

Autism Spectrum Disorder

TIPS AND RESOURCES FOR FAMILIES



What is autism spectrum disorder?

Autism and autism spectrum disorder (ASD) are general terms for a group of complex neurodevelopmental disorders. The new diagnostic classification system (DSM-5, May 2013) combines the previous subcategories of autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder—not otherwise specified (PDD-NOS) into the one category of ASD.

Autism spectrum disorder is present early in life and is characterized by varying degrees of impairment in:

- Communication/language
- Social abilities
- Restricted/unusual patterns of activities and interests

The characteristics of ASD can be present in different combinations and at different levels of severity. Often specific behaviors vary widely from person to person. ASD occurs in as many as 1 in 59 children, is about 4-5 times more common in boys than in girls, and occurs in all racial, ethnic, and social groups.

What causes ASD?

The specific causes are not yet known, although there is consensus that genetic vulnerability and unidentified environmental factors cause atypical brain development related to core features. While scientists are looking into possible environmental origins, there is no current established scientific link to proposed causes such as vaccines, diet, or toxin/environmental exposure.

How can I tell if a child has an ASD?

There are at present no medical or genetic tests specific to ASD. Diagnosis is determined by assessing and observing a child's behavior. No two children with autism are alike, but some features may be identifiable as early as 18 months, or even sooner. Early red flags include delayed language, deficits in nonverbal communication (e.g., pointing, eye contact), inconsistent response to sounds (especially name), failure to direct parent's attention, underdeveloped imitation, lack of interest in other children, and repetitive toy play. Not every child with ASD will have difficulties in all of these areas. The isolated presence of one of these behaviors does not warrant an ASD diagnosis. It is the collection of these behavior patterns that leads to a diagnosis.

What should I do if I am concerned about my child?

Parents and other caregivers are typically the first to notice unusual behaviors. Some parents describe children whose development has been atypical since birth, while others describe children who were developing typically and then seemed to lose skills. Other parents do not notice atypical behaviors until their child enters school. Early identification and early intervention are key to optimizing outcomes. If you have concerns, talk to your pediatrician or a behavioral professional immediately about getting your child screened for ASD.

How is autism treated?

At present, there is no cure for autism; however, research indicates that extensive and intensive behavioral intervention can dramatically improve the lives of children with ASD and their families. There is no single treatment protocol for all children with ASD, but many different behavioral and educational programs have demonstrated positive effects. Some of the most common interventions are applied behavior analysis (ABA), speech therapy, occupational therapy, parenting programs, and structured teaching methods. An important aspect of any intervention program is that each child's treatment is tailored to meet his or her individual needs.

Please see reverse for resources.



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RESOURCES

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. The following are some of the ways the Center's programs and staff can assist families, educators, and other service providers. Contact vk.vumc.org, (615) 322-8240, toll-free (866) 936-8852.

Vanderbilt Autism Resource Line

Free information and referral service for parents, teachers, and community professionals. Information is available about autism-specialized diagnostic evaluation services, school consultation, parent workshops, and professional training at Vanderbilt for children, adolescents, and adults with ASD. Contact autismresources@vanderbilt.edu, or (615) 322-7565, or toll-free (877) 273-8862.

Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)

TRIAD is a Vanderbilt Kennedy Center program dedicated to improving assessment and treatment services for children with autism spectrum disorders and their families while advancing knowledge and training. See triad.vumc.org or call (615) 322-7565.

TRIAD Clinical Services

TRIAD offers clinical services to families with children who have, or are suspected of having, an autism spectrum disorder. Services include diagnostic assessment and behavioral consultation for children up to age 18. Services are facilitated through the Department of Pediatrics Developmental Medicine Clinic at the Monroe Carell Jr. Children's Hospital at Vanderbilt, as well as through research projects. For information and referral contact autismresources@vanderbilt.edu, or (615) 322-7565, or toll-free (877) 273-8862.

TRIAD Outreach & Training

TRIAD provides services and training for families, educators, and other professionals, and conducts school consultations. See triad.vumc.org or call (615) 322-7565.

TRIAD Families First Program

This free training series provides parents of children with autism (ages 2-5) with techniques to enhance social and communication skills and to manage challenging behaviors. Contact familiesfirst@vanderbilt.edu or (615) 322-7565.

TRIAD Research

TRIAD-directed research programs and affiliated research partnerships examine the causes and treatment of autism. These include projects related to the development of siblings of children with autism, the identification of genetic and core behavioral features of autism, the nature and treatment of sleep disturbance in children with autism, the diagnosis of autism itself, early intervention, and understanding the health and well-being of parents of children with autism. For information on and referral to TRIAD research projects see listing on Vanderbilt Autism Resource Line.

Two Easy Ways to Take Part in Research

The Vanderbilt Kennedy Center serves families through research studies. StudyFinder is a searchable database that lists current VKC studies, including ASD research. Studies seek people of all ages with and without developmental disabilities. See vk.vumc.org/studyfinder/. Research Match is a secure place for volunteers and researchers to connect. Once you sign up and get added to the registry, a researcher will contact you if you're a possible match for the research study. See www.researchmatch.org.

Tennessee Disability Pathfinder

Tennessee Disability Pathfinder provides free information, referral sources, and help with navigating services via phone, email, and website. Assistance is available to individuals of all ages, all types of disabilities, and all languages spoken. Its website database has more than 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities. Contact www.familypathfinder.org, (615) 322-8529, toll-free (800) 640-4636.

Other National and Local Resources

- Autism Society of America, www.autism-society.org
- Autism Tennessee, www.autismtn.org
- Autism Speaks, www.autismspeaks.org
- Centers for Disease Control and Prevention – Autism Information Center, www.cdc.gov/ncbddd/autism/index.htm
- KidsHealth for kids, teens, and parents, www.kidshealth.org
- National Institute of Child Health and Human Development, www.nichd.nih.gov/health/topics/autism/pages/default.aspx
- Tennessee Developmental Disabilities Network www.tennddnetwork.org
- Tennessee Early Intervention System (TEIS), www.tn.gov/education/early-learning/tennessee-early-intervention-system-teis.html

