

Autism & Emergency Preparedness: Tips and Information for Emergency Shelter Staff and Trainers

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Emergency preparedness in the 21st century is very diverse service. You will meet people and families from all walks of life. People with autism are part of that diversity.

Autism is America's fastest growing developmental disability. Children and adults with autism are now living, going to school, working, and enjoying recreational opportunities everywhere in our communities. During and after an emergency, natural or manmade disaster, you may meet children and adults with autism and their families. The information below will provide tips and options on how to safely and effectively interact with individuals with autism, their family members and care providers.

Definition:

Autism is a neurologically-based developmental disability that seriously affects a person's ability to communicate, socialize, and make judgments. Autism also affects the person's sensory responses to even normal levels of lights, sounds, touches, odors, and tastes. It is typically observed by age three, and is more common in males than females. It is not caused by the way parents raise their children. Despite ongoing research, there is no known cause or cure, although people with autism can make remarkable gains. Autism is referred to as a spectrum disorder. It affects each person differently and ranges from mild to severe. Other terms for autism may include: Asperger Syndrome, High Functioning Autism or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Parents and professionals have learned through experience and education how to recognize the common traits of autism. Autism may or may not be physically obvious--there may be no particular physical marker. No one expects an emergency responder to be able to diagnose autism, but there are some diagnostic behaviors and characteristics you may observe.

A person who has autism may:

- Be non-verbal or have limited speech;
- Avoid eye contact;
- Prefer to be alone;
- Lack fear of real danger;
- Demonstrate apparent insensitivity or high tolerance for pain;

- Have difficulty in expressing needs; does not use gestures;
- Unusual responses to lights, sounds, or other sensory input;
- Seek sensory stimulation, including heavy pressure;
- Have difficulty interacting with others;
- Exhibit avoidance of touch;
- Demonstrate sustained unusual repetitive actions;
- Display inappropriate laughing or giggling;
- Have inappropriate attachment to objects;
- Spin or twirl objects and exhibit finger, arm, or wrist flicking;
- If verbal, may have trouble with correct speech volume (i.e., loud to whisper, and/or monotone, computer-like vocal intonation);
- Appear as if deaf, cover their ears and look away;
- Display clumsiness, toe-walk or have difficulty running;
- Rock back and forth;
- Talk to themselves or no one in particular;
- Echo words and phrases; and
- Display fascination with water, lights, reflections and shiny objects.

People with autism are as different from each other as we all are. They may inherently present autism spectrum-based behaviors and characteristics in different combinations and degrees. Each person will have a different level of independence as well. Some persons with autism will have a caregiver with them at all times. Others will live semi or fully independent lives. You will hear terms such as low functioning autism, high functioning autism, and Asperger syndrome to describe the condition. In most cases, the person will have difficulties following your verbal commands, reading your body language, and will have deficits in social understanding. As with Alzheimer's patients, a person who has autism may attempt to bolt and wander from care provider or shelter. They may be dangerously attracted to water sources, roadways, or disaster debris and emergency vehicles. They may also attempt to enter occupied dwellings.

A good training program can be designed to allow responders to better serve the public, and make the best use of valuable time and resources. (Contact author below to inquire about training and training tools.) Training designed to inform responders about the risks associated with autism and offer suggestions and options about how to address those risks is highly recommended.

Included in those risks are:

- Behaviors that draw attention
- A misinterpretation of those behaviors by others

- Person may lack fear of real dangers
- Person may not recognize authority figures or know what is expected of them if they do
- Inherent condition may present as misleading indicators of guilt such as a lack of eye contact, an apparent aloof and indifferent manner, will change topic of conversation
- Responders not being aware of associated medical conditions such as seizure disorder, asthma, or low muscle tone
- Sensory sensitivity issues that may produce fight or flight reaction
- Basic verbal and nonverbal communication difficulties
- Issues such as hypotonia-low muscle tone, high tolerance for pain and mechanical/positional asphyxia will require alternate restraint options and techniques

Communication

The person you are interacting with:

- May be non verbal or have limited verbal skills
- May not respond to your commands or questions
- May repeat or mimic your words & phrases; your body language or emotional state
- May have difficulty expressing their needs

Behavior

- May display tantrums or extreme distress for no apparent reason
- May ignore your presence
- May be extremely sensitive to lights, words, aromas or touch
- May display a lack of eye contact
- May bolt away from emergency personnel
- May have no fear of real danger
- May may not feel pain or discomfort
- May exhibit self-stimulating behavior; hand flapping. body rocking or unusual attachment to objects. If these behaviors are *not* presenting as a danger to themselves or others it is in your best interest not to interfere with it. Attempts to stop the behaviors may increase anxiety and cause the individual to act out aggressively.

Tips for Interactions with Persons with Autism

- Display calming body language; give person extra personal space

- Use simple language
- Speak slowly; repeat and rephrase questions
- Allow extra time for response
- Give praise and encouragement
- Consider use of pictures, written phrases and commands, and sign language
- Use low gestures for attention; avoid rapid pointing or waving
- Examine for presence of medical alert jewelry or tags, and ask for an autism handout card
- Model calming body language (such as slow breathing and keeping hands low)
- Model the behavior you want the person to display.

Exercise caution if restraint is indicated. The person may have seizure disorder and low muscle tone.

Avoid positional asphyxia. Keep airway clear. Turn person on side often.

Given time and space person may deescalate their behavior.

Autism Emergency Contact Questions/Triage Model

- Name of child or adult
- Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- Sensory, medical, or dietary issues and requirements, if any
- Inclination for wandering and any atypical behaviors or characteristics that may attract attention
- Favorite attractions and locations where person may be found
- Likes and dislikes, for example, food, toys, topics of conversation, music, animals
- Approach and de-escalation techniques
- Method of communication, if non-verbal - sign language, picture boards, written word
- ID wear - jewelry, tags on clothes, printed handout card

Autism and Access to Shelters

- Minimize waiting time
- Talk with parent or caregiver to determine person's unique needs
- Allow patient to tour facility, as appropriate in order to become familiar with new surroundings
- Praise or reward for cooperative behavior
- If verbal, patient may produce false complaints or misleading statements

- Consider that a child or adult with autism may need more than one personal care provider
- Offer family the most sensory free environment possible
- Allow family to bring in items that they know will help the individual be calm

Special considerations may need to be made in order for the individual to reset the sensory bombardment and drastic changes an emergency situation can create.

Shelters should make sure that space for sensory quiet time is available for person with an autism spectrum disorder. This may be accomplished by several means. Access to less used or even staff-only, authorized areas may need to be considered. Two versions of Special Needs shelters may need to be considered when individual needs are at odds with each other. For example, when a person with sensitivity to sound is in proximity with a person who needs life-saving technology that emits sound. Creative use of space will be difficult under emergency situations but making every effort to accommodate individuals with autism will add to the effectiveness of the shelter as well as the shelter staff's ability to provide services to other refugees.

Remember: Each individual with autism is unique and may act or react differently during an emergency!

The parent or caregiver is your **best resource** of information on how to effectively interact with the person who has autism. Ask how to specifically address the following needs: communication, behavior, sensory issues, anxiety responses, and rewards.

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Susan Rzucidlo, member of board of directors of the Greater Philadelphia chapter of the Autism Society of America and creator of the non-profit Silent No More--autism emergency communication boards www.dol.net/~srz

For more information visit:

Autism Society of America (search for emergency preparedness tips and Safe and Sound campaign)
www.autism-society.org

Autism Risk & Safety
www.autismriskmanagement.com

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