

What is Autism?

Autism is a complex developmental disability that typically appears during the first three years of life. Autism significantly affects verbal and nonverbal communication and social interaction which adversely affects a child's educational performance. Symptoms range from mild to severe. Activities that are often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. 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 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.

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 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.

Several outdated theories about the cause of autism have been proven to be false. Autism is **not** a mental illness. Children with autism are **not** unruly kids who choose not to behave. Autism is **not** caused by bad parenting. Furthermore, no known psychological factors in the development of the child have been shown to cause autism.

How is Autism Diagnosed?

There are no *medical* tests for diagnosing autism. An accurate diagnosis must be based on observation of the individual's communication, behavior, and developmental levels. However, because many of the behaviors associated with autism are shared by other disorders, various medical tests may be ordered to rule out or identify other possible causes of the symptoms being exhibited.

Since the characteristics of the disorder vary so much, ideally a child should be evaluated by a multidisciplinary team which may include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant, or another professional knowledgeable about autism. Diagnosis is difficult for a practitioner with limited training or exposure to autism. Sometimes, autism has been misdiagnosed by well-meaning professionals. Difficulties in the recognition and acknowledgment of autism often lead to a lack of services to meet the complex needs of individuals with autism.

A brief observation in a single setting cannot present a true picture of an individual's abilities and behaviors. Parental (and other caregivers') input and developmental history are very important components of making an accurate diagnosis. At first glance, some persons with autism may appear to have mental retardation, a behavior disorder, problems with hearing, or even odd and eccentric behavior. To complicate matters further, these conditions can co-occur with autism. However, it is important to distinguish autism from other conditions, since an accurate diagnosis and early identification can provide the basis for building an appropriate and effective educational and treatment program. Sometimes professionals who are not knowledgeable about the needs and opportunities for early intervention in autism do not offer an autism diagnosis even if it is appropriate. This hesitation may be due to a misguided wish to spare the family. Unfortunately, this too can lead to failure to obtain appropriate services for the child.

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

a 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

characterized by normal development for at least the first 2 years, significant loss of previously acquired skills. (*American Psychiatric Association 1994*)

What are People with Autism Like?

Children within the pervasive developmental disorder spectrum often appear relatively normal in their development until the age of 24-30 months, when parents may notice delays in language, play or social interaction. Any of the following delays, by themselves, would not result in a diagnosis of a pervasive developmental disorder. Autism is a combination of several developmental challenges.

The following areas are among those that may be affected by autism:

Communication:

language develops slowly or not at all; uses words without attaching the usual meaning to them; communicates with gestures instead of words; short attention span;

Social Interaction:

spends time alone rather than with others; shows little interest in making friends; less responsive to social cues such as eye contact or smiles;

Sensory Impairment:

may have sensitivities in the areas of sight, hearing, touch, smell, and taste to a greater or lesser degree;

Play:

lack of spontaneous or imaginative play; does not imitate others' actions; does not initiate pretend games;

Behaviors:

may be overactive or very passive; throws tantrums for no apparent reason; perseverates (shows an obsessive interest in a single item, idea, activity or person)

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.

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

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.

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.