

Autism Spectrum Disorders

The information that follows is intended to give adult Scout volunteers the knowledge and tools they need to serve Scouts with autism spectrum disorders (ASDs). The information is relevant to all ages of Scouting, from Tigers through Venturers. However, since this is a wide age span and symptoms of autism vary greatly across the spectrum, some information may apply to one ASD Scout more than another. You may find, though, that you don't have to be a neurologist or psychiatrist to work with these youth and enrich their lives—and your own.

Autism, Asperger's Syndrome, and Pervasive Development Disorder—Not Otherwise Specified (PDD-NOS) are developmental disabilities that share many of the same characteristics. These disorders impact social, communication, motor, learning, and emotional skills. Since ASDs have attributes in common with several types of disabilities, a child with an ASD may be misdiagnosed more than once as caregivers learn about the child.

Why Scout Leaders Need Training on ASDs

In 2012, the Centers for Disease Control reported that approximately one in 50 boys (but just one in 150 girls) have been diagnosed with an ASD. The reported rate of incidence of ASDs has been increasing in recent years, due in part to growing public awareness of these disorders and to an improvement in identification and diagnostic tools.

Most Scouting units have an ASD Scout as a member, whether the leaders are aware of it or not. Few other extracurricular activities work as well for ASD youth as Scouting, so there is a higher concentration of ASD youth in Scouting than in the general population. Based on Scouting's own information, it is estimated that approximately one in 20 Scouts have an ASD.

Nature of Autism Spectrum Disorders

Dr. Leo Kanner coined the term *autism* in the 1940s to describe a group of patients who 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. Now we realize that the patients Dr. Kanner studied represented the low-functioning end of a spectrum of disorders. Some authors use the term Kanner's autism or classic autism to distinguish these patients from those who are higher-functioning. In this document we do not address Scouting for low-functioning autistic youth. When such youth are engaged in Scouting, it is usually through a specialized Scouting unit, often chartered through the institution that is caring for them.

Higher-functioning autistic children display similar symptoms to the more profound disorder but in varying degrees. Most display some but not all of the symptoms, and the symptoms they do exhibit will be in varying degrees. Each ASD child is an individual with a unique combination of challenges. You will need to tailor your methods for working with that child specifically for that child. ASD children are subdivided into three major classifications (autism, Asperger's syndrome, and PDD-NOS) based on their symptoms. While it may help to know the vocabulary used for ASD classifications, those distinctions aren't important for Scout leaders because leadership methods will be similar for all of these children.

It is vital to understand that autism spectrum disorders are biological in nature. While ASD children benefit tremendously from interacting with caring adults, ASD children act as they do because of the way their brains are "wired," and not because of bad or disinterested parenting.

Diagnosis of These Disorders

The symptoms of ASDs usually begin manifesting themselves before age 3. For the first few years, symptoms are not often addressed because young children can have a wide range of "normal" behavior patterns. Even when the child's caregivers begin to recognize behavioral differences in the child, there may be a series of incomplete diagnoses before an ASD is finally diagnosed. On average, ASDs are formally diagnosed at about third grade in boys and fifth grade in girls.

Diagnosis of ASDs typically requires a battery of cognitive tests, completion of behavioral questionnaires by the adults who have spent time with the child, and observation by several types of professionals. You should not attempt to diagnose a child, as this needs to be left to professionals. However, you don't need to wait for a formal diagnosis to begin adjusting your methods and serving the child in Scouting.



Causes of These Disorders

Researchers are working to identify the varying cause(s) of ASDs; however, more is unknown than is known about this subject. Many children with ASDs have other family members with similar but less extreme symptoms, so it is likely that genetics influences some ASDs. Others suspect that chemical exposure or trauma in early childhood triggers ASDs. Even though there are vocal adherents and skeptics for various theories, the medical research on the subject at this time is inconclusive. As a practical matter, a Scout leader does not need to know the exact cause of a child's disorder. You do need to be aware, however, that some ASD parents have very strong feelings on the subject, and you would be well-advised to avoid the controversy.

Treatments for These Disorders

If you study the subject of ASDs, you will find rare, unconfirmed reports that a child has been “cured” of autism or “recovered” from autism. ASD children can make great strides and learn to manage their behaviors well enough that they do not stand out from the crowd too much as adults. However, barring a medical breakthrough, it is unlikely that an ASD can actually be cured.

As there are no one-size-fits-all solutions, ASD children often need some combination of speech therapy, behavioral training, occupational therapy, individualized academic instruction, and life skills training. On occasion, an ASD child can benefit from medication to help manage his emotions and impulses. Some parents have reported that a modified diet has been beneficial to their child, but medical research does not currently support this claim. Individual education and treatment plans are usually developed by trial and error to determine what is helpful and what is not.

Characteristics of ASDs

Social Behavior

Inappropriate social behavior is one of the most obvious symptoms of ASDs. Most of the inappropriate behavior occurs because ASD children incorrectly decode the social environment around them. ASD children do not learn socially appropriate behavior from context or observation as other children do. They learn about social interaction from direct instruction, which has several facets. For example, an ASD child may not understand what facial expressions mean until someone explains to them how to decode what they are seeing. Imagine how hard it would be to cope if you couldn't tell whether a person is angry with you or amused by you. Similarly, an ASD child does not intuitively understand how tone of voice can alter the meaning of a statement. “Please sit down” takes on a whole new meaning when it is said in a short staccato burst through clenched teeth.

ASD children do not easily distinguish between family, acquaintances, and strangers. As a result, they may touch people inappropriately, invade the personal space of another person, try to start a conversation with a stranger, or make physical contact in inappropriate ways. They also speak their mind without a social filter and have no idea when they are being verbally offensive. Most parents of ASD children well remember when their child said something inappropriate in public, such as, “Mommy, who is that fat lady?”

Outbursts

ASD children can seem unemotional, but they are not immune to frustration or stress. ASD children, especially older ones, realize that they are “different” and that they will always be “different,” no matter how hard they try and how much they want to fit in. They constantly use their intellect to manage the world around them because it never becomes instinctive for them. The result is that an ASD child is under a constant level of mental stress that others don't experience. If you want to understand this chronic condition, imagine how you would feel if you had to move to a new job in a different community every month and learn all the subtle differences and new people each time. The result of this kind of stress on an ASD person is that he or she has less emotional reserve than most people. It is not hard for someone to unwittingly push an ASD child's buttons and provoke an outburst of tears or of anger (also known as a meltdown). On a practical basis, a caregiver needs to develop a sense of when to stop pressing, so the ASD child is not pushed over the emotional edge. That knowledge allows the caregiver to back off and adjust while the situation is still recoverable. Rarely is a goal so urgent that it can't be put off until circumstances improve.

Special Interests

Many ASD children will develop topics in which they are deeply interested, usually to the exclusion of others. These topics may be conventional for a child, such as airplanes or cars, or they can be very eccentric, such as a fascination with prime numbers. The topics can persist for a few days or extend over several years. There may be one such topic or several that are active at any one time. When you engage an ASD child in conversation, the conversation often turns to their special interest, and it can be a challenge to get them to talk about anything else.

Teachability

A positive aspect of ASDs is that children with these disorders are very teachable. They tend to be rational and rule-oriented, so when information is taught to them in an organized way, they retain it. They can train their behavior to follow social rules even if they don't intuitively understand them. Children with these disorders can learn behavior modifications and improve their social skills, though like any child, several rounds of instruction may be needed before they incorporate what they have learned. ASD children tend to struggle with rules that have many exceptions.

Transitions

ASD children are not so free-spirited as most of their peers. They are more comfortable with structure and order, and tend to create structure and order for themselves if no one else does it for them. Among other things, this structure can take the form of repetitive routines for various tasks. ASD children tend to prefer finishing one activity or routine before willingly moving to another activity. They may also try to do more precise or detailed work than is needed and therefore complete tasks more slowly than others in the group. The consequence of these behaviors is that ASD children can be difficult to shift from one activity to another when the adult or the group is ready. This behavior is one reason that many ASD children are initially misdiagnosed as ADD or obsessive-compulsive.

Intelligence and Language

ASD children may test with average or above-average IQ. However, the nature of that intelligence is different from most children. In particular, ASD children tend to have exceptional long-term memory for information they have been exposed to. That does not mean that they can easily memorize something on purpose. Their spongelike quality impacts their language skills in that they build an extensive vocabulary more quickly than their peers and tend to use language in a precocious way. However, they also tend to understand language literally. Idioms do not come naturally to them, and they may not respond appropriately if you try to "kid around" with them.

Sensory Sensitivity

Many ASD children exhibit unusual sensitivity or insensitivity to stimuli, which can take any number of forms. For some, bright lights or visual clutter may overload the senses. Others react strongly to loud noises. Some cannot tolerate being touched by other people. For others, certain fabric textures or tactile sensations are upsetting. Still others may find smells, tastes, or textures of foods intolerable. This sensitivity can result in a positive, however. For example, your ASD Scout may notice far more natural beauty around him on that nature hike than the other Scouts who are leaving him behind on the trail.

Motor Skills

Some ASD children may have poor gross and/or fine motor skills. They may also have poor body awareness. This means that an ASD child may simply be clumsier than other children, and may trip over or bump into things or people. Since the Scouting program includes both fine motor tasks, such as knot tying, and gross motor tasks, such as hiking, there may be a need to modify your teaching methods or get alternative advancement requirements approved in order for an ASD Scout to succeed.

Endurance

An ASD youth may give the appearance of lacking endurance or physical stamina because they tend to stop or ask to stop or be released from an activity. However, this limitation is more about mind than body. For example, an ASD youth may not understand the value in a long hike, so it is logically pointless to him and he sees no reason to keep going. This can be overcome if an adult can explain the purpose in terms the ASD youth can understand.

Development

Even though ASD children may have differences, many things in their development will proceed at a normal pace, including physical growth, sexual maturation, and many aspects of cognitive development. A teen with an ASD will have many of the attributes of his age peers but will interact with the world in a different way. You can think of it as looking at an ordinary person through ASD glasses.

Why Scouting Appeals to ASD Families

Now that you know the characteristics of ASDs, you can appreciate why most extracurricular options for children—team sports in particular—are not well-suited for the ASD child. A defining characteristic of an ASD child is limited awareness of surroundings, and playing a team sport enjoyably requires paying attention to the ball and other players, even when they are not close to you.

From a developmental standpoint, Scouting has much to offer an ASD child. In Scouting, we focus on community service, which builds empathy. We place children in a wide variety of social contexts, with a wide variety of subjects, and with a wide variety of tasks. This variety is good for the ASD child because it provides social experiences they can learn from. Just as children with other disabilities do, ASD children benefit from the self-paced nature of advancement. Scouting also allows them to participate and socialize with other Scouts of different skill levels.

Tools and Tips for Scout Leaders

Communicating With the Family

You can avoid many false starts and struggles while learning to work with an ASD Scout if you can develop and maintain good lines of communication with the parents. Remember that all parents have similar dreams for their children as they grow up. For the parent of an ASD child, these dreams may include the child's living on his own, forming loving relationships with a spouse and children, and holding a good job.

First, you should determine whether the child has been diagnosed by a professional, and then assess their willingness to talk about his disability. Some parents will be very forthcoming with you 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. You can start the discussion by saying, "I want to do what I can to help your son get the most from his Scouting experience. Is there anything special I need to do or avoid doing when I work with him?" This type of question can solicit the information you need without forcing the parents' hand.

If the parents are willing to be open with you about their child's condition, you need to talk with them about information other adults in your unit need to know and establish ground rules for who may be told what. It is often beneficial if the other Scouts in your unit can be told a little about the ASD Scout's condition so that they can support and watch out for the ASD Scout. Clear this disclosure with the parents as well. It is important to remember that it is a parent's right to decide what is shared about the ASD Scout and with whom that information is shared. Even if you would prefer to have more disclosure, you need to respect the parent's wishes.

It is a good idea to have a meeting with the parents of an ASD Scout every few months to discuss how their child is maturing and to review any new adaptations that could be beneficial. If the Scout is mature enough, include him in these meetings as well. During this kind of meeting, spend more time praising the Scout's accomplishments than addressing his difficulties. Parents need encouragement too.

Communicating With the ASD Scout

Unlike most of your Scouts, you may not be able to tell if an ASD Scout has heard or understood you based on his body language alone. In particular, many ASD children have difficulty making eye contact because it disrupts their thought processes. An ASD Scout needs to learn to make or fake eye contact of some kind to be accepted in adult society, even though this may be uncomfortable for him. You may be able to help with this social skill, but don't force the issue if it is distressing to him. If you need to ensure an ASD Scout heard an instruction, ask him to repeat what you said.

Communicating With Other Scouts

As mentioned before, it is often helpful for other Scouts in your unit to be told a little about the ASD Scout. This is especially true for your youth leaders. They will respond to him in a more compassionate manner if they understand a little about his challenges. Rather than focusing on getting the ASD Scout to follow a boy leader, focus on training the boy leader to encourage and lead an ASD Scout. Any training of this kind should not be done in the presence of the ASD Scout.

You want to build empathy in all of your Scouts, including your ASD Scout. This can be accomplished by telling "social stories" in one-on-one, small-group, and large-group settings. Such stories are similar to a Scoutmaster's Minute. They are simple, step-by-step descriptions of social situations (teasing, for example) and are told from the perspective of the child. You can use these stories to help all of your Scouts recognize the patterns of a social situation and anticipate or empathize with the reactions of others.

Instruction Style

Don't forget to encourage your ASD Scout when he is striving, just as you would with your other Scouts. The EDGE teaching model (explain, demonstrate, guide, enable) will work with ASD Scouts, but you may need to go more slowly and break tasks into smaller steps than usual. This additional time isn't difficult to devote within the unit, but it may be problematic in a larger setting, such as at summer camp. At camp, instruction tends to be compressed to a rapid-fire sequence, and the teachers at camp are often older Scouts rather than adults. This increased tempo of instruction can overwhelm an ASD Scout, and since the camp counselors have limited teaching experience, they may not know how to compensate.

Depending on the needs of the ASD Scout, you may make adjustments to extend the instruction time. You may want to consider the following:

- After camp, work with the Scout and offer additional instruction as needed so he can complete his badges.
- Have an adult leader shadow the Scout to his classes and continue working with him during free time.
- Pair him with a more mature Scout as a buddy to help him during instruction time.

Transitions

If your leadership style is free-spirited and you like to “let nature take its course” in your Scout meetings and outings, you and your ASD Scout may become frustrated. Plan the sequence of activities, and foreshadow this sequence with your ASD Scout. Foreshadowing means telling all your Scouts what the sequence will be. This information allows the ASD Scout to anticipate transitions before they occur. One caveat however: Unless you know exactly what time you will change from one activity to the next, don’t give exact times to your ASD Scout because he will hold you to it. It is better to say “later” or “very soon” than to say “a half hour” or “five minutes.” Similarly, if you have planned some extra activities to do if time permits, hold off on telling your ASD Scout about them until you are sure you will get to them. At that point, add the new information to your foreshadowing. If you work with a troop or crew, you need to train your youth leaders in structuring a meeting and foreshadowing.

Inappropriate Behavior

There may be times when your ASD Scout behaves inappropriately, and you have to be careful not to overreact. The key thing to remember is that most inappropriate behavior is due to either social ignorance or incorrect interpretation of the actions of others. There will also be times when your ASD Scout will push boundaries, test limits, seek attention, or try to get out of work—just as any other Scout would do. As an ASD Scout matures and mainstreams, he will behave more and more like your other Scouts.

If inappropriate behavior does occur, it is critical to get all the facts about an incident before you choose how to respond. Be sure to ask the ASD Scout for his perspective.

In general, an instance of inappropriate behavior can become a teachable moment: You can help your ASD Scout understand a rule of social behavior he didn’t know, or you can help him see things from another’s perspective. Remember that ASD Scouts have to be taught these things in an overt manner. One advantage of working with an ASD Scout is that you can be very straightforward because their feelings are not easily hurt. In addition, an ASD youth may not comprehend subtext, so speaking plainly will help him understand your message more clearly. Be as blunt with them as they are with you, but remember that blunt is not the same as rude or harsh. You need to explain what was done, how it made others feel, and what should have been done, without belittling the ASD Scout.

Personal Safety and the Buddy System

ASD Scouts are more likely than others to put themselves in danger without even realizing it. For example, because ASD children can be more comfortable with adults than others their age, they may wander off with a stranger and not realize they are separated from the group. They may get distracted by things around them and not notice that they are off the regular trail or that the group is moving away from them. They may jeopardize their safety by inattention to things around them, such as moving cars and crossing signals.

Even though all Scouts should use the buddy system on outings, adhering to this system is even more important for ASD Scouts in public or outdoors. You also need to be thoughtful about assigning the ASD Scout’s buddy; you’ll want to choose a Scout with a good temperament for the job. The buddy may also need a little extra support, guidance, and encouragement from you. Do not rely on another special needs Scout as an ASD Scout’s buddy.

Pitching and Striking Camp

The process of pitching or striking camp can be especially stressful for the ASD Scout. In Scouting, boys lead this process, and they are still learning how to lead. If the ASD Scout is being directed by a single boy leader, the stress level can be managed, but if several boys are giving directions at once (too many chiefs), the confusion and noise can trigger a meltdown. A boy leader can be taught to pay attention to the environment and manage it, but it may also be necessary for an adult to monitor the social interactions of the patrol and provide coaching before frustration becomes unmanageable.

Sensory Issues

In time, an ASD Scout will develop coping mechanisms for his sensory overload triggers. Until that happens, adaptations can keep his stress from becoming unmanageable. For example, if visual overload is the issue, you could take down some of the decorations on the walls of your meeting space or concentrate them on one wall and turn the Scouts away from it when the meeting is in progress. If noise is an issue, consider moving the activity outside where it can dissipate better, or subdivide the group so fewer voices can be heard at one time. If food tastes and textures are an issue, creative menu planning may help. During meal time and preparation, be vigilant to make sure the ASD Scout is not always eating alone and is not the only one eating unusual foods.

Involving the Parents

The parents of an ASD Scout have conflicting interests when it comes to serving as adults in the unit leadership and/or attending meetings. On one hand, they are the most skilled at helping their child succeed at any given task. On the other hand, they need their child to be exposed to other people to learn vital social skills. You need to be thoughtful about how you involve the parents of the ASD Scout. It is easy to use them as a crutch and ask them to attend every meeting or outing, but this is a disservice to both the Scout and his parents. Although few would admit it because they love their children, parents need time away from their ASD child. On the other hand, there may special times when you need that extra set of eyes for safety's sake, especially on outings or when working with younger Scouts. You will have the best results if you can be thoughtful and rely on the parents when it matters the most.

On the other hand, if the parent of an ASD Scout simply loves Scouting and wants to be involved in your unit, go for it. However, you may want to structure your leadership team so that parent is spending much of his time with other Scouts rather than his own child. Encourage your other adult leaders to share the challenge and joys of working with the ASD Scout at unit meetings and outings.

Multiple ASD Scouts in One Unit

Given the statistics about ASDs, you may have more than one ASD Scout in your unit and even more if your unit becomes known as special-needs friendly. Whatever your number, remember that even though ASD Scouts may have similar disabilities, they are as different from each other as they are from the other Scouts. The adaptations you need to make will be somewhat different for each ASD Scout.

It is a good idea to spread ASD Scouts out among the dens or patrols of your unit if possible. This will give you the maximum flexibility to treat each ASD Scout as an individual. Do not pair the ASD Scout with another special needs Scout as tent mates or camp buddies because they cannot effectively watch out for each other, and their differing needs will almost certainly cause clashes between them.

Advancement Adaptations

In general, there are few tasks that an ASD Scout cannot accomplish if he is given enough time to learn the skill and if he can demonstrate the task when he is in a productive frame of mind. If an ASD Scout has a significant motor skill disability, advancement requirements may need adaptation. Consider adapting requirements as early as possible in the process so the ASD Scout is not unnecessarily frustrated and discouraged.

Concluding Encouragement

Since its inception, Scouting has served ASD Scouts without even realizing it. You should be confident in your ability to work with these youth even if you have not done so before. Any adult who has a heart for the development and growth of young people can work with an ASD Scout and be a positive influence for him. Your basic instincts and training as a Scout leader will guide your service to these young people. The information provided here only makes your task easier because you will make fewer false starts when you are tailoring your methods to work with an ASD Scout.

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