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Understanding Autism: How to appropriately & safely approach, assess & manage autistic patients

By Lorelee Olejnik
JEMS June, 2004

Your first response engine responds to an apartment complex to care for a six-year-old child with a complaint of difficulty breathing. The little boy is very upset and ³acting out.² He doesn't seem to respond in an age-appropriate manner and is becoming more agitated, although remaining alert and oriented. Specific instruction and eye contact have no effect.

You're beginning to think this child is a ³spoiled brat.² The ambulance arrives, and the paramedic crew also attempts to gain control. The child seems fascinated by the lights and activity. His eyes dart from object to object as he asks numerous questions. When you physically try to place the child onto the gurney to assess him on a more comfortable surface, he becomes hysterical and uncontrollable.

At this point the child's mother informs you that her son is autistic. Wow! If only you had known that from the beginning. Would it have made a difference? Do you really know the implications of this to you, the caregiver?

Captain Ralph Carrasquillo Jr., a paramedic and instructor for the San Diego Fire-Rescue Department, does. When his five-year-old son was diagnosed with autism, educating other first responders and medical personnel on autistic patients became a cause close to his heart.

³When I first heard the term *autistic*, the only thing I thought of was *Rainman*,² says Carrasquillo. ³I didn't really know much. I've educated myself about my son, but I wanted to share that information with everybody.²

Carrasquillo has taught more than a thousand fire and EMS personnel in San Diego County to improve their interactions with autistic patients, especially children. He modeled his lesson plans after those developed by Dennis Debbaudt, a Florida private investigator who also has an autistic autistic son and who took on the cause of educating law enforcement officers in the early 1990s.

Through their in-service training courses, and coming soon lessons for new recruits at police academies, San Diego County emergency responders are benefiting from education on the disorder. Firefighters, EMTs and paramedics increasingly must take a proactive approach in learning how to recognize and work with autistic patients, to better provide for their welfare and safety and to better protect themselves and their departments from liability.

³It makes me feel great that I've helped [an autistic] person's life and that family's interaction with us,² says Carrasquillo. ³What's close to my heart also is the fact that we're keeping my firefighters safe.²

Carrasquillo's work is especially effective with emergency response personnel because he's one of their own.

³There's nothing like hearing it from your colleagues,² says Debbaudt, who writes books and conducts autism workshops for emergency responders around the world. ³Ralph brings that credibility to the table. His passion<it's something you can't buy and can't hide.²

According to the Autism Society of America (ASA), autism is a neurological disorder that typically appears during the first three years of life. It specifically affects brain function in the areas responsible for the development of

communication and social interaction skills.

Centers for Disease Control and Prevention (CDC) statistics place the prevalence of the disorder at two to six per 1,000 people, and estimates are that one in 150-250 children younger than 10 years old in California alone have autism. It is four times more prevalent in boys than in girls, is not affected by race or socioeconomic level and is not caused by misguided parenting activities.

The exact cause of autism is unknown, although there may be links to genetics and brain injury. It has also been linked (controversially) to thimerosal, a mercury-laced preservative present in many childhood vaccines. Some autistic people have abnormally high levels of mercury in their bodies, and those levels have been linked to the cumulative effect of immunizations. Although thimerosal has been removed from the MMR (measles, mumps, rubella) vaccine, it is still present in others, and there's an active campaign to have mercury-based preservatives removed from all vaccines. At this time, there's no known cure for autism.

Autism is one of several disorders that fall under the umbrella category of Pervasive Developmental Disorders (PDD), along with Asperger's Disorder, Childhood Disintegrative Disorder (CDD), Rett's Disorder and PDD-Not Otherwise Specified (PDDNOS) (ASA, 2003).

(*Note: Several decades ago, autism and learning disabilities tended to be lumped beneath one diagnostic umbrella of ³minimal brain dysfunctions,² and then physicians would add ³autistic tendencies² or ³high-functioning autism² to further differentiate from severe autism. The DSM was re-configured, and many disorders were ³renamed² [as with ADD or ADHD] or named after physicians who did early research into that specific disorder, as with Asperger's syndrome (named after Hans Asperger who did the first serious research into what was known as high-functioning autism. Thus, today, many who would have been diagnosed 30 years ago as high-functioning autistic are diagnosed as having Asperger's.)*

Although individuals with autism may otherwise appear perfectly normal, the disorder makes it difficult for them to function and communicate in socially appropriate ways. The inability to be understood may cause frustration and confusion for both patients and those interacting with them, and often makes the autistic person appear to be acting abnormally or in a bizarre manner. In addition, their lack of eye contact and repetitive, nervous movements, called *stimming*, often cause emergency responders to mistakenly assume autistic patients are on drugs.

Those diagnosed with autism can exhibit such a tremendous variation of symptoms that they are said to fall on a spectrum. No two individuals display the exact same behaviors or symptoms, which can range from individuals who are severely affected by uncontrollable body movement and an inability to communicate to highly functioning, highly educated persons who suffer only mild problems in communicating and with relationships.

Most autistic patients have food allergies and intolerances, and some thrive on a gluten-free and casein-free diet (no wheat, no dairy). Diet won't ³cure² autism, but for some autistics, it makes dealing with the condition easier.

Although only 0.001% of the general population experience seizures, they are a common symptom in autistic patients, occurring in 25% of autistics. Many autistics have heightened visual acuity (e.g., some can discern the 60-cycle frequency of fluorescent lighting and/or the cycling of a computer or TV screen). Some are sensitive to flashing lights (e.g., strobe lights or pen lights directed at the eyes), which can trigger seizures. This can present unique problems for emergency responders attempting to assess or treat autistic patients.

Due to increased education and awareness of the disorder, the rate of reported autism is growing at more than 10% per year, and the ASA projects that 4 million Americans will be diagnosed as autistic during the next decade. This correspondingly increases the chances that emergency medical personnel will encounter autistic patients in the field. In fact, statistics show that autistic children and adults are seven times more likely to have contact with law enforcement or EMS than a member of the general public.

Efforts to mainstream autistics as an alternative to institutionalization have also resulted in a greater number who can function independently in society. Therefore, when first responders arrive on scene, a caretaker may not be

available to inform them of the individual's condition, unlike our scenario, which makes looking for telltale signs of autism even more important.

A first responder may come into contact with an autistic individual on a medical emergency call or even calls for missing children or adults because autistic persons, similar to Alzheimer's patients, will sometimes run away from caretakers.

This activity, called *elopement* or *running*, is one of the greatest threats to autistic patients, and emergency responders must take care not to quickly attribute the event to deliberate abuse or negligence on the part of the caretaker.

Autistic children who run away are often attracted to bodies of water. This is a dangerous combination because many show no notion of fear and don't know how to act in emergency situations. *Example:* In December, a 16-year-old autistic girl in Mesquite, Texas, died in a fire after her mother unsuccessfully struggled to remove the girl from their burning home. In an interview with *The Dallas Morning News* regarding the tragedy, Debbaudt commented, ³ Autistic people can take longer to process information and when anxiety is enhanced, like in a fire, they may not be able to understand the basic command.²

Debbaudt added, ³ They may not understand the inherent danger and refuse to leave until they get a stuffed animal they are attached to. Or a person may want to re-enter a building to retrieve a pet, because they don't understand the dangers.²

(*Note:* Autistics tend to learn by experience and education, but don't possess the innate ability to detect danger. They tend to miss non-verbal cues from the ³crowd mentality,² especially when things are going bad. For example, autistics aren't likely to see a punch coming until they've already hit the ground. Even if they are aware that a situation is deteriorating, they may not know what to do about it. Role-playing, scenarios and detailed preparation are essential for autistics to function well in any environment.)

Working with autistic patients

Because so many potential risks are involved to both the patient and the first responder, extra caution is needed when dealing with autistic individuals. *Tips for recognizing a person with autism* (as adapted from course curriculum):

- May have limited range of speech or vocabulary (50% are non-verbal);
- May appear argumentative, stubborn or belligerent;
- May exhibit echolalic (repeats what you say) or rambling speech or speak in a monotone or singsong voice. They might speak in high- or low-pitched tones or in whispers. Also, autistics quickly pick up regional accents, and their speech patterns can alter (often unconsciously) in the presence of a different accent;
- May exhibit unusual or repetitive physical actions or self-stimulating behavior, including hand flapping, finger flicking, spinning objects or self-rocking back and forth;
- May give an inappropriate response or no response (may appear deaf or like they don't care what you're saying);
- May not be able to give important information or answer simple questions;
- Are usually very honest; don't lie and are very blunt;
- May be sensitive to touch, sound, bright lights, odors or animals;
- May have difficulty judging personal space<may stand too close or too far away; and
- May have information pertaining to their condition on an ID card/bracelet or clothing tags.

How you store your equipment can make a huge difference to autistics, who have great difficulty dealing with change and/or ³out of order² materials. Hastily wadded ECG cables (inset) are going to agitate your patient. If they're neatly wrapped, you're less likely to have a problem.

PHOTOS COURTNEY McCAIN

Suggestions on how to approach an autistic patient:

- Approach in a quiet, non-threatening manner, reducing noise and stimuli as much as possible;
- Don't crowd; leave as much room as possible;
- Incorporate the caregiver (if one is present) into the call as much as possible, and solicit from them suggestions on how best to deal with the individual;
- Talk in direct, short phrases using simple language: Avoid double meanings, slang or ³ joking around.² Autistics tend to take things literally. On the flip side, be prepared for a ³ little professor² speech pattern, particularly in young patients. Many high-functioning autistics read early and develop an extensive vocabulary at a young age. They're likely to launch into a long-winded, advanced conversation about a particular interest. Looking for common ground in interests or educating them about EMS (they're likely to ask many questions) can help develop a rapport;
- Allow for delayed responses to questions or commands;
- Talk calmly and repeat questions and information if necessary; talking louder does not improve understanding;
- Avoid touching (especially the shoulders and face) unless necessary for the physical exam. The patient may be sensitive to touch and cry out. Some might jerk away, as if they were burned or touched with something very hot;
- Evaluate the patient for injury with a thorough secondary exam; they may have a high tolerance for pain;
- Use all available information: the patient's name, age, appearance, bystander statements, types of behaviors exhibited, etc. Find out exactly what's going on;
- Consider using a clipboard, tablet or a computer with responses displayed: yes/no, the alphabet, simple phrases, pictures. Before using a computer, however, to help assess an autistic patient, ask if they've ever experienced seizures. If they have, use caution with computer screens and pen lights; and
- If a patient needs to be restrained, approach them from the side. Autistic people tend to throw their head back when being restrained.

Non-skid surfaces are especially difficult for autistics because of the patterns and rough edges. Many formerly cooperative, ambulatory autistics might see this rear ambulance bumper and refuse to step onto it. If that happens, explain that the metal is shaped like that so no one will slip and fall. PHOTOS COURTNEY McCAIN

Carrasquillo said he gets the biggest satisfaction when coworkers tell him that they have utilized these tips when they encounter an autistic patient. ³ They tell me they used the techniques and haven't had to wrestle a patient to the ground. When I hear that, I feel like I *have* made a difference.²

Through education and application of this information in the field, all first responders can improve their interactions with autistic patients, thus elevating the overall quality of service and making a difference in their communities as a whole.

Recommended Reading:

1. Anderson KS: ³ Autistic girl dies in blaze. Officials: She struggled with Mesquite mother who tried to save her.² *The Dallas Morning News*. Dec. 15, 2003 <http://www.dallasnews.com/latestnews/stories/120603dnmetfiredeath.7140d64f.html>
2. Autism Society of America home page: <http://www.autism-society.org> . Accessed Feb. 26, 2004.
3. Autistic Society home page: www.autisticsociety.org. Accessed Feb. 26, 2004.

4. Centers for Disease Control and Prevention, 2001.
5. Curry K, Posluszny M., Kraska S: *Training Criminal Justice Personnel to Recognize Offenders with Disabilities*. Office of Special Education and Rehabilitative Services News in Print, Washington, D.C.: 1993.
6. Debbaudt D: ³Managing autism safety.² *Advocate*. 36(2):27-30, 2003.
7. Debbaudt D: ³Avoiding unfortunate situations." <http://policeandautism.cjb.net/> Accessed Feb. 28, 2004.

- *Loralee Olejnik is a communication instructor at San Diego State University and a freelance journalist working with San Diego Medical Services Enterprise, the City of San Diego's 9-1-1 paramedic program.*
- *Ralph Carrasquillo Jr. is a captain for San Diego Fire-Rescue and oversees the administrative staff for the EMS Division. If you have any questions concerning working with autistic patients, contact him at RCarrasquillo@sandiego.gov.*

Pensacola Police Department's *Take Me Home* Database Debuts

The seeds were sown for this innovative special needs assistance program when Pensacola, Florida PD Officer Jimmy Donohoe attended a meeting last summer of the Panhandle Chapter of the Autism Society of America. Officer Donohoe heard first-hand the concerns that many parents there had about their wandering children who have autism. Officer Donohoe, also the parent of a special needs son, decided then and there to do something to assist. He approached Pensacola PD Chief John Mathis who gave the green light to spearhead the *Take Me Home* service.

The Pensacola PD worked in partnership with *SmartCOP*, a Pensacola-based law enforcement technology and software company, to develop *Take Me Home*.

The *Take Me Home* system is a database that is maintained at the Pensacola PD of persons who may need special assistance if they are alone. The system includes a current, digital picture, demographic information and caregiver contacts. If a person in the *Take Me Home* system is encountered by a Pensacola Police Officer, the officer can query the *Take Me Home* system by name or by the person's description to locate the person's *Take Me Home* enrollment record. With the information at hand the officer can appropriately assist the person.

The *Take Me Home* system is designed for departments that utilize the *SmartCOP* onboard patrol vehicle computer technology. Over-the-air dispatching is minimized. Caregivers can be contacted by phone and provide key information directly to the first responder. *Take Me Home* is, of course, voluntary for those who participate.

The Pensacola Police Department was incepted in 1821 and continues to grow not only in personnel but also in technology, training and community outreach efforts. About *Take Me Home*, Chief Mathis recently said, "We are excited to share with you this new service designed to provide enhanced service and protection to our citizens. I strongly believe, and try to instill the same philosophy in others, that it is by working together that we can make Pensacola an even better place in which to live."

When it comes to the *Take Me Home* program, Chief Mathis and the Pensacola PD strive to make everywhere a better

place to live. The *Take Me Home* system is available to ALL public service agencies free of charge!!!

For further information and public service agency inquiries about *Take Me Home*, contact Crime Prevention Officer Jimmy Donohoe at 850-436-5416 or email jdonohoe@ci.pensacola.fl.us

Kudos to Chief Mathis, Inspector Wendell Rich and Officer Jimmy Donohoe for creating *Take Me Home*. Write thanks to the Chief at:

Pensacola Police Department
711 North Haynes Street
Pensacola, FL 32501

Contact *SmartCOP* at: 270 North Palafox Street, Pensacola, FL 32502, phone 850-429-0082

Police are Honored for Autism Efforts

Virginian-Pilot
Virginia Beach, Virginia
by Margaret Windley

In late January, Beach police officer Rachel McGraw and Mark Pantak spotted a man breaking antennas off of cars in the Lake Edward neighborhood. When the officers approached him, the man wasn't able to give his name or address.

"We asked him to speak and he could not talk to us," said McGraw. "But he was doing the hand motions that are a sign of Autism." The officers provided a pen, pencil and some paper to divert his attention and he wrote his first name. After trying to find someone who might know him at a local mental health organization, the officers checked the man's clothing and found his full name. After running a check, they were able to learn where he lived. The incident was resolved peacefully because the officers had learned appropriate ways to work with people with autism through Autism In Law Enforcement, developed by U.S. Deputy Marshal, Nick Proffitt.

Chief Jacocks received a plaque from Autism Society and two officers, Rachel McGraw and Mark Pantak, one of whom could not be present, were honored for using their training in handling Autistic Individuals in ceremonies on April 26 at the Law Enforcement Training Academy. Chief A.M. Jacocks Jr. received a plaque from JoAnna Bryant, president of the Tidewater Chapter of the Autism Society of America for his willingness to cooperate by providing proactive police programs that help autistic individuals and their families.

Autism Alert Window Gels

These gels alert first responders to the presence in a vehicle of an individual with autism. They can be used on whatever vehicle you are using, traveling in a rental car, for instance. The multi-use, easy on-easy off function offers great insurance! A superb autism awareness & safety tool!

Available through Didi Zaryczny. Email Didi at dzaryczny947@aol.com