parents featuring pediatricians, researchers and parents to help answer parent’s questions about ASD: <http://www.aap.org/audio/autism/>
- The Vermont Next Steps Guide has helpful information and statewide resources for VT families with children with an ASD: <http://www.ddas.vermont.gov/ddas-publications/publications-autism/publications-autism-documents/next-steps-autism>
- For help with paying for equipment, special toys, or services for VT children with ASD apply to the Autism Puzzle Foundation: www.vtautopuzzle.org
- Autism Spectrum Disorders: What Every Parent Needs to Know, edited by Alan Rosenblatt, MD, Paul Carbone, MD, and Winnie Yu, published by American Academy of Pediatrics, 2013.
- Making Sense of Autism Spectrum Disorders: Create the Brightest Future for Your Child with the Best Treatment Options, by James Coplan, MD, Bantam Books, NY, 2010.

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