

ACT



**Assessment and
Communication Tactics**

**A First Responder's Guide:
Individuals with Autism in Emergency
and Crisis Situations**

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Introduction

The Need for Training

Federal legislation has worked toward improving the lives of people with disabilities. As a result, individuals with disabilities are integrating more fully into the communities in which they live, work, and engage in leisure activities. Concerted effort is given to raising the level of independence for individuals with disabilities. Access and accommodations are commonplace and recognized as essential for individuals with disabilities to participate to the fullest extent. The public understands and supports the accommodations aimed at removing the physical barriers of accessibility.

Despite the strides made in the ability to access life in the community by an individual with a disability, lack of awareness of the inherent characteristics of specific disabilities has and continues to lead to interactions that end in a less than productive manner. In fact, people with intellectual, cognitive or developmental disabilities get involved as both victims and suspects/offenders more often than individuals without disabilities (Davis, 2005). In addition, instances requiring emergency assistance often result in responders being ill-equipped to deal with the special considerations needed for people with specific disabilities.

Emergency management systems need help with the very specific and often complex needs of people with disabilities and seniors. Well-intentioned emergency medical and public service personnel cannot adequately address the complex and additional needs of this population without a deep and thorough understanding not only of disabilities and of aging, but also of the values and goals of independent living and self-determination, and absolute clarity about the human and civil rights of people with disabilities and seniors. (Kailes, 2007).

According to the National Organization on Disability (NOD), local, state, regional, and federal government agencies play a major role in disaster planning and response; however, traditional government response agencies are often ill equipped to meet the specific needs of disabled and aging populations during emergencies. Education and training is vital. To stress the importance of this statement, we can learn from the results of the Report on Special Needs Assessment for Katrina Evacuees (SNAKE) Project (NOD). Findings from this report state that all levels of government experienced systemic failures in their efforts to respond to the needs of the disabled and aging populations following Hurricane Katrina (NOD). One recommendation from this report is that emergency professionals and response organizations must seek out and utilize the expertise of disability and aging networks to reduce or eliminate barriers to effective service delivery.

The ACT for Autism training module introduces first responders to the unique characteristics and needs of people with an Autism Spectrum Disorder. Understanding the relationship between an increased state of anxiety or stress and the characteristics of autism can enhance the successful delivery of service by first responders and avoid disastrous escalation.

Using This Guide

This guide was developed for use with the ACT for Autism training video to provide additional information and resources.

After reviewing the training video, participants should read each of the sections in this training guide.

The information gained from both the training video and this guide should adequately prepare the participant to take the evaluation test for this training.

Training Module Objectives

- ✓ Participants will be able to identify the characteristics of people with autism.
- ✓ Participants will recognize how and why the characteristic behaviors of autism can manifest during an emergency or crisis situation.
- ✓ Participants will understand the ACT response when dealing with individuals with autism during an emergency or crisis situation.
- ✓ Participants will be able to use information from this training to apply appropriate response protocols in the field.
- ✓ Participants will complete a competency test at the end of the module.

What is Autism?

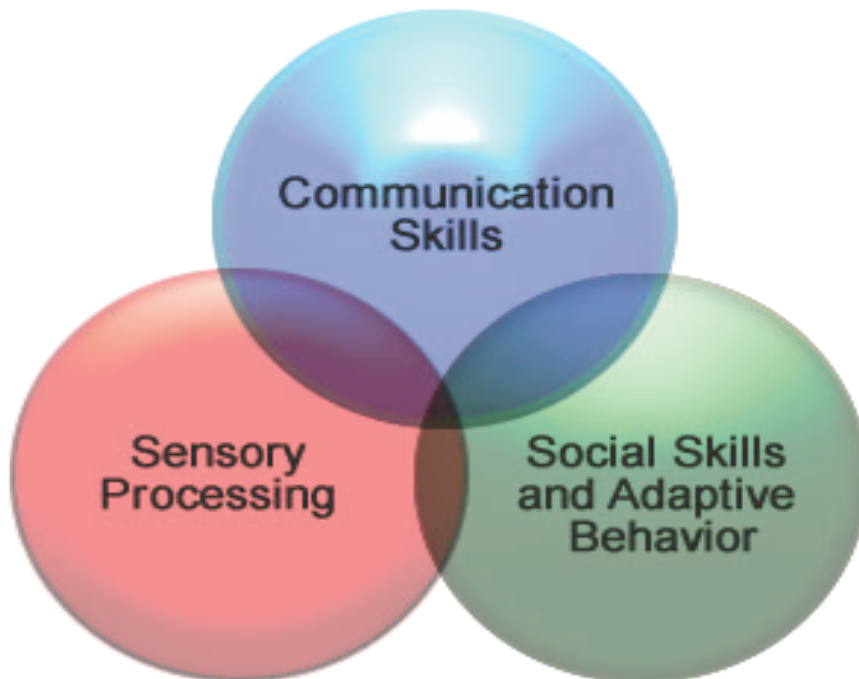
According to the Center for Disease Control and Prevention (2010), Autism Spectrum Disorders (ASDs) are a group of developmental disabilities. People with ASDs demonstrate significant social, communication and behavioral challenges. ASDs are a neurological disorder, which causes people with ASDs to interpret information differently than other people.

“Autism is also known by other names, ASD -Autism Spectrum Disorder, Aspergers Syndrome, PDD- Pervasive Developmental Delay, PDD NOS- Pervasive Developmental Delay Not Otherwise Specified and of course Autism” (Cannata, 2003, p 1).

The fact that ASDs are “spectrum disorders” means that each person is affected differently and may demonstrate a range of abilities and disabilities from very mild to severe. People with ASDs share some similar characteristics, such as problems with social interaction, sensory and behavioral excesses and communication difficulties.

“It is estimated that between 1 in 80 and 1 in 240 with an average of 1 in 110 children in the United States have an Autism Spectrum Disorder” (CDC, 2010). Autism occurs across all ethnic, racial, and socioeconomic populations. Both males and females are affected; however, Autism is 4 to 5 times more likely to occur in males than in females” (CDC, 2010).

Defining Characteristics of Autism



Individuals with autism cannot be identified by their physical appearance. They look the same as anyone else. They are identified by their behavior and because autism is a spectrum disorder, it presents differently in each individual. What works for one individual with autism may not work for another (Rzucidlo, 2005-07).

Although no two individuals with autism are alike, all persons with Autism exhibit difficulty with communication, sensory processing, and social and adaptive behavior skills with varying degrees from mild to severe. Each of these three defining characteristics are inter-related and it is often very difficult to separate the effects of one or the other on how that person will react in any given situation. Therefore, it is important to understand what you may observe, why it may be occurring and how the person with autism may react.

Let's examine each of these three areas of functioning more closely.

Communication Skills

A person with autism:

- Can be verbal, non-verbal, or echolalic.
The person may be able to use verbal language or they may be completely non-verbal. They may repeat something you said or a phrase they have heard over and over and over again. This is referred to as Echolalia. Echolalia can be calming to the individual and should not be interpreted as rude or mimicking. Because the person with autism may lack the verbal skills to generate the words necessary to meaningfully communicate their wants or needs, echolalia may serve as an attempt to communicate with you.
- May appear deaf or refuse to respond.
The person may lack an awareness of the environment. They appear disinterested in others and seem oblivious to what is happening with others (Webber & Scheuermann, 2008).
- May have difficulty in expressing needs.
- May use words, gestures, signs, pictures or a communication device.
The person may use an alternative way to communicate. These alternatives could incorporate the use of no technology (sign language and picture cards) or some type of communication device.



- May have difficulty understanding language and may interpret everything literally.
- May interpret or respond according to what they have seen or heard in prior personal experiences or on television.
- May have difficulty understanding complex sentences.
- May have difficulty understanding questions other than “yes or no” questions.
- May have difficulty following directions especially multi-step directions.
- May avoid eye contact.

Sensory Processing

A person with autism:

- May be insensitive to pain.
Some individuals with autism do not have a normal range of sensations and may not feel the cold, heat, or pain in a typical manner. Therefore, they may not seek shelter or help. In fact, they may fail to acknowledge pain in spite of significant pathology being present. They may show an unusual pain response that could include laughter, humming, singing and removing of clothing (Cannata, 2003).
- Does not want to be touched or cuddled.
Unwanted touch could escalate the person's behavior or cause them to lash out with aggressive behavior.
- May exhibit an inappropriate behavioral response to sounds or sights.
They can be oversensitive and may respond with increased anxiety, increased repetitive behavior and bolting from the area.

Social and Adaptive Behavior

A person with autism:

- May prefer to be alone.
- May have no real fear or a lack of awareness of danger.
Individuals with autism often have a general lack of awareness of the potential dangers in the environment. This could result in placing themselves further into harms way. Individuals with autism are strongly attracted to water. Drowning is a leading cause of death among children and adults with autism. In search and rescue, responders should check area pools, ponds and streams when looking for a lost child. Hoses, irrigation systems and fountains would also be very attractive to them (Rzucidlo, 2005, p 1).
- May laugh or giggle inappropriately.
- May have difficulty interacting with others.
- May insist on sameness or routine.
- May spin objects or self.
- May exhibit sustained, intense tantrums.
Tantrums can be more intense and longer in duration than typical. It takes a person with autism much longer than normal to de-escalate and recover from a tantrum. Once a person with autism is engaged in a tantrum, it is important to remain calm, talk in a quiet voice, do not restrain but maintain the safety of the child and others.
- May have an inappropriate attachment to objects.
The object often brings comfort to the individual. Do not attempt to take the object from the individual unless it interferes with the safety of the person or others. Trying to take the object away will increase anxiety and may cause the individual to act out aggressively.

- May engage in repetitive behaviors such as hand flapping, rocking, jumping, finger flicking, or talking to one's self.
These behaviors are calming to the individual, even if it doesn't appear calming. If these behaviors are NOT presenting as a danger to themselves or others it is in your best interest not to interfere. Allow the behaviors to continue as long as the individual is safe and it is safe for others. Trying to stop the behaviors will increase anxiety and may cause the individual to act out aggressively (Cannata, 2003, p 1).

Understanding the unique characteristics of a person with autism is the first and most critical step in providing the successful delivery of services. There are additional considerations that first responders need to think about when dealing with a person with autism.

General Information and Tips

The cognitive skills of a person with autism are often different. For example, these individuals may have a poor understanding of cause and effect and have little concept of consequences (Rzucidlo, 2005). They have a literal, restricted and rigid pattern of thinking. They often have a limited perspective of situations or circumstances and tend to view things as right or wrong, yes or no, black or white. They have an obsessive desire for routine and repetition. They also have a tendency to overselect irrelevant environmental stimuli (Webber & Scheuermann, 2008). For example, they may fixate on or stare at an object in the room -- a badge, earrings, buttons (Rzucidlo, 2005).

According to Cannata (2003) and Rzucidlo (2005), first responders should be conscious of the following:

- Forty percent (40%) of individuals with autism will develop epilepsy or some other seizure disorder by the end of adolescence. Consider the possibility of a seizure when dealing with an individual with autism (Rzucidlo, 2005).
- Expect the unexpected. Children with autism may ingest something non –edible (PICA tendencies) or get into something without their parents realizing it. Look for less obvious causality and inspect carefully for other injuries (Rzucidlo, 2005).
- Many individuals with autism have a poorly developed upper trunk area, which puts them at greater risk for positional asphyxiation. Steps should be taken to prevent that from happening: frequent change of position and not keeping them face down. This is especially important when considering restraint (Rzucidlo, 2005).
- Families may employ a variety of ways to help with the identification of their child (Rzucidlo, 2005).
 - The person may wear a Medic Alert Bracelet. However, individuals with autism often will not wear the jewelry because they are sensory defensive.
 - Families will thread the ID into a shoelace, into a belt, or as a zipper pull. It may also be a necklace.
 - Some families put a business card into a small case and put it in a pocket of their children's clothing.

- ID tags are sewn or stamped into the back of collars.
- On vacation or in large crowd settings, many families create temporary tattoos with the child's name and their cell phone numbers and place it on the upper shoulder.

Cannata (2003) has specific advice for first responders in rescue situations.

- Forced entry will be most likely. Families often need to lock doors including interior doors for safety reasons. Some families need to lock kitchen, bedrooms or bathrooms in the night.
- Because children with autism may bolt or wander away, first responders may encounter barred, nailed or locked windows. This is done to keep individuals from trying to run off or wander.
- Plexiglass or Lexan windows may be in place. This makes access a problem for rescue.
- Fences with locked gates present an access problem for rescue. Think about the use of bolt cutters.
- Adults with autism are just as likely to hide, like children, in a fire situation. Closets, under the bed and behind furniture checks need to be done during search and rescue.
- When moving an individual with autism quickly, wrap them in a blanket with their arms inside. This will give them a secure feeling and may help to calm them during a rescue. This will also prevent thrashing while trying to escape an emergency situation.
- Rescue from heights: Extreme caution should be used with any rescue from heights. An aerial tower or platform would be the easiest way to remove an individual with autism. This person may aggress towards the rescuer during this operation. **ALWAYS** make sure you are secured before you attempt to rescue the individual.
- Individuals with autism are a bolt risk during and after rescue. First responders must stay with the individual.

Although these are common characteristics, not every person with autism will display all of these behaviors all of the time or to the same degree. However, in times of increased anxiety, these behaviors will become more pronounced. Emergency situations increase the likelihood that the person with autism will be exposed to loud and unfamiliar sights, sounds, people, and events all leading to increased anxiety. It is important for emergency personnel to take the necessary steps to reduce anxiety and increase understanding so that emergency services can be carried out more efficiently and effectively.

ACT for Autism

ACT (Assessment and Communication Tactics) provides a framework for response from first responders. ACT takes a two-pronged approach. The first is to “assess and control the situation” and the second is to “communicate to gain understanding and compliance or to de-escalate the situation”

ACT Assessment and Communication Tactics	
Assess and Control the Situation	Communicate to Gain Understanding and Compliance or to De-escalate the Situation
<ol style="list-style-type: none"> 1. Gain as much information as possible about what led to or surrounds a situation 2. Determine the best way to approach or communicate with the individual 3. Minimize sensory stimuli such as flashing lights, sirens, high-volume walkie-talkie device, loud yelling among responders and eliminate non-essential persons 	<ol style="list-style-type: none"> 4. Approach the individual slowly and calmly keeping some distance between you 5. Use the person’s first name if you know it and assure you are there to help 6. Talk in a quiet and calm voice and try to establish a rapport no matter how urgent the situation 7. Give simple, clear directions paired with a visual or demonstration 8. Do not attempt to touch, grab, or restrain the individual in anyway without preparing him or her first for what you are going to do or want him or her to do 9. Ask yes or no questions and avoid sentences or questions that require more complex responses 10. Allow the person time to calm

Following these ten key tactics when responding to emergency situations will help to ensure that the interaction results in a positive outcome.

Let’s examine why these ten key tactics are important.

- I. It is important to gain as much information as possible that led to or surrounds the situation.

It is not always apparent what led to the situation or why a person with autism is behaving in a particular way. First impressions of why a person with autism may have done something or is behaving differently may be incorrect and misperceived.

Video Reference

Listen to the mother describe how her son's seemingly innocent wait for public transportation resulted in others misperceiving his behavior.

Speaking to others around or with the person with autism may provide vital information as to why and what has occurred.

2. Determine the best way to approach and communicate with the individual with autism (use of pictures, writing it down or use of words)

Language and communication difficulties are a signature characteristic of autism. A person with autism not only has difficulty expressing him or herself but also has trouble understanding what others are saying. A person with autism interprets language literally and struggles with language that is abstract, sayings that are figures of speech and idioms or jokes.

The ability to use language varies among individuals. Some people with autism speak quite well, others are non-verbal and still others may echo or parrot what is said to them. Echoic speech can include words or phrases they have heard which are immediately repeated or delayed in repetition.

Some individuals use pictures, gestures, sign language, written words or a communication device to express themselves and to understand what is being asked or told to them.

Video Reference

Watch as the officer gains vital information on how the child communicates from the mother whose child is lost in the woods.

3. Attempt to minimize any sensory stimuli such as flashing lights, sirens, volume that is too high on walkie-talkie devices, loud yelling among responders, and eliminate non-essential persons.

A person with autism may find sights and sounds to be over-stimulating. Sensory stimuli that most people tolerate is often overpowering and may be perceived as painful. A person with autism has difficulty understanding what is going on around them when a new situation arises. He or she may have trouble reading social cues and knowing how to respond. Raised and loud voices can increase the level of anxiety in a person with autism. Rapid or excessive talking only adds to their confusion and raises the person's sense of panic.

Video Reference

Watch as the first responder calmly approaches the vehicle from the front and slowly attempts to communicate with and calm the injured passenger.

4. Approach the individual slowly and calmly keeping some distance between you.

The inability to understand the social world or read social cues may impair the ability of the person with autism to understand the intent of others. Quick or rapid movement towards the person with autism may cause the person to exhibit the fight or flight response. Any attempt to grab or restrain the person may escalate the person's fear and anxiety resulting in increased resistance or attempts to escape. They may scream, pinch, bite or hit themselves or others in their attempt to resist or escape.

Video Reference

Watch as the emergency responders calmly approaches, keeps some distance, and gets down on the level of the child who is lost in the woods, never attempting to touch the child.

5. Use the person's first name if you know it and assure you are there to help

If at all possible, use the person's name and assure you are there to help. The person may not observe the social cues that indicate your intent to help. Simply stating this is often necessary.

6. Talk in a quiet and calm voice and try to establish a rapport no matter how urgent the situation

Emergency situations often lead to a sense of urgency. An increased sense of urgency is often accompanied by raised voices with rapid speech. Because a person with autism may take longer to process or understand information, raised voices reflecting urgency increases anxiety and decreases the ability to process the information. A person with autism will escalate when voices are raised or agitated.

Video Reference

Watch as the first responder speaks quietly and calmly to the injured passenger as he enters the rear of the car.

7. Give simple, clear directions paired with a visual or demonstration

The language deficits of a person with autism make it more difficult to understand what it is that they need to do. People with autism are concrete, visual thinkers. Abstract or more complex sentences are often confusing. Keeping directions simple and using a visual (picture) or demonstration increases understanding and the likelihood the person will comply.

Video Reference

Watch as the first responder demonstrates the flexibility of the neck collar, allows the passenger to touch the collar and demonstrates the use of the collar before attempting to place it around the passenger's neck.

8. Do not attempt to touch, grab, or restrain the individual in anyway without preparing him or her first for what you are going to do or want him or her to do.

Both sensory issues and social skill deficits play a role in the response of a person with autism to touch, holding or restraint. Most people with autism do not like to be touched and find it unpleasant or painful. It is always best to allow the person with autism to control the level of the touch. Preparing the person in advance for the need to touch, hold or restrain them or a particular part of their body is essential. Approaching them slowly and demonstrating what you are going to do helps the person understand and gives them a sense of control.

Video Reference

Watch as the first responders demonstrate the need to put on the SKED vest and to place the passenger on the backboard.

9. Ask yes or no questions and avoid sentences or questions that require more complex responses.

People with autism often struggle with open-ended questions that have no one correct answer. “Wh” questions such as who, what, where, and why require more complex processing of the information and are often confusing. Using statements or questions that require a simple “yes” or “no” answer will make it easier for the person to respond. For example, “Where do you live?” requires complex processing. The person may not understand if you want a description of where they live or if you are asking for their address. A better way to gain this information might be a statement such as “Tell me your address”.

Video Reference

Watch the techniques of Officer Smith as he questions the customer with autism in the convenience store.

10. Allow the person time to calm.

Once escalated, a person with autism requires more time than most people to regain their composure and become calm. It is always best to take the necessary preliminary steps to avoid the person escalating in his or her behavior. In the event that the person has escalated, it is important to step back and allow the person time to calm. Excessive talking to the person with autism once they are escalated does not help the person calm. It is best to back away and keep your composure.

Summary

According to the National Organization on Disability (NOD), local, state, regional, and federal government agencies are often ill equipped to meet the specific needs of disabled and aging populations during emergencies. Education and training is vital. Results of the Report on Special Needs Assessment for Katrina Evacuees (SNAKE) Project (NOD) led to the recommendation that emergency professionals and response organizations seek out and utilize the expertise of disability and aging networks to reduce or eliminate barriers to effective service delivery.

According to the Center for Disease Control and Prevention (2010), Autism Spectrum Disorders (ASDs) are a group of developmental disabilities. ASDs are a neurological disorder, which causes people with ASDs to interpret information differently than other people. People with ASDs demonstrate significant social, communication and behavioral challenges. Because autism is a spectrum disorder, each individual is unique. No two individuals with autism are alike; however, all persons with autism exhibit difficulty with communication, sensory processing, and social and adaptive behavior skills with varying degrees from mild to severe. Each of these three defining characteristics are inter-related and it is often very difficult to separate the effects of one or the other on how that person will react in any given situation. Therefore, persons with autism are especially susceptible to systems failure during emergency situations. Understanding the relationship between an increased state of anxiety or stress and the characteristics of autism can enhance the successful delivery of service by first responders and avoid disastrous escalation.

Evaluation Test

Multiple Choice ~ Circle the correct answer for each question

1. Autism is
 - A. A psychological disorder
 - B. A neurological disorder
 - C. A physical disorder

2. Autism is a spectrum disorder. This means that
 - A. No two individuals with autism are alike and therefore, each will display behaviors to varying degrees of severity
 - B. All persons with autism will respond in exactly the same way
 - C. The person has distinctive physical features

3. The areas of functioning impacted by autism are
 - A. Social and adaptive behavior skills
 - B. Sensory processing and emotional stability
 - C. Communication, sensory processing, and social and adaptive behavior skills

4. A person with autism can be identified by
 - A. Their physical appearance
 - B. Their behavioral characteristics
 - C. Their movement and facial characteristics

5. When a person with autism mimics your words or phrases or phrases from a movie or television, they are
 - A. Attempting to be rude
 - B. Exhibiting a pattern of speech called echolalia
 - C. Trying to avoid answering your questions

6. The language ability of a person with autism
 - A. Is verbal and able to talk
 - B. Is non-verbal with limited ability to talk
 - C. Can be verbal, non-verbal or echolalic

7. Upon arriving at an accident scene, you see a very anxious young man repeatedly flapping his hands, rocking, and jumping. In his heightened state of anxiety an attempt to stop this behavior may result in
 - A. The individual acting aggressively toward you
 - B. The individual quietly complying
 - C. The individual verbally expressing his fear

8. A person with autism may have trouble expressing his wants or needs. He may communicate by
 - A. Using words, gestures or signs
 - B. Using pictures, written words or communication devices
 - C. All of the above

9. When attempting to gain information from the person with autism it is best to
 - A. Use simple statements or questions
 - B. Ask the questions used in the standard protocol
 - C. Repeat the same question until you receive the correct response

10. You respond to a call for an injured child with autism. Upon arriving, you observe the child screaming, hitting himself in the head, biting himself and showing no clear sign of where the injury may be. In assessing the child for injuries you must consider that
 - A. The child has a behavioral problem
 - B. The child may have an insensitivity to pain
 - C. The child needs to first be restrained

11. You are called to a search and rescue detail for a child with autism. You should
 - A. Check area pools, ponds and streams - people with autism are strongly attracted to water
 - B. Assume the child will not go far nor move toward areas of potential harm
 - C. Yell the child's name loudly and repeatedly

12. Any attempt to grab or restrain the person with autism may escalate the person's fear and anxiety and most likely result in
- A. The person freezing and not moving
 - B. Compliance
 - C. Increased resistance or attempts to escape
13. The unique sensory processing of people with autism should be considered and first responders should
- A. Approach without sirens and lights and loud communication devices
 - B. Speak loudly and quickly for better understanding
 - C. Attempt to restrain or hold the person until they are calm
14. Because people with autism are concrete, visual thinkers, when administering emergency service to the person you should
- A. Give multiple directives to the individual
 - B. Keep directions simple and use a visual (picture) or demonstration
 - C. Assume they will not understand and proceed with the protocol
15. You have been called to rescue a person with autism from a burning building. During and after the rescue it is important for first responders to
- A. Stay with the individual because they are a bolt risk
 - B. Place them in a safe area
 - C. Explain and direct them in what to do next
16. If a person with autism becomes non-responsive while you're assisting them
- A. He or she is daydreaming and not paying attention to directions
 - B. He or she may be having a seizure
 - C. He or she is paying attention to other events they are observing

17. "PICA" tendencies mean that a person

- A. is very particular about how she looks
- B. speaks very softly and is difficult to understand
- C. is at risk for eating non-edible items.

18. If you respond to an emergency and you have concerns that the person you are assisting may have autism

- A. locate some other person nearby who can be of assistance
- B. look for medical alert or other identifying information
- C. both of the above

19. Rescue activities involving a home where a child or adult with autism lives may be more difficult because

- A. the person will generally be hiding on the uppermost floor of the dwelling
- B. they will always be silent and difficult to locate
- C. interior doors may be locked and forced entry may be necessary

20. When approaching a person known to have autism that you are assisting

- A. approach slowly with a smile on your face and identify yourself as a person to help
- B. approach slowly and touch the person's arm, assuring them you are there to help
- C. approach slowly while asking questions you need to get necessary information

True or False ~ place a T or F on the line before each numeral.

_____ 21. Persons with autism often comprehend consequences of their actions; they have an understanding of causes and effects.

_____ 22. The effects of restraint can be particularly harmful to persons with autism due to their poorly developed upper trunk area.

_____ 23. People with autism will generally pay attention to the big picture and won't require a lot of direction and explanation.

_____ 24. A rescue worker should try to use an aerial tower or platform, securing themselves first, before attempting to rescue a person with autism from upper floors of buildings.

_____ 25. Once a person with autism is rescued, they will most likely stay where they are told to wait for additional help or services.

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NOTES: