

(866) 946-9733 • TTY: (866) 933-4889 • www.omr.state.ny.us



On the Scene and Informed: First Response and Autism

Why You Need to Understand Autism

Autism and related Autism Spectrum Disorders (ASDs) are the fastest growing developmental disability in the U.S. In 2006, the US Centers for Disease Control reported that, in some communities, as many as one in every 150 eight-year olds is diagnosed with an ASD. Autism affects people of all races, genders and economic groups, and because of the tremendous social, sensory and communication challenges these disorders present, people with ASDs:

- are at a four to ten-fold greater risk than most citizens of becoming a victim of a crime;
- are seven times more likely than most to come in contact with first responders;
- may respond to law enforcement intervention in ways that suggest aggression, flight or noncompliance; and
- may require special consideration and response techniques.

The chances are very good that you will respond to an emergency situation involving someone with an ASD. As you prepare to meet the needs of your community residents, it will be essential to understand what autism is, recognize what is really happening in a situation involving someone with an ASD, and understand how to modify response techniques to avoid unfortunate and unnecessary outcomes.

Recognizing Autism - Is the situation what it appears?

What does Autism look like?

Autism is one type of disability within a range of developmental disabilities known as the Autism Spectrum Disorders (ASDs). As "Spectrum" implies, these disabilities vary widely, and each individual with an ASD is unique in how their disability affects their abilities and behaviors.

Many individuals with autism do not visibly appear to have a disability.

Some individuals with autism may be highly verbal. Others may not be able to speak at all.

Some may have above-average intelligence.

Others may be cognitively impaired.

Nonetheless, many individuals with an ASD share three similar types of challenges:

- difficulties relating to others,
- · difficulties communicating, and
- the need to engage in repetitive behaviors that either provide comfort or stimulation.

In addition, many people with autism are extremely sensitive to sensory stimulation such as lights, noise and touch. Many cannot tolerate changes in their daily routines. Some can become intensely focused on a very narrow topic, and others experience anxiety when they're in close physical proximity to others or in the presence of strangers. These challenges can cause people to act inappropriately, to respond dramatically to unexpected changes in routine or personal encounters and to misinterpret other people's intent.

Two of the biggest safety concerns for people with an ASD are the inclination to wander and the attraction of many to water bodies and pools. Tragically, drowning is a leading cause of death for a child or adult who has autism. People with ASDs may simply be seeking out places that interest them or make them feel content. They may not realize they are in danger or that they appear to be running away.

These challenges are exactly the reason why individuals with ASDs may find themselves in a situation requiring first response. Fortunately, you can learn to look for these behaviors and assess whether a situation is one caused or exacerbated by the challenges of autism.

Communication

In a first response encounter, the person with an ASD may:

- not understand what you say, disregard instructions or appear deaf
- be fixated on a particular topic, asking repeated questions
- give misleading statements or false confessions
- appear argumentative or stubborn
- echo what you say to them
- say "No!" or "Yes!" to every question
- speak in a monotone voice or with inappropriate volume
- be blunt to the point of being rude
- be unable to speak, speak with difficulty, or communicate with sign language or pictures

Actions

In a first response encounter, the person with an ASD may:

- become anxious or agitated and exhibit fight or flight responses or appear confused
- show an interest in particular objects, possibly your badge, keys or weapon
- not recognize your badge or uniform
- look at you at an odd angle or avoid eye contact
- engage in repetitive behavior such as rocking or hand flapping
- repeat your body language and emotional reactions
- act upset for no apparent reason or laugh, giggle or ignore your presence
- appear insensitive to pain
- be self-injurious
- react negatively to physical contact

If you notice these kinds of characteristics in someone's response to you or the situation at hand, that person could have an autism spectrum disorder.

It is critical that you look for any identifying card, bracelet, body tattoo or window sticker in a vehicle alerting you to the fact that the person is on the autism spectrum. Ask those present – including the person suspected of having autism - if the person has an autism spectrum disorder. The answer to that question may change the way you respond and could dramatically improve the outcome of the situation for everyone involved.

Amending Response Techniques for Improved Outcomes

General

- Approach in a calm manner. Speak softly. Avoid abrupt movements.
- Expect the person to violate conventional understanding of personal space by trying to stay either too close to you or a "safe" distance away.
- Make sure the person is clear of dangers such as busy streets. They may not recognize that danger.
- Seek information and assistance from others at the scene about how to interact with the person.
- Check for injuries. Some people with autism don't respond to pain.
- Use simple, direct, and concrete instructions. Repeat or rephrase your statements. Allow for delayed responses to your questions or commands.
- Write instructions down, if the person can read, or use sign language or pictures.
- Demonstrate what you want the person to do.
- \bullet Do not assume that a non-verbal person does not understand what you say.
- Avoid slang or literal expressions such as "Are you pulling my leg?" "Knock it
 off" or "Cut it out."

- Explain what is happening and what may happen next.
- Do not insist on eye contact.
- Do not assume odd behaviors are evidence of drug or alcohol use, psychosis, defiance or belligerence.

De-escalation

- Avoid touching the person. Guide with slow gestures.
- Find a quiet location for the person. Turn off sirens, lights. Remove canine partners and crowds.
- Do not stop obsessive or repetitive behaviors unless they are risking injury to someone. This may be their way of securing comfort.
- If the person is holding and appears fascinated by an inanimate object, allow that to continue if possible.
- Be alert to the possibility of an outburst or impulsive reaction. If the person is not
 endangering himself or anyone else, allow these behaviors to subside without
 intervention. Use geographic containment. Use of pepper spray may result in a
 sensory reaction and escalated behavior.
- Do not react to what might appear to be disrespect. It may be their best attempts to communicate.

Restraint

Despite your altered response techniques, you may find you have no choice but to restrain a person with an ASD and take them into custody. These instances require extreme care to ensure the safety of everyone involved.

- People with an ASD may have poorly developed upper trunk muscles. Physical restraint may cause positional asphyxia. Avoid a prone position and turn the person onto their side frequently to allow normal breathing.
- Monitor the person's condition frequently. The person may not recognize the futility of resistance and may continue to struggle.
- Be alert to health risks during high stress situations, as many people with autism have seizures, asthma and/or heart conditions.
- Avoid standing too close or behind the restrained person.
- Continue to use calming, de-escalation techniques.
- If transporting for care, notify the awaiting staff of the situation and request a private, quiet area be made available if possible.
- Do not place someone with an ASD with the general incarcerated population before evaluation by a mental health professional.

Being Proactive - Preparing Your Community

Beyond understanding how to recognize autism at a scene, first responders can do a lot to help prevent emergency situations in their communities and improve outcomes when they do occur. Meeting and getting to know the members of your community with autism spectrum disorders — and allowing them to meet you — can prepare both responders and people with ASD for an emergency encounter. Informing families of things they can do to prevent and prepare for emergencies can also minimize risks and improve outcomes. Finally, increasing public awareness of the needs of people with ASDs can build understanding and acceptance and further reduce the likelihood of a negative situation occurring.

Responder Preparedness

- Include autism-related training in roll-call or pre-shift briefings.
- Include autism-related training during recruit academy and veteran in-service training.
- Get to know community members with autism by holding events for that purpose, offering emergency preparation workshops, or by visiting schools or other settings. Allow individuals with autism to meet and interact with responders in uniform. Talk with them and their families about possible response situations.
- Develop a response database that will alert responders to the particular needs of people in the community with an ASD.

Family Preparedness

- Encourage families to take steps to prepare for and prevent emergencies with their loved ones. The websites listed in this brochure contain helpful resources and advice.
- Hold community and family events to review this information together and to meet each other.
- Encourage families to register or "red flag" information related to their loved one's autism with emergency 911 call centers, local law enforcement and rescue services. Information can include risk factors for that person such as their tendency to wander, communication methods, health issues, etc.

Community Preparedness

- Develop educational partnerships with schools where students with autism are taught.
- Develop an educational campaign with resources such as identification stickers, personal disclosure cards, and general information about ASDs and participate in community events where they can be distributed.
- Consider possible employment or volunteer opportunities for people with autism in your organization as another way to break down barriers, promote understanding, and support a person with a developmental disability to contribute to his or her community.

Resources

The following resources were consulted during the preparation of this booklet. They contain a wealth of information to help you and your community better understand and serve people on the autism spectrum.

Autism Risk and Safety Management

www.autismriskmanagement.com

Autism Society of America

Safe and Sound Campaign 1-800-3-AUTISM www.autism-society.org

LEAN On Us (Law Enforcement Awareness Network)

www.leanonus.org

Tips for Emergency Responders

Prepared by a partnership of the New Mexico Department of Health; the New Mexico Governor's Commission on Disability; the American Association on Health and Disability; and the Disability and Health Branch of the Centers for Disease Control and Prevention. http://cdd.unm.edu/products/tipsforfirstresponders.htm

Autism Speaks

www.autismspeaks.org

Autism Safety Project www.autismsafetyproject.org

Section 7 of this organization's "First 100 Days Kit" provides an "Autism Safety Kit" for families.



For additional copies of this booklet, contact NYS OPWDD:

www.omr.state.ny.us

A publication of NYS OPWDD Communications Office 44 Holland Ave., Albany, NY 12229

> (866) 946-9733 TTY: (866) 933-4889