

## C. Autism Spectrum Disorders

Autism Disorders are a range or spectrum of disorders characterized by delays in developing communication skills and difficulty relating to others. People with autism may have repetitive behaviors, interests and activities. Autism symptoms range from relatively mild to severe. The milder type of autism is known as Asperger's Syndrome or High Functioning Autism. Individuals with more severe symptoms are said to have Classic Autism. We will use the term "autism" in this section to describe the whole range of the disorders.

Dr. Leo Kanner coined the term "autism" in the 1940s to describe a group of patients that behaved as though they were disconnected from the world around them. The term was a contraction of auto(self)-ism, which was his attempt to describe how these people lived within themselves. At the same time an Austrian scientist, Dr. Hans Asperger, described a milder form of the disorder that became known as Asperger's Syndrome. People who are classified with autism have a wide range of abilities and respond to different types of support. Some people with autism may use picture boards, sign language, or keyboards with voice synthesizers to communicate. Leaders can expect to see a wide range of individuals with autism in the Scouting program.

Individuals with autism can exhibit such a wide range of symptoms and need different kinds of support. This section includes information about Classic Autism and milder forms. When a Scout Leader comes into contact with a Scout with autism, he will most likely see Scouts closer to the definition of Asperger's Syndrome than Classic Autism.

### 1. Incidence

Reports issued by the National Institute of Health (NIH) in 2007 and the Center for Disease Control (CDC) estimate that about 1 in 150 children have autism. Four out of five of these children are boys. This means that about 1 in 100 boys in the general population have autism. In recent years, the number of cases of autism has been increasing. The exact cause of the increase is unknown.

Autism is a neurobiological condition, meaning that it originates in the brain. It is not caused by environment or poor parenting. It appears to run in families, but genes related to autism have not yet

been identified. Currently, researchers are investigating areas such as neurological damage and biochemical imbalance in the brain in addition to genetic and environmental factors as possible causes of autism.

A diagnosis of autism can occur from ages two to adult. Asperger's Syndrome and high functioning autism are usually diagnosed about the time the child starts school or later. Researchers feel that autism is probably hereditary in nature because many families report having an "odd" relative or two. In addition, attention deficit disorder, depression, and bipolar disorder are sometimes reported in those with autism as well as in family members. At this time, there is no one method to treat autism. In school, those with Asperger's Syndrome and high functioning autism may be among the students known as "geeks" or "nerds" because of their academic interests. In adulthood, many lead productive lives, living independently, working effectively at a job and raising families. They are frequently college professors, computer programmers, mathematicians, engineers, or dentists.

## 2. Characteristics

### Classic Autism

Individuals with classic autism have difficulty with communication skills. They may:

- Not respond normally or at all to sound (may appear to be hearing impaired).
- Respond differently than others to typical situations.
- Not participate in imaginative play.
- May focus on one object in the area while blocking out others.
- Have difficulty expressing wants and needs but many communicate effectively using keyboard devices and/or picture symbols and/or sign language or some combination of these.
- Express frustration or anxiety through anger or physical aggression. Make sure to look at behavior as a form of communication. What is he trying to say?
- Have delays when responding to speech.
- Do better with visual communication than verbal.
- Giggle or cry for no apparent reason.

Individuals with classic autism have difficulty relating to others and may:

- Have difficulty socializing.
- Be too loud and noisy or withdrawn and quiet.
- May echo others' speech or songs (echolalia).
- Not respond with emotions.
- Not react to danger.
- Avoid eye contact.

Individuals with classic autism may have repetitive behaviors and/or interests. They may:

- Insist on sameness and resist changes in routine.
- Have repetitive behaviors such as hand flapping.
- Repetitively rock body back and forth.
- Spin objects or self.
- Stack objects.
- Be overly or under-active physically.
- Have behaviors that injure themselves such as head banging or hand biting.
- Be focus on parts of objects and not see the "big picture."
- Be involved in repetitive play or conversation.
- Eat a limited variety of foods because they are too sensitive to strong tastes or food textures.
- Have abnormal sleeping habits such as staying awake all night.

Individuals with classic autism may have extremely sensitive hearing, vision, smell, taste, and touch or may not seem to have these senses at all. They may:

- Have a high level of anxiety and a tendency to withdraw from interactions with people, places, pets, and anything else that might cause sensory overload.
- A tendency to taste, touch and smell things in situations where this not acceptable.
- Be bothered by certain fabrics or clothing. May be bothered with the tags in clothing, for instance. If a wearing a Scout shirt bothers a Scout, suggest wearing shirt underneath. Remember to focus on the boy's participation in the program *not* the uniform.
- Be easily over-stimulated.
- Have trouble knowing what sounds to listen to and what to ignore.
- Not like physical touching. However, some individuals with autism may be very affectionate.

- Not be sensitive to pain and need to be watched for injuries.

### **Asperger's Syndrome or High Functioning Autism**

Individuals with Asperger's Syndrome and high functioning autism can talk but still have difficulty communicating. They may:

- Not have strong conversational skills or an easy time joining groups.
- Have trouble understanding what someone else is thinking and feeling.
- Have difficulty understanding and expressing emotions.
- Have difficulty understanding the meaning of hand movements, facial expressions, and tone of voice.
- Use and interpret speech literally ("The cat's in the bag" takes on a different meaning for them). They may not understand sarcasm or figurative language.
- Talk excessively about preferred topics even though others are not interested.

Individuals with Asperger's Syndrome have trouble with social skills. They may:

- Have difficulty relating to others.
- Need to be taught social skills that others learn easily such as what to say to start a conversation.
- Have sensitive hearing, vision, smell, taste, and touch like individuals with classic autism.
- Have difficulty understanding why others don't follow rules as strictly as they do and may be seen as bossy.
- Be honest to a fault; not capable of manipulating or lying: probably doesn't understand how and why to tell "little white lies."
- Have trouble making eye contact.

Individuals with Asperger's Syndrome may have some unusual behaviors or other challenges such as:

- Odd forms of behavior such as picking at socks or chewing on shirts.
- A tendency to be worriers with high anxiety levels.
- Focusing on small details rather than the bigger picture.
- Being fact oriented and logical--liking lots of data.

- Intense or obsessive interest in complex topics, such as patterns, weather, music, history, etc. (These can be leveraged for merit badge completion.)
- Lacking common sense.
- Perfectionist tendencies.
- Difficulty with organization, starting things, and deciding what is most important.
- Clumsiness and uncoordinated movements (may have trouble tying knots, for example).
- Appearing eccentric.
- Viewing the world in black and white with difficulty compromising or seeing gray areas.
- Anxiety and/or depression. These can be major obstacles for many people with autism and may affect their ability to function. Some take medication for these conditions.

### **All Scouts With Autism**

Leaders should know that Scouts with any form of autism:

- Have a wide range of intelligence. Some have significant cognitive delays (mental retardation), while others may be extremely intelligent. Sometimes they may be gifted in only one area or topic such as math.
- Have uneven development in physical and verbal abilities.
- Have problems with abstract and conceptual thinking. They sometimes do better with hands-on skills and memorizing facts.
- May have severe food allergies and other digestive issues.
- Are easy targets for teasing and bullying because they don't always know how to recognize fake behavior. It is best to keep an eye out for "hazing" on the part of older boys.

Scouts with autism may take medication for co-occurring conditions such as AD/HD and anxiety. According to the NIH, about 1 in 4 people with autism have seizures. Check with parents to learn about any medications the Scout may take.

Remember, "Autism tells *how* a student learns. Intelligence tells how much" (Linda Hodgdon, M. Ed., CCC-SLP).

See section XII.J. for a visual list of the characteristics of autism.

### **3. Scouting and Autism**

Many of the extracurricular options for children, team sports in particular, are not well suited for a child with autism due to the social, communication, or coordination required.

Scouting has much to offer a child with autism. Scouting places its members in a wide variety of social situations with a mixture of people and tasks. This gives the Scout with autism a chance to learn acceptable behaviors. Children with autism and other disabilities benefit from the self-paced nature of the Scouting advancement system. It allows them to participate and socialize with other Scouts of different skill levels, especially in teaching situations. Scouts with autism can learn about others' feelings while performing service hours in community activities. Participating in service projects focuses on learning to be a good citizen which builds a sense of belonging to a larger community.

Scouting can help create a safe community for youth with autism. Many children with disabilities have no friends outside of their immediate family and their paid caregivers. Scouting offers a chance for them to make genuine friends. These friendships can carry over to school and other activities beyond their Scouting unit.

The Scouting program offers lots of opportunities to strengthen practical skills. For example, Scouts with autism can improve their public speaking skills while giving troop presentations on skills or merit badge topics. They can develop motor skills while learning to tie knots or working on tent set up for camping.

Leadership positions in a troop are another excellent way for Scouts with autism to learn tolerance and a flexibility of thinking. They come to realize that leading requires motivating others, which helps them understand that multiple viewpoints are valid and should be respected. Troop Leadership Training can be a great way for Scouts with autism to become more aware of what is normal behavior in social interactions.

Scouts with autism can make dedicated Troop Historians, Scribes and Quartermasters since they love to draw up lists and enjoy detailed planning activities. Sometimes they can be a bit bossy, but

what troop wouldn't benefit from a well-trained Patrol Leader at a Camporee? They can keep everyone on schedule as long as they have a copy to hold or refer to on a bulletin board.

Scouts with autism also make wonderful Den Chiefs or Troop Guides for new Scout Patrols. If the Scoutmaster asks the Scout to become an expert in teaching younger Scouts how the program runs, the Scout with autism has a chance to show off his knowledge and encourage younger boys. This is a great way to increase self esteem for individuals who may ordinarily be socially shy and awkward.

According to an article written by Temple Grandin, a university professor with autism, youth with autism need mentors to help them learn social skills. They need a chance to explore different areas of interest. These areas of interest may lead them to a career. Scouting offers such experiences. Many Scouts have explored interests which have later turned into careers or lifelong hobbies. Scouting can provide the mentorship needed for youth with autism to grow into successful adults.

#### **4. Communicating With Parents**

You can avoid many problems while learning to work with a Scout with autism if you can develop and maintain good lines of communication with the parents. Parents are key members of the support team for Scouts with autism. Section XII.F of this manual has additional information on this subject. Remember that all parents have similar, though often unstated, dreams for their children as they grow up such as living independently, having loving relationships, and finding a good job. Parents of youth with disabilities sometimes have trouble accepting that their child's life will not fulfill their dreams. Scouting can help the family see that their child is more like other youth than he is different. It can also provide supportive relationships for the parents of Scouts with autism.

If the parents are open and willing, set up a joining meeting with them and the Scout, if appropriate. Parents can provide valuable information that will help make the Scouting experience successful for all. Make sure that parents know that their presence may be required at meetings and on outings, at least until the leaders of the unit feel comfortable working with the Scout. Remember to tell parents that volunteer leaders want all youth to have good Scouting experiences but do not have the professional training that school or medical

personnel have to handle youth with disabilities. Safety must always be a leader's first priority.

Some parents will be very open about their child. Some consider the disability to be a private matter and others are not willing to acknowledge it even to themselves. It's best to tread into this water carefully. For these parents start the discussion by turning the problem around and making it *yours* and not the Scout's. "I just can't seem to get your child to join the groups. What can you recommend that might help me?" This type of question can draw out the information you need without forcing the parents' hand (see section XII.E.).

In addition to the information in section XII.F., leaders of Scouts with autism may want to know:

- What level of autism does the child have? What type of support will he need?
- How well can he communicate his needs verbally? Does he use sign language, pictures, or a keyboard to communicate? The Scout with autism might use a visual schedule or need visual pictures for rules.
- Does their son have behaviors associated with frustration and/or anxiety? How are these behaviors best handled? A Scout with autism may be difficult to "read." Parents should supply information that will help the leaders quickly get to know the Scout.
- How well does he socialize? What works best to engage the boy in activities?
- Does he have any other disabilities? If so, what does the Scout leader need to know about them?
- Does he take medication for anxiety, digestive disorders or other conditions?
- Does he need any physical help? Leaders need to know what the Scout can and cannot do on his own. How strenuous can activities be for the Scout?
- Does the youth have a school Individualized Education Plan (IEP) that is available for the Scout leaders to see? If parents are willing to share it, the information in the IEP can tell leaders the Scout's strengths, needs, and best ways to teach him skills.
- Is he involved in other activities? If so, what are they?
- How comfortable are the parents and Scout with others in the unit knowing about the disability? Can all leaders know? Can other youth in the unit know?

How much do they feel comfortable sharing? If the Scout is able, it is a good idea to let him share with his fellow Scouts about autism. In Boy Scout or Venturing units, the youth leaders could be given training about autism and how to help the youth in the troop communicate and assist the boy who has autism. For all leaders, setting the example for other adults and the youth of the unit is very important.

## 5. Tips for Leaders

- Relax! Most leadership skills used with all boys will also work well for Scouts with autism.
- Provide consistent, predictable structure. Be patient. Allow extra time for activities.
- Provide a visual schedule using words and pictures. All Scouts will find this useful. Don't put times in the schedule because a Scout with autism may expect you to follow it to the minute!
- Let the Scout know about transitions early, "In five minutes we'll be ending this activity and starting another."
- Give the Scout information about new activities ahead of time.
- Break tasks up into smaller steps.
- Alert the Scout's parents if there is going to be an activity that may cause sensory difficulties for their son. Consider moving noisy activities outside where the noise can dissipate. If the Scout has issues with food taste and texture, carefully plan the menus around these issues so the Scout can eat the same things as other members of the unit as much as possible.
- Respect body space.
- Create and implement a written Individual Scout Achievement Plan (see section X.E. for a sample).
- Assign a leader to monitor closely for dangerous situations since children with autism may not have appropriate fear of danger.
- Have written rules for meetings, campouts, and outings. Scouts with autism love agendas.
- Focus on games that develop social skills (good for all Scouts).
- Stress kindness and respect for diversity on the part of all Scouts.

- Use politically correct language and encourage others to do the same ("Scout with autism, not "autistic Scout").
- Respect and encourage the use of any type of communication that the Scout uses.

## 6. Program information

### Camping and Outings

With advance planning, a Scout with autism can have wonderful camping and outing experiences. Leaders may require a parent or guardian to accompany the Scout. At camp, leaders should work with parents to select appropriate camp programs such as Webelos achievements and merit badges for Boy Scouts. Remember that Scouts with autism may not have an appropriate sense of danger and will need to have close supervision. A Scout with autism may not have the communication skills necessary to seek help if he gets lost. The buddy system, which should be used with *all* Scouts, can help assure the safety of Scouts with autism. With the parent's permission, share the Scout's needs with other leaders and staff members at a regular summer program so that more people are aware of the potential problems.

Summer camp instruction tends to be compressed to a rapid-fire sequence and the teachers are sometimes older Scouts rather than adults. While breaking tasks into smaller steps may not be a problem within a unit, it may be a problem in the larger summer camp setting. The tempo of instruction can easily overwhelm the Scout with autism. Camp counselors may have limited teaching experience and may not know what to do to give the Scout with autism the best camp experience. If the Scout with autism has trouble with camp merit badge instruction, leaders could plan to work with the Scout after camp to finish merit badges not completed at camp. An adult leader could shadow the Scout to his classes and continue working with him during free time. Leaders might also pair him with another carefully chosen Scout as a buddy to help him during class.

### Advancement

Since no two Scouts with autism are the same, there are no set guidelines for advancement. Scouts with autism may need to communicate using pictures, sign language, or keyboards. They may need a parent present during Scoutmaster Conferences and Boards of Review. They may need a quieter, more structured setting for these meetings. Let the Scout

know what will happen at these meetings or have rehearsals beforehand. Sections V, VI, VII and X of this manual have more information on advancement for Scouts with special needs.

### **Multiple Scouts with Autism in One Unit**

Given the statistics about autism, it is possible that you may have more than one Scout with autism in your unit. While they may have the same category of disability, they are as different from each other as they are from the other Scouts. The adaptations leaders need to make will be somewhat different for each Scout with autism. It may be a good idea to place the Scouts in different dens or patrols if that is possible. This will give you the maximum flexibility to treat each Scout with autism as an individual. If there are many Scouts with autism in a troop, it is also a good idea to increase the ratio of trained adults to Scouts.