



**SOUTH CAROLINA
AUTISM SOCIETY**



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Participant

What Is Autism Spectrum Disorder?

**This booklet includes
information on autism spectrum
disorder and resources available
in South Carolina**

What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a complex life-long developmental disorder defined by diagnostic criteria that include deficits in social communication and social interaction, and the presence of restricted, repetitive patterns of behavior, interests, or activities that can persist throughout a person's life. It affects individuals differently and to varying degrees. ASD typically appears during early childhood (first three years of a person's life) and affects a person's daily functioning. It is the result of a neurological disorder that affects functioning of the brain. As of April, 2018, research indicates that approximately 1 in 59 individuals have an autism spectrum disorder.

ASD is reported to be four to five times more common in males than females. It is reported to occur in all racial, ethnic, and social economic groups. Family income, lifestyle and education do not affect the chance of occurrence.

ASD interferes with the development of the brain in reasoning, social interaction and communication skills. People with ASD typically have deficiencies in verbal and non-verbal communication, social interactions and leisure or play activities. The disorder makes it hard for individuals to communicate and relate to others. Persons may resist changes in routine, demonstrate unusual responses to people or attachments to objects, and exhibit repeated body movements (i.e., hand-flapping, body rocking, etc.). Due to an inability to communicate in a socially acceptable manner, sometimes aggressive or self-injurious behavior may occur.

About 4 million people in the U.S. and over 72,000 in South Carolina have an autism spectrum disorder. Its prevalence rate now places it as one of the three most common developmental disabilities, and much more common than Down Syndrome. Yet the majority of the public, including some professionals in the medical, educational and vocational fields, are still unsure of how ASD affects behavior. Progress is being made in developing more effective teaching methods and other positive interventions for individuals with ASD.

Is There More Than One Type Of ASD?

ASD is a spectrum disorder, meaning that the symptoms and characteristics can present themselves in a wide variety of combinations, which may range from mild to severe. This is why the term autism spectrum disorders is used. Although ASD is defined by a

families and other caregivers. Information provided by SCAS, combined with personal support by other families and assistance from others, can help to minimize this stress.

SCAS Programs & Services

- **Information and Resources:** This service is provided to families and professionals about ASD, available services and providers in South Carolina.
- **Case Management:** This service helps SCDDSN qualified individuals and families identify and obtain services. Services are consumer driven and based on the appropriateness and availability of the service. People with ASD are unique with their own needs, wants, desires, goals and dreams. Through our case management efforts, SCAS ensures the persons we serve always has a choice and voice.
- **Parent-School Partnership:** The Parent-School Partnership Program (PSP) is designed to assist families that have school-aged children with ASD to reach their academic and functional potential in the public educational system. The program strives to build collaboration between parents and school personnel recognizing that both are essential partners in a child's education. Parent Mentors are available throughout the state to assist school personnel and parents with building strong positive relationships through the Individual Education Plan and 504 processes.
- **Trainings and Workshops:** SCAS holds local and regional trainings/workshops regarding specific topics or best practices for persons with ASD. We strive to present information on research-based practices for families, professionals and others involved with a person affected by ASD. Our organization is currently assessing other possible trainings in reference to understanding and addressing the needs of persons impacted by ASD.
- **First Responder Training:** This is an awareness and training service that is designed to provide essential information, to prevent the occurrence of a serious injury, trauma or an inappropriate arrest which may result from an encounter between persons with ASD and community emergency personnel during critical or sensitive situations. The goal of this training service is to create an atmosphere of understanding among public safety personnel with the hope that unfortunate situations can be avoided.

- 2) For children under the age of 18, it is necessary to apply for Medicaid through the TEFRA (Katie Beckett) program. This program is for children with disabilities, and considers only the applicant's income. TEFRA Medicaid forms are available online at <https://www.scdhhs.gov/eligibility-groups/disabled-children>.

Please note that the application process can take several months. When completing the forms, be very detailed and attach additional documentation if available. Before mailing, please make a copy of the entire packet to have as a backup. If your TEFRA application is denied, you can appeal.

What is the South Carolina Autism Society?

Mission Statement

The mission of the South Carolina Autism Society (SCAS) is to equip those affected by autism spectrum disorders with knowledge and supports to maximize their quality of life.

In the early 1970's, a group of dedicated parents of children with ASD came together for fellowship. The parents realized how little was known about ASD and recognized that children with this disorder have their own special needs. Services were nonexistent or inappropriate during their children's early years. The parents stood together as a unified voice and worked diligently to improve life for individuals with ASD and their families in our state. Their grass roots efforts would come to be known as the South Carolina Autism Society.

Through their grass roots efforts, SCAS was chartered by the State of South Carolina in 1972 and received its 501(c)(3) status from the Internal Revenue Service in 1974. SCAS has been a United Way agency partner since 1976. Other financial support is provided by personal donations, grants and fund-raisers.

For all who provide care for children and adults with ASD, SCAS provides information and resources regarding services available across South Carolina. SCAS is also a strong advocate for state and federal legislation to provide appropriate and needed services for South Carolinians who have ASD.

ASD is a life-long disorder that can put great stress on parents, professionals and direct care providers. Little was known about ASD in the past, but progress continues to be made in making life easier for

set of specific behaviors, children and adults can exhibit any combination of them with any degree of severity.

ASD can be difficult to diagnose because no objective test has been developed, so far to identify the disorder. For instance, there is no blood test. An accurate diagnosis depends instead on perceptive observations of the child, ideally across several settings by professionals who have substantial knowledge about ASD (i.e., home, school, clinic, etc.). Even then, a parent may receive more than one label applied to their child. For example, families are given the labels of autistic-like, communication disorder with autistic tendencies or high functioning autism. Different labels may be the result of differences in the professionals' training, vocabulary and experience with ASD. Previous and separate diagnostic conditions also included Asperger's Syndrome and PDD-NOS. These disorders are now included under the umbrella of autism spectrum disorders, but these labels may still be heard when a person has been diagnosed with ASD.

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) provides the current diagnostic criteria for a determination of autism spectrum disorder. It includes: 1) Deficits in social communication and interaction across multiple contexts; and 2) Restricted, repetitive patterns of behavior, interests, or activities. The symptoms must be present in the early developmental period and cause clinically significant impairment in social, occupational, or other important areas of current functioning.

For the most accurate diagnosis, parents are advised to seek out professionals with substantial knowledge about ASD who will observe the individual in different settings. *Then, whatever the exact diagnosis turns out to be, parents need to remember that all children with an autism spectrum disorder are likely to benefit from similar approaches to education and therapy.* In other words, the exact name may not make much difference when it comes to the types of intervention likely to help the individual child or adult.

What Causes ASD?

Medical researchers are exploring different explanations for the various forms of ASD, including genetics and environmental factors early in prenatal development. Although no one specific cause of ASD is known, current research links ASD to biological or neurological differences in the brain. Brain scans indicate abnormalities in the

structure of the brain, with significant differences in more than one area.

In some families' there appears to be a pattern of ASD, although the pattern of actual inheritance is not yet clear. Autistic-like traits may be seen in other family members, as well as problems such as intellectual and learning disabilities. This further suggests there may be a genetic basis to the disorder, although no one gene has been directly linked to ASD.

Several previous theories about the cause of ASD have been proven false. ASD is not a mental illness. Children with ASD are not unruly kids who choose not to behave. The disorder is not caused by bad parenting; in fact, no psychological factors have been shown to cause ASD.

How Is ASD Diagnosed?

There is no single medical test for diagnosing ASD. An accurate diagnosis must be based on observations and diagnostic tools which are used to assess an individual's communication, social, behavior and developmental levels. However, because some of the characteristics associated with ASD are shared by other conditions, a doctor may order a variety of medical tests to rule out other causes. For example, a doctor may recommend genetic testing.

There are two types of ASD evaluations. A medical diagnosis is done by a medical or mental health professional, and helps determine eligibility for services out in the community, such as through SCDDSN or SCDHHS. An educational classification is done by the school system, and helps determine eligibility for services while in school.

Because the characteristics of ASD and degree of impairments tend to vary in each individual, a diagnosis may be difficult for a practitioner who has limited training or experience with the disorder. Locating a medical specialist or diagnostician who has experience with ASD is strongly recommended. Ideally a child should be evaluated by a multidisciplinary team which may include a psychologist, developmental pediatrician, speech/language therapist, learning consultant or other professionals. These persons should be very knowledgeable about ASD.

The following traits are often seen in persons who have ASD:

- unusually intense or focused interests.
- stereotyped and repetitive body movements (i.e., hand-flapping, body rocking and spinning, etc.).
- repetitive use of objects, (i.e., repeatedly switching lights on and off, lining up toys, etc.).
- insistence on sticking to routines (i.e., travelling the same route home each day, doing things in exactly the same order on a daily basis, etc.).
- unusual sensory interests (i.e., sniffing objects or staring intensely at moving objects, etc.).
- sensory sensitivities (i.e., avoidance of everyday sounds and textures, hair dryers, vacuum cleaners, sand, etc.).
- limited use and understanding of non-verbal communication, (i.e., eye gaze, facial expressions, gesture, etc.).
- difficulties forming and sustaining friendships.
- lack of seeking to share enjoyment, interests and activities with other people.
- delayed language development or no language at all
- stereotyped and repetitive use of language (i.e., repeating phrases from television shows or videos).
- Lose skills they once had (i.e., stop saying words they were using, etc.).

Next Steps After Diagnosis

CASE MANAGEMENT INTAKE: Individuals must be eligible through the South Carolina Department of Disabilities and Special Needs (SCDDSN).

To pursue case management via the intake route (call 1-800-289-7012). An assigned person will assist you through the entire intake process.

MEDICAID: Medicaid may be available for an individual. There are two different types of Medicaid to consider.

- 1) Traditional Medicaid is based on the family's income, and there is no disability requirement. For more information, please visit <https://www.scdhhs.gov/Getting-Started>.

Experience has shown that individuals with ASD respond well to a highly structured environment, specialized education and behavior training program that is tailored to the individual needs of the person. A well designed intervention approach will include some level of communication therapy, social skill development, sensory impairment therapy and behavior training. It should be delivered by professionals who are trained in ASD and in a consistent, comprehensive and coordinated manner. The particularly severe challenges of some children may be addressed most effectively by a structured education and behavior program that contains (a 1:1) teacher to student ratio or a small group environment.

Students with ASD should have consistent teaching and training, vocational and community living skills at the earliest possible age. Learning to cross a street safely, making a simple purchase or asking for assistance are critical skills that may be difficult for even those with average intelligence to learn. Tasks that enhance independence, give more opportunity for personal choice or allow more freedom in the community are especially valuable.

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 the caregivers. Rarely can a family, teacher, or other caregiver provide effective habilitation for a person with ASD unless offered consultation or in-service training by a specialist knowledgeable about autism spectrum disorder.

Just a generation ago, the vast majority of people with ASD lived at least a part of their lives in institutions. As a result of appropriate and individualized services and programs, today even severely disabled individuals can be taught skills to allow them to develop to their fullest potential and live a meaningful life.

Characteristics can range from mild to severe, and they will be different from one person to the next. The characteristics usually occur across many different situations and are consistently inappropriate for the person's age. Many traits can be addressed in carefully planned therapy plans.

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM) provides the criteria for autism spectrum disorder. Multiple screening and diagnostic tools may be used to help professionals make an accurate diagnosis. They include, but are not limited to:

- ADI-R: Autism Diagnosis Interview – Revised
 - ADOS: Autism Diagnostic Observation Schedule
 - ASQ: Ages and Stages Questionnaires
 - CARS: Childhood Autism Rating Scale
 - CSBS: Communication and Symbolic Behavior Scales
 - GARS: Gilliam Autism Rating Scale – Second Edition
 - MCHAT: Modified Checklist for Autism in Toddlers
 - PEDS: Parents' Evaluation of Developmental Status
 - SCQ: Social Communication Questionnaire
 - STAT: Screening Tool for Autism in Toddlers and Young Children
- *Adapted from the Centers for Disease Control (CDC)*

A brief observation in a single setting cannot present a true picture of an individual's abilities and behaviors. At first glance, the person with ASD may appear to have an intellectual disability, a behavior disorder or even problems with hearing. It is important to distinguish ASD from other conditions, since an accurate diagnosis can provide the basis for building an appropriate and effective educational and therapeutic program.

What Are The Characteristics Of ASD?

Children with ASD often appear relatively normal in their development until the age of 18 to 24 months. This is the time period when parents notice delays in language, play or social interactions.

The following areas are among those most frequently affected by ASD:

Communication Skills: Language develops slowly or not at all; words are used without attaching the usual meaning to them; persons communicate with gestures instead of words; or via their behaviors.

Social Interaction: A person may spend time alone rather than with others; show little interest in making friends; and be less responsive than others social cues such as eye contact or smiles.

Sensory Impairment: Unusual reactions to physical sensations such

as oversensitivity to touch or under-responsiveness to pain may occur; and responses to sights, sounds, touch, smells and tastes may be affected to lesser or greater degrees.

Play: Lack of spontaneous or imaginative play; does not imitate the actions of others; and does not initiate any pretend games.

Behaviors: May be overactive or very passive; has tantrums for no apparent reason; perseverate on a single item, idea, person, phrase or word; and may display aggressive or self-abusive behavior.

There are great differences between each person with ASD and the degrees of severity can vary significantly from person to person. Some mildly affected individuals may exhibit only slight delays in language but have significant challenges with regard to social interactions. An individual may have average or above average verbal, memory or spatial skills but find it difficult to be imaginative or join in a game of softball with others. More severely affected individuals may need more assistance in handling day to day activities like crossing streets or making simple purchases.

Contrary to popular belief, many children and adults with ASD make eye contact, show affection, smile, laugh and express a variety of other emotions. However, this may vary in degrees from person-to-person. Like their same-age peers, children with ASD respond to their environment in positive as well as negative ways. ASD may affect their range of responses and make it more difficult for them to control how their bodies and minds react. People with ASD live normal life spans. Some of the behaviors associated with ASD may change or disappear over time, although this will vary from one individual to the next.

It can be difficult to predict which children will become more or less self-sufficient over time. However, some adults with ASD do live independently, attend colleges or university's, and find employment in their communities. Others will depend on the support of family and professionals. Adults with ASD can benefit from vocational training, as well as training that will enable them to participate in social and recreational programs. They may live in a variety of residential settings, including living on their own, with family members, in group homes or supervised apartments, and in structured residential care.

Individuals with ASD may have other disorders which affect the functioning of the brain, such as epilepsy, intellectual disability, obsessive compulsive disorder, attention deficit hyperactivity disorder, attention deficit disorder, communication disorder, oppositional defiant disorder, or genetic disorders such as Fragile X syndrome. Many individuals with ASD have test scores that fall in the range of intellectual disability. However, experts question the validity of tests that require communication skills and an understanding of the purpose of the testing that students with ASD often lack. Approximately one third of individuals with ASD have seizures at some point during their lifetime, with onset frequently occurring during adolescence.

Is There A Cure For ASD?

Our knowledge in the state of South Carolina about ASD has grown tremendously since it was first described in 1943. Some of the early searches for "cures" now seem unrealistic in terms of today's understanding of this brain-based disorders. To cure means "to restore to health, soundness or normality." In the medical sense, there is no cure, as of yet, for the differences in the brain that result in ASD.

Researchers are finding better ways to understand ASD and help people live with its symptoms. Some symptoms may lessen as the individual ages; others may disappear altogether. With appropriate intervention, many behaviors may become less severe, sometimes to the point that to the untrained observer the individual may not appear to have ASD. However, the majority of children and adults with ASD will continue to exhibit some degree of characteristics throughout their lives.

What Are The Most Effective Ways Of Working With Someone With ASD?

Because of the spectrum nature of ASD and the many combinations of behaviors that can occur, there is no single approach that will alleviate all characteristics in every case. Various types of therapies are available, including behavioral training, teaching, communication and socialization systems, speech/language therapy, sensory integration training, vision therapy, music therapy, auditory training, medications and dietary interventions.