

Autism Society of America

What is Autism



**A Resource on: Autism, Asperger's
Syndrome, Pervasive Developmental
Disorder, and PDD-NOS**

This information is brought to you by:

Autism Society of America

*The voice and resource of
the autism community.*

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What is Autism?

Autism is a complex developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects the functioning of the brain, autism and its associated behaviors have been estimated to occur in as many as 1 in 500 individuals (Centers for Disease Control and Prevention 1997). Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence.

Autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. In some cases, aggressive and/or self-injurious behavior may be present. Persons with autism may exhibit repeated body movements (hand flapping, rocking), unusual responses to people or attachments to objects and resistance to changes in routines. Individuals may also experience sensitivities in the five senses of sight, hearing, touch, smell, and taste.

Over one half million people in the U.S. today have autism or some form of pervasive developmental disorder. Its prevalence rate makes autism one of the most common developmental disabilities. Yet most of the public, including many professionals in the medical, educational, and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with autism.

What is the Autism Society of America?

Founded in 1965 by a small group of parents, the Autism Society of America (ASA) continues to be the leading source of information and referral on autism and the largest collective voice representing the autism community for more than 33 years. Today, more than 24,000 members are connected through a volunteer network of over 240 chapters in 50 states.

The mission of the Autism Society of America is to promote lifelong access and opportunities for persons within the autism spectrum and their families, to be fully included, participating members of their communities through advocacy, public awareness, education, and research related to autism.

In addition to its volunteer Board of Directors, composed primarily of parents of individuals with autism, the ASA has a Panel of Professional Advisors, comprised of nationally known and respected professionals who provide expertise and guidance to the Society on a volunteer basis.

The ASA is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families, and the professionals with whom they interact. The Society and its chapters share common goals of providing information and education, supporting research, and advocating for programs and services for the autism community.

Is There More Than One Type of Autism?

Several related disorders are grouped under the broad heading "Pervasive Developmental Disorder" or PDD—a general category of disorders which are characterized by severe and pervasive impairment in several areas of development (American Psychiatric Association 1994). A standard reference is the *Diagnostic and Statistical Manual (DSM)*, a diagnostic handbook now in its fourth edition. The DSM-IV lists criteria to be met for a specific diagnosis under the category of Pervasive Developmental Disorder. Diagnosis is made when a specified number of characteristics listed in the *DSM-IV* are present. Diagnostic evaluations are based on the presence of specific behaviors indicated by observation and through parent consultation, and should be made by an experienced, highly trained team. Thus, when professionals or parents are referring to different types of autism, often they are distinguishing autism from one of the other pervasive developmental disorders.

Individuals who fall under the Pervasive Developmental Disorder category in the *DSM-IV* exhibit commonalities in communication and social deficits, but differ in terms of severity. We have outlined some major points that help distinguish the differences between the specific diagnoses used:

- ▲ **Autistic Disorder** — impairments in social interaction, communication, and imaginative play prior to age 3 years. Stereotyped behaviors, interests and activities.
- ▲ **Asperger's Disorder** — characterized by impairments in social interactions and the presence of restricted interests and activities, with no clinically significant general delay in language, and testing in the range of average to above average intelligence.
- ▲ **Pervasive Developmental Disorder—Not Otherwise Specified** — (commonly referred to as atypical autism) a diagnosis

of PDD-NOS may be made when a child does not meet the criteria for a specific diagnosis, but there is a severe and pervasive impairment in specified behaviors.

- ▲ **Rett's Disorder** — progressive disorder which, to date, has occurred only in girls. Period of normal development and then loss of previously acquired skills, loss of purposeful use of the hands replaced with repetitive hand movements beginning at the age of 1-4 years.

- ▲ **Childhood Disintegrative Disorder** — normal development for at least the first 2 years, significant loss of previously acquired skills.

(American Psychiatric Association 1994)

Autism is a *spectrum disorder*. In other words, the symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit *any combination* of the behaviors in *any degree of severity*. Two children, both with the same diagnosis, can act very differently from one another and have varying skills.

Therefore, there is no standard "type" or "typical" person with autism. Parents may hear different terms used to describe children within this spectrum, such as: autistic-like, autistic tendencies, autism spectrum, high-functioning or low-functioning autism, more-abled or less-abled. More important to understand is, whatever the diagnosis, children can learn and function productively and show gains from appropriate education and treatment. The Autism Society of America provides information to serve the needs of all individuals within the spectrum.

Diagnostic categories have changed over the years as research progresses and as new editions of the DSM have been issued. For that reason, we will use the term "autism" to refer to the above disorders.

What Causes Autism?

Researchers from all over the world are devoting considerable time and energy into finding the answer to this critical question. Medical researchers are exploring different explanations for the various forms of autism. Although a single specific cause of autism is not known, current research links autism to biological or neurological differences in the brain. In many families there appears to be a pattern of autism or related disabilities—which suggests there is a genetic basis to the disorder—although at this time no gene has been directly linked to autism. The genetic basis is believed by researchers to be highly complex, probably involving several genes in combination.

autism when assessing learning and behavior to ensure effective intervention. Individuals with autism can learn when information about their unique styles of receiving and expressing information is addressed and implemented in their programs. The abilities of an individual with autism may fluctuate from day to day due to difficulties in concentration, processing, or anxiety. The child may show evidence of learning one day, but not the next. Changes in external stimuli and anxiety can affect learning. They may have average or above average verbal, memory or spatial skills but find it difficult to be imaginative or join in activities with others. Individuals with more severe challenges may require intensive support to manage the basic tasks and needs of living day to day.

Contrary to popular understanding, many children and adults with autism may make eye contact, show affection, smile and laugh, and demonstrate a variety of other emotions, although in varying degrees. Like other children, they respond to their environment in both positive and negative ways. Autism may affect their range of responses and make it more difficult to control how their bodies and minds react. Sometimes visual, motor, and/or processing problems make it difficult to maintain eye contact with others. Some individuals with autism use peripheral vision rather than looking directly at others. Sometimes the touch or closeness of others may be painful to a person with autism, resulting in withdrawal even from family members. Anxiety, fear and confusion may result from being unable to "make sense" of the world in a routine way. With appropriate treatment, some behaviors associated with autism may change or diminish over time. The communication and social deficits continue in some form throughout life, but difficulties in other areas may fade or change with age, education, or level of stress. Often, the person begins to use skills in natural situations and to participate in a broader range of interests and activities. Many individuals with autism enjoy their lives and contribute to their community in a meaningful way. People with autism can learn to compensate for and cope with their disability, often quite well.

While no one can predict the future, it is known that some adults with autism live and work independently in the community (drive a car, earn a college degree, get married); some may be fairly independent in the community and only need some support for daily pressures; while others depend on much support from family and professionals. Adults with autism can benefit from vocational training to provide them with the skills needed for obtaining jobs, in addition to social and recreational programs. Adults with autism may live in a variety of residential settings, ranging from an independent home or apartment to group homes, supervised apartment settings, living with other family members or more structured residential care. An increasing number of support groups for adults with autism are emerging around the country. Many self-advocates

are forming networks to share information, support each other, and speak for themselves in the public arena. More frequently, people with autism are attending and/or speaking at conferences and workshops on autism. Individuals with autism are providing valuable insight into the challenges of this disability by publishing articles and books and appearing in television specials about themselves and their disabilities.

Autism Check List

Individuals with autism usually exhibit at least half of the traits listed below. These symptoms can range from mild to severe and vary in intensity from symptom to symptom. In addition, the behavior usually occurs across many different situations and is consistently inappropriate for their age.

- ▲ Insistence on sameness; resists changes in routine
- ▲ Severe language deficits
- ▲ Difficulty in expressing needs; uses gestures or pointing instead of words
- ▲ Echolalia (repeating words or phrases in place of normal, responsive language)
- ▲ Laughing, crying, or showing distress for reasons not apparent to others
- ▲ Prefers to be alone; aloof manner
- ▲ Tantrums—displays extreme distress for no apparent reason
- ▲ Difficulty in mixing with others
- ▲ May not want cuddling or act cuddly
- ▲ Little or no eye contact
- ▲ Unresponsive to normal teaching methods
- ▲ Sustained odd play
- ▲ Spins objects
- ▲ Inappropriate attachment to objects
- ▲ Apparent oversensitivity or undersensitivity to pain
- ▲ No real fear of dangers
- ▲ Noticeable physical overactivity or extreme underactivity
- ▲ Not responsive to verbal cues; acts as if deaf although hearing tests in normal range
- ▲ Uneven gross/fine motor skills (may not kick a ball but can stack blocks)

Please note this symptom list is not a substitute for a full-scale diagnostic assessment.

Consult your health care provider to obtain a complete diagnostic evaluation.

What are the Most Effective Approaches?

Evidence shows that early intervention results in dramatically positive outcomes for young children with autism. While various pre-school models emphasize different program components, all share an emphasis on early, appropriate, and intensive educational interventions for young children. Other common factors may be: some degree of inclusion, mostly behaviorally-based interventions, programs which build on the interests of the child, extensive use of visuals to accompany instruction, highly structured schedule of activities, parent and staff training, transition planning and follow-up. Because of the spectrum nature of autism and the many behavior combinations which can occur, no one approach is effective in alleviating symptoms of autism in all cases. Various types of therapies are available, including (but not limited to) applied behavior analysis, auditory integration training, dietary interventions, discrete trial teaching, medications, music therapy, occupational therapy, PECS, physical therapy, sensory integration, speech/language therapy, TEACCH, and vision therapy.

Studies show that individuals with autism respond well to a highly structured, specialized education program, tailored to their individual needs. A well designed intervention approach may include some elements of communication therapy, social skill development, sensory integration therapy and applied behavior analysis, delivered by trained professionals in a consistent, comprehensive and coordinated manner. The more severe challenges of some children with autism may be best addressed by a structured education and behavior program which contains a one-on-one teacher to student ratio or small group environment. However, many other children with autism may be successful in a fully inclusive general education environment with appropriate support.

In addition to appropriate educational supports in the area of academics, students with autism should have training in functional living skills at the earliest possible age. Learning to cross a street safely, to make a simple purchase or to ask assistance when needed are critical skills, and may be difficult, even for those with average intelligence levels. Tasks that enhance the person's independence and give more opportunity for personal choice and freedom in the community are important.

To be effective, any approach should be flexible in nature, rely on positive reinforcement, be re-evaluated on a regular basis and provide a smooth transition from home to school to community environments. A good program will also incorporate training and support systems for parents and caregivers, with generalization of skills to all settings.

Rarely can a family, classroom teacher or other caregiver provide effective habilitation for a person with autism unless offered consultation or in-service training by an experienced specialist who is knowledgeable about the disability.

A generation ago, the vast majority of the people with autism were eventually placed in institutions. Professionals were much less educated about autism than they are today; autism specific supports and services were largely non-existent. Today the picture is brighter. With appropriate services, training, and information, most families are able to support their son or daughter at home. Group homes, assisted apartment living arrangements, or residential facilities offer more options for out of home support. Autism-specific programs and services provide the opportunity for individuals to be taught skills which allow them to reach their fullest potential.

Families of people with autism can experience high levels of stress. As a result of the challenging behaviors of their children, relationships with service providers, attempting to secure appropriate services, resulting financial hardships, or very busy schedules, families often have difficulty participating in typical community activities. This results in isolation and difficulty in developing needed community supports. **The Autism Society of America is here for you.**

Members of the ASA represent all walks of life from rural to metropolitan communities. Embracing the *diversity* of our group, the ASA seeks to provide an open forum for the exchange of ideas. At the very core of the ASA's philosophy is the belief that no single program or treatment will benefit all individuals with autism. Furthermore, the recommendation of what is "best" or "most effective" for a person with autism should be determined by those people directly involved — the individual with autism, to the extent possible, and the parents or family members.

The ASA provides information and education (including results of empirically-based scientific research on effective strategies) to assist parents, educators, and others in the decision-making process. Providing information on available intervention options, rather than advocating for any particular theory or philosophy, is the focus at the ASA.

Is There a Cure?

Understanding of autism has grown tremendously since it was first described by Dr. Leo Kanner in 1943. Some of the earlier searches for "cures" now seem unrealistic in terms of today's understanding of brain-based disorders. To cure means "to restore to health, soundness, or normality." In the medical sense, there is no cure for the differences in the brain which result in autism.

However, better understanding of the disorder has led to the development of better coping mechanisms and strategies for the various manifestations of the disability. Some of these symptoms may lessen as the child ages; others may disappear altogether. With appropriate intervention, many of the associated behaviors can be positively changed, even to the point in some cases, that the child or adult may appear to the untrained person to no longer have autism. The majority of children and adults will, however, continue to exhibit some manifestations of autism to some degree throughout their entire lives.

The ASA Promotes Research Through the ASA Foundation

The Autism Society of America Foundation (ASAF) was founded with the primary mission to raise and allocate funds for research to address the many unanswered questions about autism. We are still far from fully understanding autism and knowing how to prevent it.

The ASAF has implemented action on several pressing autism research priorities as areas of initial focus: developing and publicizing up-to-date prevalence statistics; quantifying the societal and family economic consequences of autism; developing a national registry of individuals and families with autism who are willing to participate in research studies; and implementing a system to identify potential donors of autism brain tissue for research purposes and facilitating the donation process. In addition, the Foundation is contributing substantial funds for applied and biomedical research in the causes of and treatment approaches to autism.

References:

Dr. Christopher Gillberg, Centers for Disease Control and Prevention Conference *Autism: Emerging Issues in Prevalence and Etiology*, 1997
Diagnostic and Statistical Manual of Mental Disorders 4th ed., (DSM-IV™), American Psychiatric Association, Washington, DC, 1994.

Where Can I Get More Information?

Educating yourself and others about autism is a critical way to assist with the education and development of the individual with autism and to help society understand the nature of this common developmental disorder. Information packages on a variety of autism-related topics are available from the Autism Society of America. To request additional information or to find answers to other questions on autism, please call or write ASA. *We are here to help.*

Autism Society of America Services and Benefits

The Autism Society of America prides itself on being a vital source of current information and support for parents, educators, service providers, and medical professionals.

The Advocate Newsletter

Frequently referred to as the "best" benefit of membership in the Society, the ASA publishes the largest, most comprehensive national newsletter devoted to autism. Six issues each year present the latest developments in the field. Articles written by respected autism professionals sit side by side with stories from parents sharing the triumphs and challenges of life with autism.

Information and Referral

Staff at the ASA national office respond to requests from more than 1,500 callers each month and distribute information on a variety of autism related topics.

- ▲ The ASA provides a toll-free line for information, **800-3AUTISM, Extension 150**
- ▲ ASA's award winning World Wide Web Site allows access to vital autism and ASA information <http://www.autism-society.org/>
- ▲ Responding to the needs of approximately 300 members outside the U.S., ASA has expanded the range of materials available about autism and other related disorders in English, Spanish, French, Chinese, and Vietnamese.
- ▲ Two ASA Chapter operated mail-order bookstores offer over 160 titles covering both classic and contemporary publications.

Autism Society of America Foundation

The latest step in ASA's long-term commitment to autism research was made with the formation of the ASA Foundation (ASAF) in 1996. The ASAF is committed to advancing research that will yield new information about autism, lead to better treatments, and ease the challenges that autism presents us with every day. ASAF projects include the Autism Research Registry, to enhance research capabilities by giving researchers controlled access to potential research participants; the Autism Tissue Program, to make available brain tissue for biomedical research; Applied Autism Research Projects, designed to advance research into the social, cognitive, educational, and behavioral issues associated with autism; and Biomedical Research Projects, to advance better understanding and treatment of autism. For more information on the ASA Foundation, please call 800-328-8476.

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