Autism INFORMATION FOR PARAMEDICS AND EMERGENCY ROOM STAFF

PARAMEDICS AND HOSPITAL EMERGENCY ROOM STAFF MAY ENCOUNTER OR BE ASKED TO PROVIDE SERVICES TO A PERSON ON THE AUTISM SPECTRUM. RECOGNIZING THE SIGNS AND KNOWING THE CORRECT APPROACHES CAN ASSIST ALL INVOLVED TO ENSURE THAT THE PERSON WITH AUTISM IS PROVIDED AN APPROPRIATE RESPONSE AND THEIR TRAUMA FROM THE EMERGENCY SITUATION IS MINIMIZED. WHEN AN EMERGENCY ARISES, WORKERS ARE TRAINED TO PROVIDE CARE AS QUICKLY AS POSSIBLE WITHIN A DETERMINED PROTOCOL. WHEN INTERACTING WITH INDIVIDUALS WITH AUTISM SPECTRUM DISORDER (ASD), SOME ADJUSTMENTS TO THE EMERGENCY RESPONSE MAY BE REQUIRED.

An individual with ASD may not be able to assimilate and communicate what has transpired or understand their need for care. It is of the utmost importance that medical professionals learn how to recognize autism in order to provide an appropriate response, deliver medical services, and gather physical evidence. Individuals with disabilities are 4 to 10 times more likely to be victims of crime (Sobsey, et. al., 1995) and may be taught “compliance” from a very young age, making them easy targets for criminals. Crime victimization of individuals with autism may result in injuries that require an emergency medical response and care. When addressing physical and sexual assaults, there will be additional challenges faced by professionals trying to preserve evidence and provide appropriate medical care.
What is Autism?

Autism is a spectrum disorder that affects every individual to a differing degree. Autism is a complex developmental disability. It is a neurological condition with a variety of symptoms that affect individuals in different ways. It knows no racial, ethnic or social boundaries. People with autism may have difficulties in communication and social understanding. They may also have unusual reactions to sensory input, and may demonstrate what appear to be inappropriate behaviors. Autism Spectrum Disorders (ASD) are now known to be more common than previously thought, affecting as many as 1.5 million individuals nationwide.

Considerations for Paramedics and Emergency Room Staff

There are a variety of reasons why emergency medical professionals may come into contact with individuals with ASD, from search-and-rescue efforts when wandering occurs to suspected abuse by a care provider. Emergency medical professionals should be aware that because it is a spectrum disorder no two people with ASD are the same; some individuals may be highly verbal while others are nonverbal, have above-average intelligence or cognitive limitations (mental retardation), and may respond differently to sensory stimuli. During instances of heightened anxiety or when they do not know what is expected of them, individuals with ASD may also lose some of their abilities more readily. Providing reassurance will assist in alleviating the individual’s anxiety and discomfort; however, the characteristics of autism may pose challenges to providing medical care and crime victim services.

In an emergency situation, the natural response is to provide care as fast as possible and within your department’s deemed protocol. This may be a time, however, when adjustments are needed to meet the unique needs of an individual with ASD. Medical professionals should be aware that most individuals on the autism spectrum have sensory issues that could affect their ability to be treated. Tactile hypersensitivity may mean the person is unable to have adhesive products applied. Auditory sensitivity should also be considered and the use of sirens should be avoided when possible. Individuals with visual sensitivities may react to flourescent lighting often found in hospitals. Some individuals may be resistant to being in a reclined position or strapped down. Providing simple explanations prior to each step in treatment will assist in calming the individual.

Knowledge of the individual’s method of communication is vital to providing medical care and crime victim services. It is estimated that 30% to 50% of individuals with autism are nonverbal and even those who are verbal may process and communicate information in different ways.

Especially in stressful situations, individuals may display immediate or delayed echolalia (the repetition or echoing of verbal utterances made by another person). Immediate echolalia may be used with no intent or purpose or may have a very specific purpose for the individual. Delayed echolalia appears to tap into long-term auditory memory, can involve the recitation of entire scripts, and can also have both noncommunicative and communicative functions. Communicating with someone who knows the individual well is key to understanding his or her specific use of echolalia and other communication traits.

Although visual representations may help, some individuals with ASD may not respond to the Wong-Baker FACES Pain Rating Scale, due to an inability to read facial expressions. Many individuals with autism also have either a hyper or hypo tolerance of pain and may not feel typical sensations to heat or cold. As many as 30% of individuals with autism have a seizure disorder that typically develops during adolescence, and individuals may also have other co-occuring disorders or medical conditions. This information, and any other unique needs of the individual, should be obtained through medical records or from care providers. The Autism Society offers a personal identification record as part of its Safe and Sound Initiative. This record allows individuals on the spectrum or their caregivers to keep this information with them for easy referral or in case they become incapacitated during an emergency.

In instances where sexual assault is suspected, an individual with ASD may not understand what has occurred and an explanation of all exams and medical care will be needed. Lack of educational programming regarding maturation and sexuality may result in the victim being unaware that a crime has taken place. At these times, it is best to have a person familiar with the individual, or at least knowledgeable about autism, involved. When an exam is to be conducted for forensic purposes, a Sexual Assault Nurse Examiner (SANE) who has experience with individuals with disabilities is preferred.
**APPROPRIATE RESPONSE/DELIVERY OF SERVICE**

When providing emergency services to individuals with ASD it is important to establish what is typical behavior and communication for the individual. This is vital and will assist you in monitoring levels of anxiety or stress. Talk to friends, family members or caregivers to obtain an accurate medical history and knowledge of prior contacts with emergency medical professionals. Following are tips that will assist you in conducting examinations:

1. Move slowly, performing exams distal to proximal. Allow patients time to process what you are explaining to them and ensure they understand, if possible, before proceeding. Due to receptive and expressive language delays, this may require more time than is typical.

2. If there is a need to move or transport persons with ASD, explain what will be happening and use gestures so individuals can follow where they will need to go.

3. Within the assessment process, obtain as much information from a care provider as possible, including functioning level and what will make the individual feel more secure or calm. If transporting or relocation is needed, allow a care provider to come along.

4. Presume the person's competence. If they cannot speak, this does not mean they will not understand you and comprehend what you say. Adjust your language level as necessary.

5. If unable to speak, make sure individuals have a method of communication familiar to them, such as a communication device, paper and pen, picture symbols, etc.

6. Speak in simple phrases, not in medical terminology. However, do use age-appropriate phrases during the initial assessment process. Terms may need to be changed if a person is not able to understand.

7. Whenever possible, avoid physical contact. If it is necessary, explain what you will be doing prior to doing so.

8. If a person becomes fixated on an object or has the need to perform self-stimulating activities or body movements, do not interrupt unless necessary. This may be a way for the person to calm down and self-regulate sensory needs.

9. Many individuals with ASD may be self-injurious, especially if anxious.

10. Individuals may have pica and may ingest anything from metal to wood products.

11. Be aware that there may be a fight or flight response to the emergency situation and the person could bolt.

12. If transporting for care, notify the awaiting staff of the situation and request a private, quiet area for the patient if at all possible. Waiting in a busy hall or admitting room could increase levels of stress or anxiety.

**CHARACTERISTICS OF AUTISM**

Persons with ASD may act in any of the following ways in an encounter with paramedics and hospital emergency room staff. Care should be taken not to misinterpret some of these actions as deliberate, disrespectful or hostile. Persons on the autism spectrum may:

- Not recognize a first responder vehicle, badge, or uniform
- Not understand what is expected of them
- Not respond to commands
- Run or move away when approached
- Be unable to communicate with words
- Only repeat what is said to them
- Communicate only with sign language, pictures or gestures
- Avoid eye contact
- Appear argumentative or stubborn
- Say "No!" or "Yes!" in response to all questions
- Have difficulty judging personal space
- Try to avoid sensory input (e.g., flashing lights, sirens, crowds) due to hypersensitivity
- Have a decreased cognitive ability when experiencing heightened anxiety or frustration
- Become anxious or agitated, producing fight or flight responses or behaviors such as screaming, hand flapping, or self-injurious behaviors
- Appear to be under the influence of narcotics or intoxicants
- Have an associated medical condition such as seizure disorder
- Be fixated on a particular object or topic, and may ask repeated questions
- Speak in a monotone voice with unusual pronunciations
- Reverse pronouns ("Can I stop?" instead of "Can you stop?")
- Give misleading statements
- Have problems speaking at the correct volume
- May, if verbal, be honest to the point of bluntness or rudeness
- Not acknowledge physical pain or trauma due to hyposensitivity
- Not be able to communicate the extent of trauma due to a lack of understanding of healthy sexuality or appropriate boundaries in care provider or other relationships
- Have the need for a Forensic Interviewer with knowledge of autism
- Not have knowledge of the criminal justice system and the expectations to assist in prosecution

First responders involved in search-and-rescue response should be aware that individuals with autism will seek out items and locations that hold fascinations for them, such as water, trains and cars, and may do so without realizing the dangers involved. In fires, individuals with autism have been known to hide in closets or under beds to escape from the sound of fire alert systems.
REFERENCES:

RESOURCES:
Autism and Crime
Autism Society ~ 1-800-3AUTISM
www.autism-society.org/safeandsound
Find, or contribute, local resources for victims of crime at Autism Source™, the Autism Society’s on-line referral database:
www.autismsource.org
Office for Victims of Crime, U.S. Department of Justice ~ 1-800-851-3420
National Center for Victims of Crime (NCVC) ~ 1-800-394-2255
Disability, Abuse & Personal Rights Project www.disability-abuse.com
L.E.A.N. On Us (Law Enforcement Awareness Network) www.Jeanonus.org
Autism Risk and Safety Management www.autismriskmanagement.com

Crime Victim Organizations
Office for Victims of Crime, U.S. Department of Justice ~ 1-800-851-3420
National Center for Victims of Crime (NCVC) ~ 1-800-394-2255
National Domestic Violence Hotline 1-800-799-7233
National Organization for Victim Assistance (NOVA) ~ 1-800-879-6682
National Resource Center on Domestic Violence ~ 1-800-537-2238