

Autism Awareness

A Patroller's Guide

AT THE END OF A LONG DAY you receive a radio call about a child who is running wild outside the lodge, apparently unsupervised. He's reported to be wearing no jacket or shoes and is acting erratic.

You jump on a snowmobile and cruise to the lodge, but the boy runs away, screaming, as you approach. When you shine the light of the snowmobile on him, he starts screaming even louder and heads toward the busy parking lot. You shut off the snowmobile and sprint to catch up with the kid, but he doesn't appear to notice you or the oncoming traffic. He even seems to ignore your shouts asking him to stop. He is halfway through the lot before you catch up to him and grab ahold of his arm.

The boy is clearly alert but very agitated, and he won't look at you or answer any questions. Is he drugged up, drunk, in insulin shock, psychotic, or having some sort of seizure? He squirms around, trying to escape your grip, and his eyes dart from side to side. He does settle down a bit when you release your hold on his arm. He rocks back and forth for a moment, then begins to tear off the few clothes he has on. Concerned that he might hurt himself or you, you follow your local area's protocol for restraining an unruly guest and call for additional patrollers and a spineboard. He continues to resist, and this time he doesn't settle down. Instead, he begins to bang his forehead on the pavement until it bleeds. When help arrives you place him on a spineboard to get him out of the parking lot, but this agitates him further. All of his vitals are elevated.

As you and the other patrollers approach the lodge, carrying him on the spineboard, a concerned woman runs toward you. She explains that she is the

child's mother and insists you remove him from the spineboard. The woman quickly gets her son calmed down by deeply massaging his limbs and face and then explains that he has autism, which causes him to react this way in unfamiliar or uncomfortable situations. With her help, you're able to treat the boy for frostbite and the gash on his forehead, but you feel bad that you weren't able to prevent the entire situation from the outset by recognizing the child's condition and special needs. You've heard of autism, but, frankly, you don't know much about its symptoms.

cases, people with autism can become highly educated and function normally. Others might completely retreat into a world of their own.

Race, socioeconomic level, family income, lifestyle, and education levels are not factors in the development of ASDs, and they are certainly not caused by misguided parenting activities. The exact cause of ASDs is unknown, but some doctors and researchers believe they are caused by a genetic predisposition, which is then triggered by a number of environmental issues including pollution, food

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Autism, a condition depicted by Dustin Hoffman in the movie "Rainman," generally appears between 15 and 20 months of age and lasts throughout a person's lifetime. It is one of five pervasive development disorders (PDDs) more commonly known as Autistic Spectrum Disorders (ASDs). The other disorders on the spectrum include Rett's Syndrome, Fragile X Syndrome, Childhood Disintegrative Disorder (CDD), and Asperger's Syndrome. My son was diagnosed with autism when he was 18 months old. In most cases, a child with autism develops normally, but then begins to show signs of regression by losing speech, social skills, and physical abilities, though they may appear perfectly normal otherwise. No two individuals with ASDs exhibit the same symptoms or behaviors, but all display some deficit in communication abilities, problems with social interaction, or a tendency for repetitive behaviors. In some

additives, pesticides, or industrial chemicals. Some people in the autism community advocate a theory that the disorder may be linked to an accumulation of mercury and other heavy metals in the body. One theory suggests a connection between autism and Thimerosal, a mercury-based preservative that was once common in children's vaccines, but to date there has been no conclusive evidence linking childhood vaccines to autism.

Individuals with an ASD might also have a host of biomedical and neurological problems related to food allergies and intolerances. Many of these individuals are on gluten-free or casein-free diets (no whole grains or dairy products) because their digestive systems are unable to properly process the substances. In addition, some individuals have reactions to peanuts or any tree nuts. Eating or drinking any of these substances can immediately cause shock at worst or increased

hyperactivity at best. Because these foods are not properly digested by the gastrointestinal tract, they instead enter the blood and travel straight to the brain where they act like narcotics. In other words, individuals with an ASD might literally get high after eating a cookie. Therefore, patrollers should be careful when offering food to a child with an ASD, particularly if the child is non-verbal.

Chronic diarrhea is another potential problem. Because their gastrointestinal tracts are damaged, some individuals also have trouble absorbing vital nutrients, minerals, and vitamins necessary for optimal brain function. Simply put, these individuals can experience a bunch of hidden complications that may compromise proper evaluation and treatment. The best intention of giving a child a cookie to calm him or her down could have drastic consequences.

The latest statistics from the Centers for Disease Control and Prevention state the disorder is being diagnosed in as many as 1 in 166 children with males being four to five times more likely than females to develop an ASD. With numbers like that, there's a good chance you might encounter a person with an ASD who is in need of care on the mountain. The very nature of their disorder might predispose them to winding up in dangerous situations that result in injury, and the symptoms of the disorder might make it very difficult for you or others to provide care. However, there are ways to recognize autism, and methods you can use when approaching and treating someone with an ASD.

SIGNS OF AUTISM AND ASDS AND WAYS TO DEAL WITH THEM

Every person who suffers from an ASD exhibits different behaviors at different times, but there are several characteristics and trends you might recognize and watch for if you suspect a guest is autistic.

Elopement

A very frightening aspect of autistic disorders is the tendency for a person to wan-

der off unexpectedly. This is called elopement, and explains why the boy in the opening scenario was by himself outside the lodge. Breaks or transitions in routines can be extremely upsetting to a person's sense of security and can cause him or her to run off in an attempt to escape.

If you believe a person has run off from his or her parent or guardian, notify the patrol room of your location and do what you can to spread the word that the individual has been located. Often, family members will be looking for the person who has wandered off and, if brought to the scene, can offer reassurance and calm the him or her down. Because every child or adult with an ASD acts differently in different situations, the family members will know how best to respond.

Stimming

When they find themselves in unfamiliar situations—as the boy in the opening scenario might have if this was his first time at a snowsports area—people with autism will engage in repetitive, nervous movements called self-stimulatory behaviors, or “stimming.” This helps them “block out” the scary and unfamiliar surroundings. They may exhibit unusual or repetitive physical actions such as flapping their hands, flicking their wrists or fingers, spinning objects, or rocking back and forth. My son twirls string and then begins a monotonous chant in order to retreat into his own world, and his stimming and behavioral problems will increase if he eats a food to which he is sensitive.

When they finally block out the bad stuff, people with ASDs can become unaware of what is going on around them. They have been known to run across busy, multi-lane highways as though they were in a park. They often seek out high places or water. Water hazards are significant, because about 40 percent of deaths of children with ASDs are due to drowning. Some people are drawn to mechanical objects, particularly if the machines are not making loud noises. People with ASDs can also take longer to

process information, and when anxiety is heightened, they may not be able to understand any basic commands.

When approaching an autistic person experiencing a traumatic episode, it's best not to interrupt the stimming behavior—provided the individual is not in immediate danger. This mechanism helps people with ASDs adapt to new situations. In a scenario like the one described previously, you could place yourself between the boy and the parking lot to ensure he doesn't run into the traffic, but still give him plenty of room—don't threaten his personal space. If you need to give the person direction, try to use a variety of communication styles. If he or she doesn't respond to your verbal directions, try pointing or gesturing, and give the individual plenty of time to respond because it might take longer to process your instructions.

Sensory Overload

Many people with ASDs also have heightened sensitivity to stimuli, causing constant sensory overload. This can take many forms. Some people become intensely aware of the texture and color of an object, the sensation of each article of clothing they are wearing, the sounds they hear around them, and bright lights or reflections. They may be sensitive to touch, sound, bright lights, odors, or animals. Conversely, they may be fascinated by water, lights, reflections, or shiny things.

In the opening scenario, the sound of the snowmobile, the bright light, and the physical contact added to the boy's sensory overload and caused him to begin behaving frantically. The boy became even more agitated when his senses were overwhelmed, and he shed his clothes as a way to remove himself from the situation.

If you must approach the person, do so in a quiet and non-threatening manner. Compliment him or her and offer reassurance that you're there to help. Avoid touching the individual, especially on the shoulders and face, unless necessary during

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a physical exam. Remember that the person may be sensitive to touch and might jerk away or cry out. When using a stethoscope or other devices, make sure to warm them up before using them in an exam.

Strobe lights or penlights directed at the eyes and sirens can cause seizures, which are a common symptom affecting 40 percent of individuals with ASDs. For this reason, when examining a person with an ASD it's important to refrain from using such devices.

And if the individual must be restrained, approach from the side, as people with autism may throw their head back in an attempt to resist. Never hold someone in a prone position unless absolutely necessary. Many have underdeveloped trunk muscles (hypotonia) and may not be able to support an airway.

Finally, transportation can also be difficult. You or another patroller may need to ride with the person in the toboggan, or the autistic individual may not be able to ride in it at all due to sensory issues. Use of snowmobiles should probably not be considered due to the noise and possible safety concerns. As a last resort and as long as injury doesn't preclude it, you might have to convince the individual to take your hand for a walk to the patrol room.

Communication Problems

Up to 50 percent of individuals with autism are nonverbal and learn to communicate using sign language, picture cards, gestures, pointing, or computers. Nonverbal individuals might simply stare at you or gaze off into space when you try to address them, or they might act as if they are deaf and can't hear you at all.

Those who are verbal might be difficult to understand or have variable communication styles. For example, they might simply repeat everything you say, a phenomenon that is called echolalic speech. They might ramble or speak in a monotone, computer-like, or singsong voice. Sometimes they speak in high or low-pitched tones or in whispers, and

their speech patterns can change (often unconsciously) in the presence of a different accent. Like young children, they might say "no" or "why" in response to every question or give inappropriate responses. And even if they won't talk to you, they might talk to themselves or to no one in particular. Autistic individuals are not especially tactful, but they are typically very honest; they don't lie.

Obviously, the inability to communicate can be confusing for the individual and those interacting with him or her. In emergency situations, the individual might not be able to provide his or her name or any other important information, and if a parent or guardian isn't present, gathering that information can be difficult. Fortunately, people with autism sometimes carry or wear identification

Signs and Characteristics of Autism

- Limited range of speech or vocabulary (50 percent are nonverbal)
- Echolalic, rambling, monotone, computer-like, or singsong speech
- Unusual or repetitive physical actions, self-stimulatory behavior, or self-injurious behavior
- Inability to understand or engage in nonverbal communication
- Tendency to avoid eye contact, cover ears, look away, or be left alone
- Pigeon-toed gait or contorted posture
- Uncomfortable with change
- Inability to recognize danger
- Attachment to objects that are not age-appropriate
- Sensitive to touch, sound, bright lights, odors, or animals
- Fascination with water, lights, reflections, or shiny objects
- Difficulty judging personal space (may stand too close or too far away)

When Treating or Interacting with a Person with Autism

- Approach in a quiet and non-threatening manner.
- Reduce noise, light, and stimuli as much as possible.
- Do not crowd the person.
- If the individual needs to be restrained, approach them from the side.
- Incorporate the caregiver (if one is present) when communicating with the person.
- Use deliberate, one-step commands or instructions.
- Allow for delayed responses to questions or commands.
- Model the behavior that you want the individual to display.
- Never place the individual in a prone position unless absolutely necessary. Many have underdeveloped trunk muscles (hypotonia) and may not be able to support an airway.
- Avoid touching (especially the shoulders and face) unless necessary for the physical exam.
- Ignore repetitive behaviors that appear odd unless injury may result.

Other Helpful Autism Resources

- Center for the Study of Autism: <http://www.autism.com>
- Cure Autism Now: <http://www.cureautismnow.org>
- Law Enforcement Awareness Network (L.E.A.N.) On Us: <http://www.leanonus.org/pages/1/index.htm>
- North Shore-Long Island Jewish Health System: <http://www.northshorelij.com>
- Project Lifesaver: www.projectlifesaver.org
- Specialized Training of Military Parents (STOMP): <http://www.stompproject.org>
- Unlocking Autism: <http://www.unlockingautism.org>

—Scott Campbell

tags or have non-permanent tattoos describing their condition and any allergies or medical concerns.

If a parent or guardian is present, solicit suggestions on how best to communicate with the individual, de-escalate interfering behavior, and avoid sensory triggers that might intensify the situation. Whenever possible, use the person's first name, communicate on one issue at a time, and use one-step directions. Even if the person is verbal, he or she still might be unable to coherently communicate with you.

Nonverbal individuals can hear you and might be able to respond without speaking. It's best to speak to them in direct, short phrases using simple language and a quiet voice. Avoid double meanings, slang, or jokes, because people with ASDs tend to take things literally.

Conversely, some higher-functioning people, such as the character in "Rainman," learn to read early and develop an extensive vocabulary at a young age. They might initiate a conversation about a particular interest that has nothing to do with the situation at hand. In this instance, take advantage of the opportunity to gain their trust by discussing common interests or educating them about what patrollers do.

Social Interaction Difficulties

In addition to their difficulty communicating, individuals with ASDs might also have an underdeveloped sense of appropriate social behavior. In some cases, they'll appear anxious, argumentative, stubborn, or belligerent. They may avoid eye contact, cover their ears, look away, or prefer to be alone. It's not uncommon for them to have difficulty judging personal space, and they may stand too close or too far away from people with whom they're interacting.

When people with ASDs get frustrated or upset, they might exhibit forms of self-injurious behaviors, spitting, screaming, tantrums, stripping, or self-induced vomiting. Furthermore, they sometimes grow attached to objects that

are not age-appropriate. Do not take away a favored object, even if the item seems inappropriate for that person. Instead, use it to connect with the individual.

When examining or helping people with autism, try to work with them where they're most comfortable, even if that's on the floor. If they seem nervous or don't act appropriately for the situation, model the behavior you would like them to display. If they are interested in a piece of equipment you're using for an exam, let them hold it or play with it while you use a second one. You can demonstrate how you'd use the device on a doll before using it on them.

Delayed Response to Pain

Another frightening aspect of these disorders is the way the brain receives and processes information. While the senses might pick up on stimuli, the brain can take awhile to get the proper response started. Pain, or more accurately a delayed response to pain, can be a big problem. Many individuals with ASDs seem to withstand a great deal of pain before they react, which can be a serious problem in an on-mountain emergency.

Combined with his or her inability to communicate, an autistic patient might not notice a serious injury or be able to alert patrollers to the discomfort. In the opening scenario, the boy might have become frustrated or scared enough to bang his head against the ground but might not have noticed any pain. For this reason, it's important to conduct very thorough and deliberate exams in case the person can't tell you if something is hurt.

CONCLUSION

People with autism can be loveable and capable individuals who can learn to enjoy snowsports as much as the rest of us, but an unfamiliar situation can quickly turn scary for them. Considering the growing numbers of the autistic population in the United States, it is likely that while patrolling you could encounter someone with autism or another ASD. Recognizing the behavior and being sensitive to the

needs of these individuals will help you maintain a high quality of care. +

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Scott Campbell and his wife, Debbie, are parents of a young, nonverbal son with autism, and they are active in the autism community in Northern Virginia. Due to frequent moves as part of active military service, Scott is currently with his eighth patrol in 14 years of volunteer NSP service at Liberty Mountain Resort in Pennsylvania. He trains first responders to identify, evaluate, and treat individuals with autism in emergency situations. Scott is also an NSP OEC, S&T, MTR, and Avalanche instructor. For more information on autism awareness, please contact Scott at scott.alan.campbell@atec.army.mil.