

ASW on . . . AUTISM SPECTRUM DISORDER

Courtesy of the **Autism Society of Wisconsin**

Autism is a **neurobiological disorder** most frequently identified by difficulties and differences in a person's ability to communicate, understand language, play, and relate to others. Autism is described as a **spectrum disorder**. Individuals display a wide variety of characteristics, ranging from a few to many symptoms. Currently, there is **no known cause**. Autism has been found throughout the world in families of all racial, ethnic, and social backgrounds. Autism affects approximately 67 out of 10,000 people and occurs more frequently in boys than girls. The characteristic behaviors of autism may or may not be apparent in infancy, but become more obvious during early development. Autism can occur in combination with other disabilities and be present in a child who is also affected by other physical or environmental stressors. **Without early identification and appropriate intervention, progress can be limited.**

Autism was first brought to the attention of the medical profession in 1943 by Leo Kanner. Kanner described a group of children who displayed behaviors that later became defined as a separate syndrome. Initially, it was thought that these individuals' problems were due to social and environmental factors. As more information became available, it became obvious that the disorder was a result of a neurological impairment.

Autism is defined by observed behaviors. **There are no medical tests that identify individuals with autism.** There are medical tests that rule out or identify other, possibly underlying, problems. Diagnosis is usually made based on a child displaying a certain number of behaviors on a checklist, on early developmental history, and parent reports.

People with autism process and respond to information in unique ways. Educators and other service providers must consider the unique pattern of learning strengths and difficulties in autism when assessing learning and behavior to ensure effective intervention. Children with autism can learn when information about their unique styles of receiving and expressing information is incorporated into their programs.

The behaviors associated with autism are often most prominent during the early years. The communication and social deficits continue in some form throughout life, but difficulties in other areas may fade or change form with age, education, or level of stress. Often, the person begins to use skills in important, natural situations and to participate in a broader range of interests and activities.

Until recently, autism was considered a life-long disability with poor prognosis. Now, with early and appropriate treatment, many people with autism are able to live, work, and play in their communities. People with autism can learn to compensate for and cope with their disability, often quite well.

- Children with autism are **learning in regular education classrooms**, with and from their peers.
- Students with autism **continue their education beyond high school**. Some people with autism graduate from college.
- Adults with autism, even those who face many challenging symptoms, are **capable of holding jobs in the community**.
- Fewer people with autism live in institutions or large group living arrangements, more are **living in a home and community of their own**.
- People with autism receive assistance in the form of **support in the natural settings of daily life** (at school, on the job, and in their homes).
- People with autism are **becoming self-advocates**. Some are forming networks to share information, support each other, and speak up for themselves in the public arena. More frequently, people with autism are attending and/or speaking at conferences and workshops on autism.
- People with autism are **providing valuable insight into the challenges of this disability** by publishing articles and books and television specials about themselves and their disabilities.

CHARACTERISTICS OF AUTISM

Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. Some of the characteristics that occur more frequently in people who have autism are described below. A particular characteristic may or may not be present in a particular individual.

Development

Development may appear normal until about age two, when characteristics of autism begin to be noticed or a regression in previously acquired skills occurs. Alternatively, interactions with others may be impaired from birth.

Difficulties or delays in acquiring daily living skills may result from difficulties conceptualizing time, processing body signals or sensory information, movement disturbances, anxiety, or other causes. These skills can include toileting, dressing, eating particular foods, using table utensils, sleeping, and other activities performed by most of the child's peers.

Pretend play, such as play-acting adult roles, is absent during early childhood development. A child may show no interest in imaginative events and stories but be very interested in specific factual information, such as maps, presidents, trains, Africa. The variety of activities may be very limited. Play is a source of pleasure but is unusual in form, such as putting a puzzle together upside down, lining up toys, or throwing crayons down a heating vent.

Some children are very active, others very quiet, and some alternate between the two. Many have difficulty waiting and want things right away.

Some carry around favorite objects that provide comfort and/or calming during transitions from one activity to the next or reflect an intense interest in certain objects.

Seizure disorders may be present in addition to autism. Onset of seizure disorders is frequently at the time of puberty. Other disorders may coexist with autism, including obsessive-compulsive disorder, anxiety, and hyperactivity.

Communication and Social Characteristics

Most preschool children have difficulty understanding language. Some show no communicative babbling, facial expressions, gesture, spoken language.

Most have difficulty in letting others know their needs. They get what they want by themselves or by difficult behaviors (e.g., tantrums aggressions) until the person correctly guesses what is wanted. Others show what they want by taking a person's hand and placing it on the desired object.

Most have difficulty using nonverbal communication in social interactions, such as eye gaze, facial expressions, body posture, or gestures. The baby or toddler doesn't anticipate being held, stiffens when held, doesn't look or smile as approaching others, greet parents or visitors.

Verbal children may repeat words and phrases heard in the past, or repeat what was just said; use "you" for "I" (e.g., "You want a cookie" means "I want a cookie"); repeat stories, TV shows, commercials; and ask the same questions over and over. Some not only repeat words/conversations heard, but also imitate others' movements and gestures.

Often children use phrases and sentences that have personal meaning, but aren't understood by others ("Go to green riding" means "I want to go on the swing").

The child may have difficulty in communicating to others when ill, hurt, or tired and may not seek comfort. Others may rely on familiar routines/phrases to signal discomfort (e.g., always wants a band-aid when in pain regardless of the cause). The child can be difficult to console when upset. The child may laugh or cry or show distress for reasons not observable to others.

The child may have difficulty initiating and/or maintaining a conversation, keeping a conversation going. Communication is described as talking at others (e.g., a monologue on a favorite subject that continues despite attempts to interject comments).

Often the child has difficulty in knowing how to make friends and maintain relationships with others. There may be difficulties in initiating interactions with others and showing their awareness of the views of others. The child may intrude on others' privacy without realizing it.

Many children are interested in a limited variety of activities, such as gathering information on meteorology, doing puzzles, pretending to be a fantasy character. Sensory, social, and communication impairments limit the range of activities and interests.

Doesn't show pretend play, such as play-acting adult roles. No interest in stories or imaginative events, but be very interested in factual information (e.g., maps, presidents, Africa). Play is a source of pleasure, though unusual in form (e.g., putting a puzzle together upside down, throwing crayons down a heat vent).

Learning Characteristics

Process information in unique ways and have difficulty learning under ordinary teaching methods. Some learn to read and/or master math concepts at a very young age.

Abilities can fluctuate from day to day due to difficulties in concentration, processing, or anxiety. The child shows evidence of learning one day, but not the next. Changes in external stimuli and anxiety can affect learning.

Often children have difficulty when daily routines are changed, such as when a different route is taken on a shopping trip. The resulting confusion results in severe anxiety. The child needs things to remain the same to be able to cope with the environment and/or the impact of stimuli.

Sensory Characteristics

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Smell and taste are used to explore the world. The impulse to respond to the sensory environment may put the person in danger.

The touch or closeness of others may be painful, resulting in withdrawal even from the family members.

Repeated movements or spinning objects or self is theorized to be a need for sensory stimulation, response to over-stimulation, reaction to stress, outlet for high activity level, or difficulty finding a way to structure time, or inability to inhibit movement.

Oversensitivity to sounds may be present and result in covering their ears. Responses to sound may be inconsistent or dependent on pitch.

Lining up objects or insisting on sameness in routines and the physical environment may be a means of creating order and lessening processing demands. Even very small changes (an object is moved from its usual position, a teacher wears a different perfume or gets a haircut) may be upsetting.

Emotional outbursts may be the response to severe difficulties in processing sensory information. Anxiety, fear and confusion may result from being unable to "make sense" of the world in a routine way. Routine stimuli may be perceived as novel, and the child may not attend to novel stimuli.

DIAGNOSIS AND EDUCATIONAL INTERVENTION

Medical diagnosis and educational identification of autism is sometimes difficult or confusing due to the wide range of behaviors and abilities present among people with autism. **Medical diagnosis** is most frequently made according to the diagnostic and statistical manual DSM-IV, 1994) of the American Psychiatric Association. This manual guides physicians in diagnosing autistic disorder, asperger's disorder, and pervasive developmental disorder-not otherwise specified according to a specific number of symptoms in the areas of social interaction, communication and restricted repertoire of activities and interests.

Identification of the **educational disability of autism is made by a multidisciplinary evaluation team** (M-team) of a school district or other education agency responsible under federal and state law for providing a free and appropriate public education to children with disabilities. The identification is made according to the definition of autism in the Individuals with Disabilities Education Act (IDEA):

" 'Autism' means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics 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 role of the m-team is to identify whether an educational disability exists, not to make a medical diagnosis. The use of the term "autism" for both the medical diagnosis and the educational disability can be confusing. **A child identified with the educational disability of autism may or may not have a medical diagnosis of autism**, or may have a medical diagnosis other than autism. A Wisconsin educational criteria and definition was adopted in 1995.

Some parents and professionals avoid using the label "autism", due to misconceptions about autism. Parents usually know their child is different from children with other disabilities, and are often the first to diagnose their child. Until autism is identified, many parents continue to

search for answers. Support from other parents of children with autism is important. **When parents learn about autism and understand why their child learns and behaves in his or her individual way, they can work with and advocate effectively for their child.**

FAMILY ISSUES

After their child is diagnosed, **many parents are left alone to adjust their lives.** A common problem is the need to make an avocation out of searching for services. Many diagnosticians are not familiar with programs and services in the community. Helping parents take advantage of available services is crucial.

Often parents' biggest problems are not their children's handicap, but their relationships with service providers. Parenting is made more difficult and frustrating by the frequency with which they need to see teachers and case workers, fill prescriptions, endure the results of testing, coordinate therapies, find and train baby sitters, monitor the child's bus schedule, etc. Without support, parents suffer from the crippling syndrome of, "Them vs. Us."

Families of people with autism can experience high levels of stress. As a result of the challenging behaviors of their children, families have difficulty participating in typical community activities. This results in isolation and difficulty in developing needed community supports.

Thomas McKean, an adult with autism, gives advice to parents: Parents need to be educated and develop understanding. Read the books written by people with autism. Read the books by your fellow parents. The main concern they have is for their children. Read the books by the professionals for a different view. Be sure that what you read by professionals is positive. There are some negative books on autism. You need to know there is hope, not that there is none.

Investigate treatment claims and ideas. Look at the results and talk to people who claim both that it did work for their child and that it did not. If you feel you understand the treatment and you feel the potential benefits are great and the risks few, then act.

When you take your child to a **doctor or other professional, make sure they are educated on autism.** A good rule: if you are paying a professional to sit there while you teach him (or her) about autism, it is time to find another professional.

What if your child is an adult? What can you do to assure a quality of life? Give them a life that is as independent as possible. If the individual needs a residential facility, try to find one that is flexible when it comes to lifestyle and the wishes of the individual. Try to find competitive employment. Treat the adult as an adult. This is very important when it comes to self-esteem.

PROGNOSIS

Currently, there are few guidelines in predicting future outcome in young children. As adults, some select occupations that involve routines and don't need a great deal of social interaction. Remaining **deficits can interfere with the achievement of a job status related to their educational level.** However, adults with autism have jobs such as data entry, medical transcriber, janitor, chemist, piano tuner, computer analyst, and bookkeeper. Others work in supported employment or sheltered workshops.

A number of adults with autism have discussed their earlier experiences. Common to all of these accounts is the word "confusion." One person described this as, "I did not know what was wanted from me." People with autism sometimes describe themselves as lonely and scared. **They need the support of people who understand their learning problems and how to help them organize information so that the world is more understandable.**