

# **AUTISM SPECTRUM DISORDER**

## **ABSTRACT**

Autism spectrum disorder is a chronic neurological disorder that severely affects an individual's ability to understand, communicate, and interact with other people and begins to develop in early childhood. The causes of autism are not known. One of the defining criteria for diagnosing autism spectrum disorder is that the communication problems, repetitive and restrictive behaviors, and social deficits are seen by age three. There is no cure for autism spectrum disorder but there are medical, non-medical and behavioral treatments.

### Learning Objective:

1. Describe autism and how it can limit a person's ability to interact with other people
2. Identify the signs and symptoms of autism.
3. Describe how to work with a person who has autism spectrum disorder.

## **Introduction**

Autism spectrum disorder is a chronic neurological disorder that severely affects an individual's ability to understand, communicate, and interact with other people. Autism is identified as a spectrum disorder because of the wide variation in symptom type and severity diagnosed in individuals throughout life. Autism spectrum disorder occurs in all ethnic, racial, and economic groups, and in all age groups although it is typically diagnosed in early childhood. There is no cure for autistic individuals and the disorder can be lifelong. The causes of autism are not known. Although each person with autism spectrum disorder is affected in different ways, autism spectrum disorder is defined by the presence of the following three significant problems that everyone who has the disorder struggles with: communication problems, repetitive behaviors and restricted behaviors, and social deficits. Treatments and services can improve a person's symptoms and ability to function. New professional guidelines recommend that all children be screened for autism.

## **Autism Spectrum Disorder Overview**

Autism spectrum disorder is a chronic neurological disorder that severely affects an individual's ability to understand, communicate, and interact with other people. There are millions of people in the United States who suffer from autism spectrum disorder. The number of people diagnosed with this disorder has been increasing. Whether this is due to better diagnosis of the disorder or if the incidence of autism spectrum disorder is increasing is not clear.

Autism spectrum disorder is more common in males. In terms of race, it is more common in Caucasians than in African Americans, Hispanic Americans, or Asian Americans. Some people with autism spectrum disorder may be able to function independently if their condition is diagnosed when they are young and if they receive early and intensive therapy.

Many individuals who have autism are severely limited in their ability to understand other people and to communicate with others. They have no capacity, or very limited capacity, to interact in ways that most people find meaningful or socially acceptable. Some people with a mild form of the disorder can have friends, hold a job, and form attachments.

If autism spectrum disorder is recognized early in life and the appropriate therapies are applied, a child may thrive. In some cases, they may lead a close to normal life. There is no cure for autism, and many people who have autism spectrum disorder will need lifelong care and supervision. Unfortunately, the majority of children with autism spectrum disorder will not spontaneously change or improve as they get older.

As with many chronic diseases, autism spectrum disorder is complex and it affects people in different ways. There are mild, moderate, and severe forms of the disorder. The term autism *spectrum* disorder is used to indicate the complexity of this disorder; it indicates a variety of behaviors, which require real challenges for those with the disorder; and it indicates that the manifestations of autism are unique to each person.

Autism is one of five brain disorders that are called pervasive developmental disorders (PDDs). Asperger's syndrome and Rett's syndrome are other examples of PDDs. These PDDs are sometimes considered to be so similar that they are grouped together and called autism spectrum disorders but the following sections will include the term autism spectrum disorder to refer only to autism.

## **Signs and Symptoms**

Although each person with autism spectrum disorder is affected in different ways, autism spectrum disorder is defined by the presence of communication problems, repetitive behaviors and restricted behaviors, and social deficits. These three significant problems are what people with autism spectrum disorder struggles with in everyday life.

These difficulties are seen by the age of three. Many people who have autism spectrum disorder also have a language problem and/or an intellectual disability. Taken together, the communication problems, repetitive and restrictive behaviors, and the social deficits isolate the person who has autism spectrum disorder. It is often said that someone who has the disorder is "living completely in his or her own world."

## **Communication Problems**

The communication problems of people who have autism spectrum disorder can be quite severe and very limiting. There are certain communication behaviors that are common to the disorder.

People with severe autism often do not make eye contact. When someone speaks to them, they act as if they did not hear and they

may not respond to their name. If they do hear, they do not respond or they respond in inappropriate ways. Many people with autism never talk and if they do talk, what they say does not make sense to the people they are speaking to and/or does not seem to be related to what is happening. The person with autism may also not have the ability to use gestures to communicate. The speech of someone with autism can seem bizarre. They may repeat a phrase over and over (a phenomenon called echolalia), mimic what someone else is saying instead of initiating their own speech, or use one group of words to respond to every situation.

### **Repetitive and Restrictive Behaviors**

The repetitive and restrictive behaviors of someone who has autism are often what people think of when they imagine someone with this disorder. This is not surprising because it can be said without judging that these behaviors are odd and striking. For caretakers and parents, they are often the most disturbing aspect of autism spectrum disorder.

Repetitive behaviors associated with autism are behaviors that are repeated over and over. The restrictive aspect of these behaviors refers to focusing on and performing these behaviors to the exclusion of everything else. It also refers to the implications this has for socialization, and how upset a person with autism spectrum disorder will become if these behaviors are interrupted.

People with autism often exhibit obsessive behavior. They will become absorbed with the same activities, objects, and interests for hour after hour. They will watch the same movie repeatedly, they will play with one toy continuously for long periods of time, or they will constantly

arrange and rearrange their favorite objects. Their motor behavior is often repetitive. People with autism have odd movements that they repeat when they are upset or stressed. This includes rocking back and forth, flapping their hands, or continually repeating a favorite phrase. Their behavior is often very rigid and inflexible.

People who have autism have routines that they do not vary from. They can become extremely upset if these routines are changed or disrupted. Their behavior often seems inappropriate to stimulation. For example, if there is even a small change in a routine, or if one of their repetitive behaviors is interrupted, they will become extremely upset, and occasionally, they may act out aggressively and violently if this happens.

Someone who has autism may completely ignore sensory input; for example, this person may ignore loud noises, intense physical discomfort from an injury, or sensory input that other people would find unpleasant. However, they will become extremely upset if a piece of clothing does not fit quite right or when a parent brushes their hair. The child who has autism spectrum disorder is often hypersensitive to what most people would consider "normal" physical sensations.

### **Social Deficits**

The social deficits of people who have autism are the third defining characteristic of this disorder. Someone who has autism spectrum disorder is likely to have poor or almost no social skills because they cannot understand other people. When someone smiles at them, they do not know what this means. When someone talks to them, they do not "hear" the tone of voice that indicates that the speaker is happy or

angry. If a parent hugs a child who has autism spectrum disorder the child will not interpret this as a gesture of affection, or if the parent was to raise a hand as if to strike the child he or she would not understand this gesture as a threat.

This problem is made worse because a person who has autism spectrum disorder does not have the ability, or has a limited ability, of knowing that other people have feelings, thoughts, and emotions. If a person tells someone with autism that he or she was worried or frightened, it is unlikely the autistic person would understand. An autistic person will seldom understand anyone else's emotions.

People with autism spectrum disorder have their intellectual and emotional life but they seldom share it. Many people with autism prefer to be alone and have no interest in or need for socializing. They may be able to empathize, but they cannot do so in ways that most of us can comprehend. In general, the autistic individual does not understand social behavior, they cannot respond to social behavior, their social behavior is limited or lacking, and what they have to offer as social behavior is not recognizable as such to the people around them.

Some people with autism spectrum disorder may have a highly developed skill such as an extensive memory or an ability to perform complicated mathematical calculations within seconds, such as the autistic savant made famous by the movie Rain Man. This sort of ability - the person who suffers from autism spectrum disorder but who also has a deep, broad, and brilliant set of talents in several areas such as mathematics and music - is an extremely rare phenomenon,

and people who have autism spectrum disorder are more likely than the general population to have an intellectual disability.

The term intellectual disability has replaced the term mental retardation. As previously mentioned, intellectual disability is a relatively common problem for people who have autism spectrum disorder. However, it is important to remember that intellectual disability and autism spectrum disorder are two separate and distinct neurological conditions. It should never be assumed that because someone has autism spectrum disorder that he or she is intellectually disabled.

### **Diagnosis of Autism Spectrum Disorder**

The signs of autism spectrum disorder begin early in life. One of the defining criteria for diagnosing autism is that the communication problems, repetitive and restrictive behaviors, and social deficits are seen by age three. A baby who will eventually develop autism spectrum disorder does not respond to cuddling. An older child with autism will not respond when you call his or her name, or will not make eye contact with others. These children are often withdrawn and do not like to play with other children or adults. The child with autism spectrum disorder starts to speak, if he or she does speak, much later than other children. The child's verbal skills are very poor and/or abnormal.

Autism spectrum disorder does share some issues with other neurological and psychiatric conditions. If it is suspected that a child has autism, he or she should be examined by an expert to confirm its presence. There is no blood test, x-ray, or physical test that can be



used to diagnose autism spectrum disorder. It is diagnosed by observing behavior. Physicians and psychologists use the American Psychiatric Association's diagnostic criteria to look at a child's social interaction, communication skills, and the behavior to make the diagnosis.

The American Psychiatric Association's diagnostic criteria for autism spectrum disorder are listed below.

1. Deficits in communication and social interaction that are present over time. Examples of these are listed below.
  - a. Abnormal social exchanges such as not sharing ideas, emotions, or activities. Failing to have back-and-forth conversations, and not initiating or responding to social interactions.
  - b. Poor use of, or inability to use and/or understand non-verbal communication such as eye contact, body language, and gestures. The child with autism spectrum disorder may not have any facial expressions or non-verbal communication skills.
  - c. Deficits in developing and maintaining relationships or a complete lack of interest in doing so.
  
2. Repetitive and restricted behaviors. At least two of the following must be present.
  - a. Stereotyped or repetitive motor movements, use of objects, or speech. Examples would include lining up or arranging toys, repeated movements, echolalia, or persistently using odd phrases.
  - b. Insisting on keeping routines, inability to change routines or tolerate change to these routines, and insisting on and adhering to ritualized patterns. The child will be extremely distressed if

- there are any changes in these routines. He or she cannot tolerate even small changes in a need to do certain things the same way every time.
- c. The child has very restricted interests. He or she will be abnormally and intensely absorbed and preoccupied in specific objects or activities.
  - d. The child will have noticeable hyper-reactivity or hypo-reactivity. For example, a child who has autistic spectrum disorder, can ignore a painful stimulus that would be intensely uncomfortable for anyone else. But if the child is wearing a shirt that is even slightly ill-fitting, a high level of agitation will likely result.

The characteristic signs and symptoms must be present at an early age and cause serious difficulties in social functioning. The characteristic signs and symptoms are not better explained by another condition, such as intellectual disability.

The diagnosis of autism spectrum disorder will be made if the child has six or more characteristic behaviors from the three categories (communication problems, repetitive and restrictive behaviors, and social deficits) that are used as diagnostic criteria. The child should also be evaluated to make sure that the abnormal behavior, social issues, and communication problems are not caused by a metabolic disorder, a toxic exposure, such as lead poisoning, or another neurological disorder.

Once the diagnosis of autism spectrum disorder has been made, the severity of the condition will be categorized as level 1, 2, or 3, with level 3 being the most severe. These levels are determined by

assessing the degree of communication and social deficits, repetitive and restrictive behaviors, and the amount of support someone needs.

The amount of support is divided into three categories: 1) very substantial support, 2) substantial support, and 3) support. Someone who has level 3, has severe deficits in communication ability and social skills. The autistic individual cannot speak or interact, has very rigid repetitive and restrictive behaviors, and has an extremely difficult time coping with change. Someone with level 3 autism spectrum disorder requires substantial support. In contrast, someone who has level 1 autism spectrum disorder, requires support and if support is not available then the person's communication and social deficits will be noticeable.

### **Screening for Autism Spectrum Disorder**

It is estimated that there are almost 4.7 million people in the United States who have autism spectrum disorder. Because of its prevalence and seriousness, early treatment can make a significant difference in the lives of children who have autism spectrum disorder. Therefore, screening is very important. Screening can be done by pediatricians and primary care physicians. If it is suspected that a child has the disorder, referral to an expert may be made. If a child has any of the signs listed in Table 1, an immediate referral to an autism specialist specialist should be done.

**Table 1: Indications for Immediate Referral to an Autism Specialist**

<p><b>Child is not babbling by 12 months</b> <b>No gestures such as waving bye-bye or pointing by 12 months</b> <b>Child has not used single words by 16 months</b> <b>Child has not used appropriate two-word phrases by 24 months</b></p>
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**Language or social skills are lost at any age**

### **Etiology of Autism Spectrum Disorder**

No one knows what causes autism spectrum disorder. It was once thought that it was caused by an abnormal home environment, by parents who did not provide the child with affection and attention and who never touched or interacted with the child. However, it has been proved that neglectful, emotionally abusive, and emotionally distant parenting does not cause autism spectrum disorder.

Researchers and physicians now believe that autism spectrum disorder is a neurological disorder caused by abnormal brain functioning or abnormal brain structures. How and why the brain functions abnormally or how the brain structures are damaged is not known, but the most likely causes are a) genetic factors, b) infections, c) complications during delivery or pregnancy or maternal health issues, and d) exposures to toxins.

#### **Genetic Factors**

There is strong evidence that autism spectrum disorder is to some degree an inherited, genetic disorder. One researcher found that a child who has sibling with autism spectrum disorder is almost 19% more likely to develop the disorder than a child who does not have a sibling who is affected.

However, no single gene has been identified that causes autism spectrum disorder. It may be that there are multiple genes responsible

for its development and an environmental "trigger" stimulates these vulnerable genes in a susceptible child. Autism is more common in males by a 3:1 to 4:1 ratio. At this point, researchers believe that genetics plays a big part in autism spectrum disorder but they have not been able to use this knowledge to accurately predict who will, or will not develop it.

### **Infections**

Some research has suggested that infections such as rubella (commonly called German measles) may cause autism spectrum disorder if the infection occurs in a woman who is pregnant. The infection may damage vital parts of the brain of the unborn child and result in autism spectrum disorder. Infections may contribute to the development of the disorder, but this theory has not yet been proved true.

### **Maternal Health Complications**

Complications during delivery and pregnancy and maternal health status have been associated with an increased risk for autism spectrum disorder. Factors such as cigarette smoking, low birth weight, the use of antiepileptic drugs during pregnancy, advanced age of the mother, and maternal infections such as rubella have been associated with an increased risk of developing autism.

### **Exposures to Toxins**

Toxins in the environment such as air pollution, mercury, pesticides, and additives that are placed in plastics may increase the risk of developing autism spectrum disorder if the mother is exposed during

pregnancy. However, at this time there is no clear evidence that exposure to toxins is a direct cause of autism spectrum disorder.

## **Vaccinations**

Tiny amounts of mercury in the form of a compound called thimerosal were once used as a preservative in mumps, measles, and rubella vaccines that were given to children. In 1998 an article in a very prominent scientific journal claimed that this mercury preservative was the cause of many cases of autism spectrum disorder. This resulted in widespread fear of these vaccines and for some period of time childhood vaccinations declined, causing many illnesses and deaths. However, an in-depth investigation of the author's research showed that he had manipulated data and misled the medical community and the public. The conclusions of the paper were discredited and the physician's medical license was taken from him. Subsequent investigations by the American Medical Association, the American Academy of Pediatrics, the Centers for Disease Control and Prevention, and other medical and scientific organizations found *no* evidence that proved vaccination was a cause of autism spectrum disorder.

## **Treatment of Autism Spectrum Disorder**

There is no cure for autism spectrum disorder but there are treatments. These treatments are 1) non-medical interventions such as speech therapy and special education, 2) behavioral therapies that help improve behavioral, verbal and social skills, and 3) medical interventions such as special diets, special food supplements, and medications. There are literally dozens of different treatments that have been used for helping people with autism spectrum disorder and

describing them all here would be impossible. The key point to remember is that each person who has autism spectrum disorder is unique and the most effective treatment is the one that works. Clinicians and Certified Nurses Assistants should also remember that although autism spectrum disorder cannot be cured, treatment can make living with the disorder much more tolerable and excellent results are possible.

As previously raised, one of the defining criteria for diagnosing autism spectrum disorder is that the communication problems, repetitive and restrictive behaviors, and social deficits are seen by age three. The following treatments involving the non-medical interventions, behavioral therapies, and medical interventions will be outlined in greater detail next.

## **Medications**

The behavioral and emotional problems of people who have autism spectrum disorder are similar in nature to the behavioral and emotional problems of people who have attention deficit hyperactivity disorder, depression, and other psychiatric disorders. Not surprisingly then, medications that are commonly used to treat hyperactivity or depression have been used as therapy for treating someone who has autism spectrum disorder.

Antipsychotics:

Antipsychotics are medications that are used to treat severe psychiatric disorders such as schizophrenia and psychosis. They are sometimes called major tranquilizers because they can be effective for controlling severe agitation and emotional outbursts. Aripiprazole

(Abilify) and risperidone (Risperdal) are approved by the Food and Drug Administration (FDA) for treating irritability in children who have autism spectrum disorder and they can be very effective for this purpose. The antipsychotics can also decrease hyperactive behavior and stereotyped, repetitive and restrictive behavior in these patients.

#### Stimulants:

Methylphenidate (Ritalin) can be helpful at reducing hyperactivity and impulsive behavior in children who have an autism spectrum disorder.

#### Antidepressants:

Antidepressants such as fluoxetine (Prozac) may help children, adolescents, and adults cope with the anxiety and compulsive behavior that often accompanies autism spectrum disorder.

Although these medications and other drugs such as atomoxetine (Strattera), clonidine, and lithium can be helpful for the treatment of children and adolescents who have autism spectrum disorder, only Abilify and Risperdal are FDA-approved for treating this patient population. Also, these drugs can have serious side effects and their long-term safety has not yet been determined. At this time the role of medications for patients who have autism spectrum disorder is the treatment of behaviors such as aggression, emotional outbursts, and hyperactivity that are caused by the core problems of the disorder and medications should be used in conjunction with behavioral therapy.

Medications can be helpful for people who have autism spectrum disorder but they are only an addition to the therapeutic regimen. Medications should not be the primary method of treatment for autistic individuals.



## **Early Intensive Behavioral Interventions**

Research has consistently shown that the future for children who have autism spectrum disorder depends on two things: 1) Screening the pediatric population so that children who are at risk for autism spectrum disorder or who have been diagnosed with autism are identified early in their lives, and 2) Using early intensive behavioral interventions. If children who have autism spectrum disorder are diagnosed when they are young and if they receive early intensive behavioral interventions (as explained later) many children will make significant improvements and some may be able to function independently, to work, to marry, and to have children.

Early intensive behavioral interventions can be defined as an approach, not a specific style of therapy, and there are numerous different types of this therapy such as Pivotal Response Training, the Lovaas method, and the Early Start Denver Model. The basic principles of early intensive interventional are: 1) understanding how people learn, 2) assessing the needs and skills of each child, 3) Identifying areas that need help and improvement, 4) using specific interventions to reward the desired behaviors and discourage the undesired behaviors, and 5) frequently measuring the success of the interventions.

When early intensive behavioral interventions are described in this way it is difficult to see why they are considered different from any other form of childhood education. However, early intensive behavioral interventions are different in that they are started early in the child's life. They are also very intensive; some children will spend 20 or 30

hours or more five days to seven a week working with a therapist and the course of therapy can last for several years. The therapies are also flexible.

Although there is a solid background of theory and experience behind the treatments, the therapist is always evaluating what the child needs, what is working and what is not. Finally, these therapies are based on known principles of how people learn and the results are designed to be objectively measured. This last point is very important. For example, it is not enough to simply say that the goal of therapy is to "improve the child's social skills." The goal must be measurable and observable and it is achieved by using positive or negative reinforcement.

There are different approaches to early intensive behavioral interventions such as the Lovaas technique, Pivotal Response Training, and the Early Start Denver Model. Several examples of the techniques these approaches use are given below.

#### Discrete Trial Technique:

The child is given a cue or an instruction such as "Show me the picture of the cow. Show me the cow." The child will then respond and will be given feedback on the response. This may seem simple but for a child who has autism spectrum disorder it helps the child to understand the environment and develop language, play, and social skills.

#### Incidental Teaching:

In this technique if a child reaches for an object he or she is asked to first say the name of the object, repeat the name, and is then given the object.

Shared Control:

In this technique a particular task is examined, something like putting on a coat before going outside. The teacher or therapist will decide how much of this will be done by the child and how much by whoever is assisting. Gradually the child does more of the activity without help and this process establishes social skills, communication skills, and appropriate behavior as well as the process of cooperating with others.

### **Caring for Autism Spectrum Disorder**

Working with a person who has autism spectrum disorder can be challenging but as with most challenging clinical situations, knowledge and preparation are the keys to a successful experience. The following are important points to remember. By keeping these points in mind, working with someone with autism spectrum disorder will be much less difficult.

Adaptation:

Most people have a reasonable ability to adapt to the environment. The person who has autism spectrum has a very limited ability to adapt so as much as is reasonably possible, the environment must be adjusted to suit the needs of the person who has autism spectrum disorder. The clinician will need to determine what level and type of stimulation that person can tolerate. Safety is also very important. People with autism spectrum may not be able to protect themselves from danger, so the environment must be made safe. Of course, there will be many situations in which the environment cannot be adapted. A crowded shopping mall would probably provide too much stimulation

for someone who has autism spectrum and there would be too many opportunities for self-injury. In that situation the environment cannot be changed so the sensible thing would be to avoid such situations.

#### Communication:

Although many people who have autism spectrum disorder have a limited ability to communicate and some have essentially no ability to communicate, they do try and communicate but not in ways that are easily understood. When working with someone who has autism spectrum disorder the Certified Nursing Assistant will need to learn how that person communicates, and that is a process that takes time and patience. For example, when the autistic person wants something that is enjoyed, for example, a particular food, one phrase may be used to express pleasure, but to anyone else that phrase may not be associated with food or eating.

The other part of communication that is important when working with a client who has autism spectrum disorder is praise. Research has shown that autistic people respond much better to praise than to criticism or strict discipline. The health team working with an autistic person should use communication that is clear, simple, and consistent.

#### Routine:

Routines are typically very important to a person who has autism spectrum disorder. They are most comfortable with rigid schedules and they thrive on predictability. As a caretaker the Certified Nurse Assistant must learn what routines are important for the autistic person and make sure these routines are not disrupted. A change can be extremely upsetting. If a change in a routine must be made, it

should be done slowly and gradually and only after a discussion with other health care professionals and caretakers.

Meltdown:

Meltdown is an informal term for emotional and/or behavioral outbursts. People who have autism spectrum disorder, and especially children, are prone to emotional behavioral outbursts and they may have intense meltdowns characterized by screaming, crying, intense physical activity, and attempts at self-harm.

Handling a situation of meltdown involves three steps. First, make sure that the patient does not injure himself or herself or others or cause damage to property. Second, everyone involved in the care of this person should use the same approach and the best approach is to not be confrontational and do not respond. Many times the meltdown will simply have to run its course. Finally, look for the reason the meltdown occurred. The reason may have been a change in routine or a physical sensation that the patient with autism found noxious. It may also be that the patient was frustrated. Perhaps the autistic person could not express feelings, did not get what was wanted and could not ask for it, or made a request for something and the request was not understood. Poor communication is often the reason why these outbursts happen.

### **Summary**

Autism spectrum disorder is a chronic disability that severely affects an individual's ability to communicate and interact. The exact cause of autism spectrum disorder is not known but it is probably caused by a complex interaction of genetic and environmental factors. The diagnosis is made by observing behavior, and physicians and

psychologists look for characteristic changes in social behavior, communication skills, and physical behavior. Typical signs of autism include lack of interest or ability to socially interact, lack of speech or very diminished capacity for speech, and repetitive and restrictive behaviors that appear to the outsider to be bizarre, obsessive, and repetitive. Because of these social, communication, and behavioral characteristics, the person with an autistic spectrum disorder often cannot interact in ways that most people understand or find meaningful. In many ways the person with autism spectrum disorder lives completely in an isolative world from others.

Autism cannot be cured but there are degrees of the disorder that are not intensely disruptive and every person who has autism can, with support, treatment, and understanding, be helped. Research has shown that if autism is detected early in life and that proper care is provided, it is entirely possible for some autistic people to lead an essentially normal life. Early intensive behavioral interventions have been proven to be very successful in this respect. Medications can be a helpful adjunct for the autistic patient but they should not be the primary method of treatment. Although there are similarities among people with autism spectrum disorder, each person who has autism expresses these characteristics in an individual way.