Autism Safety: The Criminal Justice System and First Responders

By Nora Baladerian, PhD
Executive Director
The Disability and Abuse Project

Children and adults with autism, like others, may in their childhood or adulthood experience encounters with law enforcement. This may occur when the child/adult with autism discloses abuse or their abuse is witnessed or suspected and reported for investigation. At this sensitive point in their lives, it is important not only that the law enforcement, protective services, and qualified forensic interviewer have the attitude, skills and knowledge (ASK) needed. It is also important that the child/adult have information about how best to deal with the situation in which they find themselves. Whether they are a child or an adult with an autism spectrum disorder, whether they are brought in for suspected bad behavior or as a victim of bad behavior, some preparation is needed - or things can go terribly wrong.

Abuse and trauma play a significant role in the lives of those with autism and other developmental disabilities. In their seminal research on abuse among children with disabilities, Sullivan and Knutson (2006) published their findings that children with disabilities in general experience abuse at 3.4 times the rate of their generic counterparts. In 1994, Sobsey’s review of studies indicated that adults with developmental disabilities are abused at rates ranging from 4-10 times that of neurotypical individuals. In the absence of a national survey, the Disability and Abuse Project (Baladerian, Coleman & Stream, 2012) conducted one to learn about prevalence as well as sequelae of abuse. Garnering 7,289 responses, findings include that over 70% of people with disabilities had been abused (Baladerian, Coleman & Stream, 2012). However, most abuse was not reported. Survey respondents indicated that the reason for not reporting was predominantly fear that nothing would be done. Among respondents who indicated they reported the abuse, over half said nothing was done by law enforcement (full research findings are available on our website at www.disabilityandabuse.org).

It is my experience of over 35 years that when police/sheriff and protective services workers begin their jobs, they do not receive training to work with individuals with intellectual and developmental disabilities. I was recently asked to speak on the training provided to Adult Protective Services workers in Los Angeles County. I learned that over the past 25 years there have been three announcements of a new online training. I took this training and found that it included the words “developmentally disabled” once, and none of the training was directed to this population. The entire focus was on the elder population. As to the other counties in California, I do not know. I do know that the few people who conduct such trainings mourn the lack of training nationally. The situation is similar for law enforcement. Several years ago I had a grant to provide training at no cost to law enforcement officers around the state using a POST-Certified training curriculum. This training was specifically

see Training on page 24

Autism, Law Enforcement and Disclosure: Advice from 20 Years in the Training Room

By Dennis Debbaudt
Managing Partner
Debbaudt Legacy Productions, LLC

Advice for the autism community from law enforcement professionals at training sessions over the past twenty years in training facilities throughout the US, Canada and elsewhere is very consistent: accurate autism information, even when generic in nature, will inform their response. Information that is specific to the person becomes clearly advantageous for a responding officer.

In the training room setting, generic information is extremely useful for the law enforcement professional. For example, understanding our population, people with autism spectrum disorder (ASD), from the viewpoint of independence level becomes essential background about autism related field interactions.

The term “less independent” may be used to describe children and adults who will have difficulty in areas involving basic life skills such as safely crossing a street, negotiating a financial transaction, and making sense of social interactions. Often, these individuals are also nonverbal and may use alternative forms of communication such as sign language. Picture Exchange Communications Systems (PECS), or computers that can speak for them. If verbal, their communications may be understood only by a family member, caregiver, or teacher. More often than not, they have a caregiver accompanying them and will be dependent on parents, siblings, or others to provide the basic necessities of life.

More independent young people and adults may be able to fully express needs, use public transportation, learn to drive, attend college or university, be employed with surprisingly powerful and professional careers, marry, and have children. However, they are challenged by the same issues as their less independent peers, albeit to a lesser but still significant degree (Debbaudt, 2013). This report will focus on safety strategies that families, caregivers and everyone involved can develop and implement for the less independent individual.

Law enforcement professionals advise that approximately eighty percent of patrol responses do not involve criminal activity. Research indicates that persons with developmental disabilities, ASD being the most prevalent, are approximately seven times more likely to interact with law enforcement than others (Curry, Poslusnzy & Darska, 1993). Additionally, the estimated rate of occurrence of ASD has grown dramatically; from two to five of every ten thousand Americans in the 1980s to one in sixty-eight (CDC, 2014). Considering this, law enforcement is now receiving training to prepare for contact with people with ASD (Debbaudt & Rothman, 2011).

Field contacts regarding a suspicious person, aggression and missing children and adults are three predictable autism related interactions that are best described as high risk interactions. The first two are high risk for all involved, fraught with communication and proximity issues. The third, tragically, is too often a cause of death for the vulnerable child, young person or adult.

Since each individual with autism is unique and may act or react differently (Debbaudt & Legacy, 2005), the responsibility of providing information for persons with autism, family members and care providers

see Advice on page 23
# Table of Contents

**Autism Safety: The Criminal Justice System and First Responders**

1. Individuals with ASD and Law Enforcement Benefit from Training
2. Advice on Autism, Law Enforcement and Disclosure
4. The Importance of Community in Preventing a Wandering Incident
5. Skills for Individuals with ASD to Interact Safely with Police
6. Helping Individuals in Emergencies: First Responder Training
7. Traveling Safely with Students on the Autism Spectrum

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Please contact David Minot with any questions at dminot@mhnews.org or (508) 877-0970
Keeping Kids with ASD Safe: Understanding the Creep Factor and the Hidden Curriculum

By Gary Weitzen
Executive Director
POAC Autism Services

It was Middle School Day at Medieval Times in Lyndhurst, NJ and I was the chaperone for my son's "self-contained" autism class. Christopher's entire school went to the show - including the two autism classes. During intermission, I was asked if I could take the eight teenage boys, all on the autism spectrum, into the restroom, as I was the only male adult on the trip. In the restroom, there were eight urinals and seven of the boys lined up and lowered their pants and underwear down to the knees or below to use the urinals. There I was with my son and his classmates - seven hairy tushes in a row for the world to see, or at least all the other students and teachers who entered the bathroom after us. There was laughter, questions, and people just stopping in their tracks not sure what was going on. Then there was me trying to get the boys to pull up their pants and wishing they didn't have free refills on their soft drinks. I share this story at many of my lectures and it always gets a laugh. Let's face it - this is a funny story but after the laughter, so many parents share their stories of their own sons engaging in the same behaviors in school and public restrooms with horrible and sometimes tragic results.

The fact is there is a very specific culture and etiquette in the typical men's room and we need to teach proper bathroom behavior/rules for our boys. If we don't, they can become vulnerable to anything from teasing or bullying to victimization. Knowing how far down to pull one's pants is only the beginning. Our boys need to know which urinal to use if there is more than one person in the restroom. Most of our children are taught to line up. This doesn't work in the men's room. Here's what I mean - imagine a woman sitting alone in a 500 seat movie theater with every other seat empty and right before the movie starts, in walks an unknown man and out of the available 499 empty seats the man sits directly next to the woman. Creepy, right? This is tantamount to how a typical male would feel if another man entered the restroom and walked by all the empty urinals to stand at the one directly next him. Individuals with Autism Spectrum Disorder (ASD) don't understand the "creep factor." So you see, there exists a hidden curriculum that every non-autistic person just seems to know, but those rules need to be taught to our children on the spectrum.

The sexual abuse rate of individuals with ASD by predators is between 40-70% (Sobsey & Richard, 1994). 49% of people with developmental disabilities who are victims of sexual assault will experience 10 or more abusive incidents (Valenti-Heim, D. & Schwartz, L., 1995). Among adults who are developmentally disabled, as many as 83% of females and 32% of males are victims of sexual assault (Johnston, I. & Sigler R., 2000). These statistics see Hidden Curriculum on page 20

Gary with his son Christopher, who is 21 years old and loves riding the train with his dad
**ABOUT THE ELIJA FOUNDATION**

The ELIJA Foundation is a not-for-profit, 501c(3) organization serving parents, educators, professionals, and caregivers of children with Autism Spectrum Disorders (ASD) on Long Island, New York, since 2002. The ELIJA Foundation has provided the community with educational opportunities that focus on improving the quality of programs and services available to children with Autism. In 2006, The ELIJA School opened its doors to extend the mission of the Foundation and start helping children with Autism. The Foundation’s focus is to empower families and improve the competency levels of professionals, by providing training on the most advanced treatment and educational strategies that maximize the potential of those affected by Autism. The ELIJA Foundation is committed to offering the most comprehensive information that is geared toward improving the lives of persons with Autism and their families.

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**KEYNOTE SPEAKER:**

Gregory Hanley, Ph.D., BCBA-D
Director, Behavior Analysis Doctoral Program, Western New England University

**INVITED PRESENTERS:**

Kathleen Doyle, Ph.D., Executive Secretary, NYSED Office of the Professions (ABA)
Randy Horowitz, MS Ed, SAS, Associate Executive Director of Program Development, The ELIJA School
Monica Howard, Ph.D., BCBA-D, LBA, Associate Executive Director, The ELIJA School
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Nicole Weidenbaum, MS Ed, SAS, Executive Director, Nassau Suffolk Services for Autism

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The Importance of Community Involvement in Preventing a Wandering Incident

By Michael V. Maloney, MA
Executive Director
Organization for Autism Research

Approximately 48% of children diagnosed with autism have been reported to elope at some point in their lives, frequently from places that are considered the safest environments for them to be in, such as homes and schools. People who elope place themselves in harm’s way and increase their risk of death (e.g. traffic accidents and drowning) by at least twice the rate of the general population (Anderson et al., 2012; Shavelle, Strauss, & Pickett, 2001).

It is no surprise that the risk of these behaviors can be a great source of anxiety for parents and families. Among parents of children that elope, 62% reported that they forego participating in activities outside the home out of fear of wandering (Anderson et al., 2012). Whether families choose to stay home for safety reasons or to avoid the misjudgment of bad parenting, this behavior can decrease a family’s network of social supports over time.

Yet, when children do go missing, neighbors are mobilized to help with the search over 50% of the time (Anderson et al., 2012), followed by police officers and school personnel. Thus, it is important not only for parents to have a support system, but also to learn how their children can successfully interact with first responders (e.g. neighbors, police officers, teachers, and caregivers). To begin this process, it is crucial to implement a number of prevention measures in the event a crisis arises. The following tips are excerpted from A Guide to Safety, a free resource published by the Organization for Autism Research (www.researchautism.org/resources/reading/index.asp?AGuideToSafety).

Identify and Address the Cause

To start, it is important to recognize why children with autism elope. Most times, their eloping behaviors are goal-oriented. Individuals with ASD tend to run around excitedly, explore, or seek out places they enjoy, whereas those with Asperger Syndrome tend to feel anxious before running away to avoid an unpleasant experience (Anderson et al., 2012).

Parents should be proactive by gathering information on the challenging behavior exhibited by their child. Track the ABCs (antecedents, behaviors, and consequenc- es) of eloping incidents in order to predict and prevent problems before they arise, and to mitigate potential crises in the future. It is important to collect specific data, such as dates, times, duration of event, and environments. Once enough data is collected, assess the underlying cause before implementing a behavior intervention plan. The goal is to replace elopement behaviors and limit the triggers that evoke the behaviors in the first place.

Create a Safety Network

Once a family is ready to implement a behavior intervention plan, it is time to create a safety network. Having a safety network is not only helpful, but also necessary in many cases. Because neighbors are most commonly directly or indirectly involved in searches, it is critical to share information about your child’s wandering with them. Along with neighbors, a safety network may also include teachers, caregivers, co-workers, and law enforcement personnel.

A key prevention measure then is to inform the safety network that a person with autism lives in the area and may not respond to communication cues. Make sure your network is knowledgeable about your child’s needs, interests, and challenging behaviors. Some people may be unfamiliar with autism and wandering, so it is important to inform them about this issue and how they can help. This is particularly important if the child who wanders does not respond when their name is being called. Children who do not respond to their names are not only more likely to exhibit eloping behaviors (Anderson et al., 2012), they are also more challenging to find during searches.

By sharing information about your child, you are arming your safety network with important knowledge.

Another prevention measure parents can take is to prepare a document, maybe even an annotated Google map that identifies all the possible locations their child may go based on past history and known interests. Make sure that there are enough copies of the document to immediately issue to the safety network should the child wander again.

see Community on page 14
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Parents of children with Autism Spectrum Disorder (ASD) often have a long list of safety concerns, no matter the age of their children. Parents need to focus on creating a secure home environment, preventing wandering and teaching water safety. Yet there is another critical area of need that parents may not consider: teaching their child, teen or adult how to interact safely with law enforcement officials and other first responders.

One reason to pay attention to this issue is that individuals with ASD are more likely than typical peers to have an encounter with police - whether they need help, are the victim of a crime, are a witness, or a suspect. In addition, they may be at greater risk during an interaction with police. For example, a child with autism who has wandered away from home may be afraid of first responders and run away from them. A teen driver with ASD may be pulled over for speeding and reach into a bag for her license. An adult on the spectrum may find himself in the middle of a misunderstanding; when police are called the adult may become overwhelmed by the chaos and panic. More dangerous still, he might try to reach for an officer’s badge or gun.

These sobering examples illustrate the risks that those with ASD may face in everyday life, and the importance of being sure they know how to have safe encounters with police. The interaction in any situation can go better or worse, based on how prepared the person with autism is for the encounter.

“How prepared the person with autism for the encounter is?” you may be asking yourself. “Shall the police be trained to interact with people with ASD?” Yes. Peace officers should definitely be trained to recognize and respond to individuals with ASD. But remember that autism is an invisible disability, and even trained officers will not always know that someone has ASD. It is not enough to hope or expect that the police will always get it right. Training the police is only one side of the safety equation.

Many individuals with ASD don’t have the communication or social skills needed to interact safely with police. They may not understand police procedures and expectations. Tens of thousands of children with ASD who are growing up need to learn crucial safety skills that will work in their favor when they meet the police. They need to be explicitly taught what to do. This applies to individuals across the spectrum. It is especially true for individuals who are likely to be unaccompanied in the community or have other risk factors, like behavioral issues or limited communication.

Teach Essential Safety Skills

We all watch the news. More and more news stories across the country focus attention on individuals with ASD and related disabilities who have unsafe or even disastrous encounters with law enforcement officials. It is a fact that certain behaviors can escalate a police encounter. Other actions will help things go more smoothly. Teaching specific safety skills is a much better option than leaving safety to chance!

It is not hard to identify some of the factors that have caused escalation in police encounters. News stories reveal that some particular actions or “triggers” can cause the situation to worsen dramatically (both for the general public and individuals with disabilities). An example is hitting an officer (also known as assault). What follows is never good. It is important to identify triggers and carefully teach alternate behavior, what to do instead.

Start by “reframing” specific problematic behaviors into positive safety skills. The chart on page 21 identifies the risky action and the reframed essential safety skills to teach. You can use this list to teach in a way that is well-matched to a particular individual’s developmental age, verbal ability and cognitive level. It’s ideal to teach these kinds of skills from an early age, because in fact most of the positive skills apply to other situations in everyday life. Also remember that it is never too late to start teaching these things, and it could make all the difference in the world.
Helping Individuals in Emergency Situations Starts with First Responder Training

By Glenn Sloman, PhD, BCBA-D, NCSP

Behavior Therapy Associates

Emergency situations are by their nature often unpredictable. Accompanying many of these situations are unfamiliar sounds, sights, and smells. For many people, the stress, anxiety, and uncertainty of these types of situations can be overwhelming. For individuals diagnosed with an Autism Spectrum Disorder (ASD) who experience challenges with communication, behavior, novelty, disruptions in routine, and hyper/ hypo sensory sensitivity, the situation can add even greater upset. Added into the event is the arrival of unfamiliar people in the form of First Responders. Given these challenges, individuals with an ASD may have more difficulties than other citizens in responding appropriately to First Responders. As the prevalence of ASD diagnoses increase, it is more likely that First Responders will encounter emergency situations where a person with ASD is present, increasing the need for First Responder training.

Who are First Responders? First Responders include fire, police, and emergency medical personnel such as an emergency medical technician. They are likely to be the first individuals certified to provide basic life support services that arrive and assist with the emergency. Additionally, they are likely to be the first unfamiliar people to arrive at an unfamiliar and stressful situation who make contact with individuals at the scene.

Therefore, training First Responders in how to respond to individuals presenting with an ASD is key. Many organizations such as the Autism Society, Federal Emergency Management Agency (FEMA), Autism Risk and Safety Management, and the American Red Cross offer supportive materials and training recommendations for First Responders in working with individuals with developmental disabilities and ASD. Common components of these emergency preparedness materials include:

- Introduction on ASDs including characteristics of Children, Teenagers, and Adults with ASDs
- Anticipated Behavior of Individuals with ASDs in an Emergency Situation
- Communication Strategies
- Behavior Management Strategies
- Training Familiar Individuals
- Developing Emergency Protocols/Plans

Introduction to ASD

It is important to provide First Responders education about the nature and the characteristics of persons presenting with ASDs across the life span. This introduction may highlight behavioral deficits in communication and social understanding, as well as repetitive and restrictive behavior often seen in persons diagnosed with an ASD. Furthermore, characteristics such as accompanying deficits in intellectual functioning and language impairments may be discussed. The concept of ASD as a spectrum disorder should be emphasized, bringing awareness to the individualized presentation of the disorder.

Anticipated Behavior

Training may explore how individuals with ASD may respond to emergency situations. For example, First Responders may see individuals engaging in different types of repetitive behavior such as rocking or hand flapping, attempts at stimulus reduction in the form of covering their ears or eyes, and self-injury. They may appear very anxious or nervous, attempt to dart away, and may not understand the consequences of their actions. Trainers may consider using videos to prepare First Responders in these characteristics and teaching tactics to respond appropriately when these behavior are seen.

see Helping on page 26
Safety in Numbers: Traveling with Students on the Autism Spectrum

By Ernst VanBergeijk, PhD, MSW
New York Institute of Technology
Vocational Independence Program

Traveling with students on the autism spectrum is a fun and rewarding experience provided that planning and forethought are engaged before going on a trip. Domestic local day trips differ from multi-day international excursions. However, some basic tenants pertain to the planning of each kind of trip. Previewing the trip highlights, reviewing safety procedures, and practicing contingency plans all help make the execution of the trip go smoothly.

Travel Training Classes

Learning to travel independently is a critical skill for individuals on the autism spectrum. It is an essential activity of daily living that helps a person on the spectrum gain and maintain employment. The ability to successfully execute activities of daily living is a better predictor of post-secondary success and employment than I.Q. or academic achievement. Enrolling a student on the spectrum in a program that has a travel training curriculum can be a key bridge to independent living.

The travel training course must incorporate not only academic classroom learning, but also practical in vivo learning experiences where the student is able to practice traveling in groups of his or her peers. Fixed route travel training is not sufficient. The students must learn contingency management - i.e., what to do when something goes wrong with his or her travel plans. Any rider on public mass transit has had to deal with delays or cancellations. They have had to learn to find alternative routes or modes of transportation to reach their final destination. While some students on the spectrum have outstanding skills when it comes to memorizing route maps or timetables, many struggle with the anxiety that comes with the sudden change in plans that a service disruption engenders. Many freeze and cannot problem solve in the moment. The travel training curriculum needs to emphasize how to remain calm and remain flexible in order to find alternative solutions.

Probably one of the most terrifying thoughts for students, parents, and teachers is the thought of a student becoming lost. Prevention is key. Assigning students to pairs of travel buddies is one way to help reduce the probability that a single student will become lost while on a trip. A second method is to further subdivide a large group of students into smaller teams led by an adult team leader. The number of students assigned to the team leader is dependent upon the age and developmental level of the students as well as the students’ experience with group travel and familiarity with the route and final destination. Developing a team identity helps foster cohesion and a sense of looking out for each other. Emphasizing repeatedly the need to stay with one’s buddy and sticking with the team leader during the travel training class goes a long way in preventing a student separating from the group. A third method for preventing a student from getting lost is to conduct frequent head counts. A head count should be conducted by team leaders at every transition point. This means every time the group gets on or off a bus or train, goes through a turnstile, or turns a corner on a busy street, team leaders should be taking a count. The overall group leader should poll each team leader at these transition points asking them if they have all of their team members. On the day of the trip the group leader should remind the students to have a buddy for the entire trip and who their team leader is.

What should happen if a student gets lost on a travel training trip? This is one of the first topics that needs to be covered in a travel training course. The student needs to stay calm and relaxed. The teaching of relaxation techniques is imperative for this to occur. Next the student must be trained to stay where they are as long as they are in a safe location. The student should be trained to observe their surroundings and look for recognizable landmarks, street signs, and logos of restaurants and stores nearby. Once the student determines his or her location, then he or she should call the school with his or her coordinates and await the arrival of a teacher. At the NYIT Vocational Independence Program, we give our students a credit card size instruction sheet to put in their backpacks which includes instructions on what to do if they get lost. The sheet includes how to find a place that they are familiar with and how to get directions back to the meeting point using a public service or other means. The sheet also includes a phone number for the student to call the school and the school office number.

Ernst O. VanBergeijk, PhD, MSW

See Traveling on page 19
Autism was born in 1997 and is now aged 18 - what a journey we have all had! He was born 2 years after Maia, his sister, and in the early years developed as we expected him to. He was a very easy baby, sleeping soundly with very little disruption. His motor development was normal and early language development including several words such as "mommy," "daddy," "kitty," etc. seemed to indicate that all was well.

However all that was to change when Logan at around 2 stopped talking completely and began to cry a lot. He became very active and often ran off without any reason. He started a habit of clearing entire shelves in supermarkets, dumping boxes of toys and emptying out drawers.

In the US, children are monitored by the Birth to 3 team and it was this group who picked up the changes and suggested to all the people Logan was 2 ½ years old that we begin an intervention on an educational level. Logan was 2 ½ years developed as we expected him to. His motor development was normal and early language development was normal and early language development including several words such as "mommy," "daddy," "kitty," etc. seemed to indicate that all was well.

However all that was to change when Logan at around 2 stopped talking completely and began to cry a lot. He became very active and often ran off without any reason. He started a habit of clearing entire shelves in supermarkets, dumping boxes of toys and emptying out drawers.

By Glen Dobbs, BS
President, LoganTech

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By Christopher T. Greco
Detective and PBA President
New Rochelle Police Department

As a police detective in the New Rochelle Police Department (NY) and President of the New Rochelle PBA, New Rochelle is a 10 square mile city located within Westchester County, NY. Westchester County offers Project Lifesaver to all qualified residents within the County. I live in New Rochelle with my wife Tracy and two children, Christopher, 9 and Gabriella 4.

If you asked me what autism was 20 years ago when I was a rookie police officer, I probably would not have had an intelligent answer. If you asked me 20 years ago if I would be in charge of my agency’s Project Lifesaver program I likely would have passed so that I could continue being a “street cop.” Fast forward 20 years and here I am, the parent of a 9 year old boy with autism and a local detective that facilitated the development of the New Rochelle Police Department’s Project Lifesaver program.

Although I am far from an expert on autism, I am certainly an expert when it comes to my son Christopher and his safety. Christopher was diagnosed with autism at 11 months and has since been in early intervention and other special services to help him. He remains nonverbal and significantly developmentally delayed. Christopher is at high risk for “wandering” and has very little situational awareness. Jumping in a pool on a hot summer day is as fun for Christopher as it is for any other kid, except my son doesn’t know he can’t swim! Christopher can never be unsupervised; whether in the backyard, on the beach, at school or in the supermarket, he requires one-on-one attention 24 hours a day. Although my wife Tracy and I do our best to ensure his safety, we are not free of having one or two mishaps over the last 9 years.

One such mishap occurred while vacationing in a beachfront home at the Jersey Shore. While doing something as simple as talking to a neighbor, Christopher was able to wander away from me. When I went back inside the house my wife calmly asked, “Where is Christopher?” As fast as I could I started to give orders. “Check the front of the house,” I yelled to my wife. “Check the bedrooms,” I yelled to my friends. My request to check the front of the house and the bedroom was just a ploy because I already knew where Christopher was since I was the idiot that left him there - 20 feet from the beach and about 100 feet from the unforgiving Atlantic Ocean. I frantically ran back to the beach and toward the crashing waves, scanning the beach and shoreline with every step I took. Thankfully within seconds Christopher was found walking happily along the beach but with no awareness of how much danger was lurking just steps ahead of him. An angel was certainly watching over him because like so many children with autism, Christopher loves to be in the water.

It was at that moment that I started to think about how wandering could be prevented and committed myself to buying the best available equipment to safeguard Christopher and other similar children and adults in my hometown of New Rochelle.

I began searching the internet and various sources to locate an effective perimeter alarm and locate system - one that could create an invisible fence around Christopher; one that would sound an alarm the second the perimeter is violated and one that would allow me to immediately start searching for Christopher if the alarm is missed (of course after calling the police). Most of the products I discovered were GPS systems which require a monthly subscription and cell service. GPS can be a very effective tool for parents and law enforcement, but it also has a significant disadvantage to my

see Project Lifesaver on page 22
Imagine celebrating a birthday party in your home. You have friends, family, neighbors, and colleagues over for a joyous occasion filled with laughter, celebration, and a relaxing evening of catching up with those you care about the most. The evening is going smoothly when all of a sudden you hear the screeching sound of car brakes in front of your house and notice your child has somehow managed to escape from the backyard and out the front door chasing after their soccer ball. Your heart immediately drops and panic begins to overtake. So many emotions are running through your mind and adrenaline has consumed you as you frantically run across the street to check on your child. The thought of entertaining your guests has now been the last thing on your mind as you are fearful to see the state in which your child is in. Thankfully you find the driver aiding your child and physically your child is well. You wipe the sweat off your brow and tears flood your eyes as you gratefully cling onto your child and thank God that they are perfectly fine. Sadly, incidents like this occur in the lives of countless families, however, this is a daily fear many parents endure with a child with autism.

Over the past decade there has been a 289.5% increase of children diagnosed with Autism Spectrum Disorder (ASD), resulting in 1 out of 68 children diagnosed yearly (Centers for Disease Control and Prevention, 2015). Unfortunately with this increase of children being diagnosed with ASD, 49% of those diagnosed wander from a safe environment at least once after the age 4 (Anderson, Law, Daniels, Rice, Mandell, Hagopian, & Law, 2012). Sadly, incidents of elopement can result in death. This horrific consequence became all too relevant for the family of 14-year-old Avonte Oquendo in Queens, New York in 2013. Video footage captured Avonte escaping the doors of his middle school with his teachers taking hours to report that he was even missing (Evans & Eyewitness News, 2014). After Avonte was reported missing, a full-fledged search went into effect that involved rescue teams and missing person posters plastered throughout Queens. After months of tireless days and nights of searching for Avonte, a parent’s worst nightmare came true when his body was discovered in the East River.

Avonte’s story was heard nationwide and with such devastating and tragic news, Senator Charles Schumer proposed Avonte’s Law in May 2014. Unfortunately, the bill did not gain momentum through the Senate until it was revised in January, 2015 (Jones, 2015). Senator Schumer proposed a grant-funded, voluntary program aimed for parents with children with autism by providing them with tracking devices along with providing trainings for law enforcement, first aid responders, school officials, clinicians, and community members to “reduce injury and death relating to the wandering and safety of individuals with disabilities” (Avonte’s Law Act of 2015). The proposed trainings would focus on how to safely interact and communicate with individuals with autism and other disabilities. Often these individuals are mistaken for acting as defiant when they do not respond to law enforcement or first aid responders, resulting in physical altercations. The
The Center for Children with Special Needs & The Center for Independence

Dr. Michael D. Powers, Director

- Diagnosis and evaluation of children and adults
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Community from page 6

Work with Law Enforcement Personnel

Law enforcement personnel play a central role in a family’s safety network. Visit police stations and fire departments with the child so that he or she can become familiar with their uniforms and how to interact with them. At the same time, inform these agencies of the child’s special needs, how they must be addressed, and anything else that might be useful to know in a wandering situation. For example, if the child has a favorite song, let the agencies know in case playing it might help draw the child.

It is also important for them to know whether the child has any sensory issues like an aversion to loud sirens or difficulty with bright lights. It is also a good idea for parents to provide their personal contact information in the event a law enforcement officer sees their child in a concerning location in the community.

In anticipation of eloping incidents, register a child’s information with local law enforcement and public safety offices. Some 911 call centers also offer the option of registering a child with special needs. If parents are able to submit information about their child, that information will be readily available should a wandering incident necessitate a search. Parents may also choose to set up an “in-service” training module that addresses the issues both parents and law enforcement personnel may face in the event of a missing child call.

Adult Elopers and Self-advocates

For some families, elopement can be a life-long concern. Adults who are severely impacted by autism may continue to elope from the safety of their homes (Matson, Rivet, 2008), which stresses the importance of increasing awareness and preparation among community members, as well as finding sustainable solutions among primary caregivers.

Self-advocates who are less impacted by autism and are able to advocate for themselves face different challenges. It is critical for self-advocates to understand that police officers and first responders may not know anything about autism, and may attribute any unusual behaviors or nervousness with suspicion. Prevention strategies can be used to avoid any major misunderstandings. One way is for self-advocates to get to know local law enforcement agencies. The more sensitive law enforcement personnel are with disability needs, the more successful they will be in serving and protecting everyone in the community.

Knowing when and how to disclose the diagnosis in emergency situations is also good practice. Having a disclosure statement ready and even an ID card can be useful in the event of an emergency. Role-play a scene to practice specific behaviors (e.g., pulling out the ID card slowly).

Spread the Word

For parents and self-advocates alike, addressing wandering and preventing emergencies is critical, and learning how to engage the community for this purpose is the first step for addressing these concerns. Knowing the facts about wandering and learning how to prevent and address a wandering occurrence with first responders is essential for parents to keep their children safe. For self-advocates, knowing how to communicate with local law enforcement personnel is crucial to avoid major misunderstandings in emergency situations. Although the reality may seem overwhelming at times, there are supports in place to help keep our loved ones safe. Sharing knowledge, best practices, and community resources can make the difference should an emergency event arise.

Michael V. Maloney, MA, is the Executive Director of the Organization for Autism Research (OAR). To learn more about OAR and its autism safety initiative, visit http://www.researchautism.org or email oar@researchautism.org.

References


The Ultimate Question: Would I Change Him?

My kids went back to school this week, and in preparation for my son Jack’s move to 6th grade, I took out the folder. The one that holds every single piece of paper and prescription and description, dating back to the day he was officially diagnosed in November of 2006. Referrals for early intervention. Recommendations for occupational therapy and speech therapy and physical therapy. Random articles about cures and services and how to hold your family together in the midst of a diagnosis. And finally, the judgment. The verdict, the finding, the truth; pervasive developmental disorder, not otherwise specified, which eventually became just plain old autism.

Our folder is blue. It’s a mess. I probably should have organized it with tabs and dividers, but to be honest, I couldn’t bring myself to arrange all the paperwork into neat sections - to take the papers out one by one and re-read them and sort them and catalogue them. Somehow, this would have made autism too permanent, too everlasting.

For years and years, I held on to a single thought: He might outgrow it. I thought that with enough speech and therapy and love, by the time he was five or eight or even ten years old, his symptoms might magically disappear like a bunny inside a deep, plush hat.

He didn’t outgrow it. He isn’t going to outgrow it.

Stuffed way in the back of the folder, in the bottom of one of the pockets, is a greeting card that I bought about ten years ago in some Hallmark store. I can’t remember where or when exactly, but I do remember how I felt that day. I felt exhausted by my 14-month old son. I felt helpless and weary and annoyed. I saw this card and the picture of the boy on it looked exactly - I mean exactly - like Jack at the time. Chubby, irritable, cute, fussy, and somehow endearing.

For years and years, I held on to a single thought: He might outgrow it. I thought that with enough speech and therapy and prayers and love, by the time he was five or eight or even ten years old, his symptoms might magically disappear like a bunny inside a deep, plush hat.

The cheese from the pizza, the meat from his taco, the hot dog from his bun. To say this is annoying is like saying it’s hot when you stand near the Equator.

“Child hears background noise and foreground noise simultaneously.”

When I talk with Jack, I am competing with every single sound in the atmosphere; garbage trucks driving down the street, a dog barking next door, his brother playing Minecraft on the computer three rooms away. He cannot differentiate between the scratch-scratch-scratch of the pencils in the classroom and the teacher’s voice. Within the canal of his sensitive ear, they are all important, all a priority, and all very, very loud.

“Jack has delayed cognitive abilities when it comes to flexibility and executive functioning.”

Um…he’s incredibly, rigid. I’m not sure what else I can even say about this, except to give an example. Jack makes waffles every Thursday morning. For well over a year now, I have woken to the steady whisper of “waffles today, today is waffles let’s make waffles” by 6:03 am on Thursday mornings.

Last February, NBC Nightly News did a segment on our family and autism. It was crazy exciting. They sent a camera crew to see Ultimate Question on page 23
Students with Disabilities and the Juvenile Justice System: What Parents Need to Know

By Carolyn Reinach Wolf, Esq. and Jamie Rosen, Esq.
Abrams, Fensterman, Fensterman, Eisman, Formato, Ferrara & Wolf, LLP

Students with disabilities, including emotional and behavioral disorders, or learning and developmental disabilities, are at a higher risk for involvement in the juvenile justice system. A disabled youth may enter the “School-to-Prison Pipeline” because of the lack of an Individualized Education Plan (IEP) or 504 Plan, “Zero-Tolerance Policies” in schools, bullying, and school absences. Parents must be aware of several school-related factors that may lead a disabled student to end up in the juvenile justice system as well as strategies to protect the child’s rights in school and in court. First, parents should become familiar with the school policies and procedures and create an IEP or 504 Plan to ensure that the school is responsive to the child’s emotional, behavioral or learning needs. Second, many states developed “Zero-Tolerance Policies” due to concerns of student violence; however, now many schools use these policies as a response to nonviolent and other behavioral offenses. Not only are children with disabilities disproportionately affected by these behavior-based policies but they also suffer more severe consequences when it comes to missing school because of suspensions. Third, children with disabilities are more likely to experience bullying in school and as a result find themselves being disciplined, suspended or arrested more often. Finally, students with disabilities may avoid or refuse to attend school due to bullying, anxiety, depression or other diagnoses and/or behavioral disorders. This may result in truancy charges if not properly handled. Parents should work with the school to incorporate letters from health care providers or other relevant documentation into the child’s IEP or 504 Plan regarding excused absences and how a child’s disability may affect school performance and/or attendance. In order to prevent involvement in the juvenile justice system parents can use an IEP or a 504 Plan as a tool to protect their child’s rights in school; make sure faculty, administrators and school officers are aware of the disability and how to appropriately intervene, prevent bullying, and avoid truancy charges.

It is important to note that adults suffering from a mental illness, emotional and behavioral disorders, or learning and developmental disabilities, are also at increased risk for contact with the criminal justice system. These adults and/or their support system must advocate for sentencing alternatives, placement in appropriate correctional programs with monitoring such as case management, and comprehensive discharge plans including community services and interventions when on probation or parole. Police officers, correctional facility staff, and administrators must be made aware of the individual’s mental illness and the possibility that the illness contributes to continued criminal involvement and/or will impede justice system.

Helping First Responders to Understand and Assist Individuals with Autism in Emergency Situations

Mary Jane Weiss, PhD, BCBA-D, Frank L. Bird, MEd, BCBA, and Jennifer Croner, MSEd, BCBA

Melmark

Children and adults with autism engage in many challenging behaviors, many of which pose safety concerns. These concerns can increase the likelihood they will interface with police officers and other first responders. In fact, individuals with autism are seven times more likely to encounter the police than their typically developing peers (Curry, Posluszny, & Draska, 1993).

The intensity and severity of aggression and self-injurious behaviors in individuals with autism can be extreme. These unpredictable and unique behavioral challenges of individuals with autism increase the likelihood they will interface with law enforcement officials and other first responders. In some cases, the severity of an individual with autism’s aggression might create a crisis. Others may be at risk or may be unable to calm the individual with autism. As an emergency measure, first responders may be called to assist. In the worst case scenarios, misunderstanding can lead to increased agitation, the use of unnecessary force to calm the person with autism, or accusations of abuse toward the family (Debbaudt, 2002).

Alternately, the person with autism may go missing. Police and other emergency workers may be notified when it is discovered that the individual with autism cannot be located. One recent report found, for example, that over half of children with autism engage in eloping (escaping/leaving the environment). In one third of those cases, police were notified and became involved (Anderson et al., 2012).

Training First Responders About Autism

Perhaps the first intervention is to train first responders in the characteristics of autism. While often they will be called to assist in managing a person with autism, they may sometimes not be aware they are walking into a situation with a person with autism. Law enforcement officials who are contacted in these situations may not have experience in dealing with individuals who are developmentally disabled. Furthermore, they may never have encountered a person with autism. With the increasing prevalence of autism and the trend for individuals with disabilities to be increasingly integrated into their broader communities, it is important to educate and train first responders so that they are prepared to assist them in emergency situations.

Justice System from page 16

the ability to comply with conditions of release.

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Melmark provides clinically sophisticated, evidence-based services within the ABA model to children and adults with autism spectrum disorders or other developmental and intellectual disabilities.

Melmark actively recruits and supports a program team that includes a high ratio of BCBA staff, graduate training opportunities and a range of opportunities for career advancement.

www.mhnews-autism.org
A persistent and much-debated question for criminal justice professionals has been the treatment of individuals with developmental disabilities as criminal defendants, as victims of crime, and as witnesses of crime. Issues arise from the moment of contact with a first responder. Since the mid-90’s, the U.S. Department of Justice has provided billions of dollars to state and local police agencies to increase training aimed at working with minorities, persons with mental illness, and persons from different cultural backgrounds - in other words, people who may present as very different from the law enforcement officers patrolling the streets. The results of this training, which vary in quality and quantity, are mixed but research does demonstrate that when ongoing relationships of trust can be built in a community, anxiety levels are reduced. When anxiety levels on the part of first responders can be reduced, they are better able to establish control without escalating into a situation where suspects or officers are injured. Across the country, implementation of community policing ideals has increased first responder training. In response to publicized occurrences, most of the attention and training is focused on people with mental illness, rather than on people with developmental disabilities who present a different set of concerns and needs.

Jurisdictions have created materials for first responders, aimed at helping them address people with developmental disabilities in crisis settings. See for example: Florida Department of Law Enforcement Training Curriculum: Persons with Retardation in the Criminal Justice System, 1997; On The Scene and Informed: First Response and Autism, NYS OPWDD; First Responder’s Guide to Assisting People with Disabilities: A Reference for Law Enforcement, Monmouth County Prosecutor’s Office, NJ; Justice for All: Investigating Crimes Against People with Disabilities, NJ Division of Criminal Justice, Department of Law and Public Safety). These are just a few examples of the materials created throughout the years and throughout the country to train and assist law enforcement, other first responders, courts, prosecutors, and defense attorneys to increase understanding of the needs of this population. Nonetheless, instances of police use of force on individuals with developmental disabilities and other cognitive limitations continue to occur. Obstacles may include: investigative techniques of interrogation which do not take into account a limited cognitive ability; the ability of an individual to understand and knowingly waive constitutionally afforded rights; the ability of the individual to formulate the needed criminal intent for prosecution; the need for the system to adequately address problems of substance abuse and concomitant mental illness; the lack of appropriate alternatives to incarceration and generally, a whole host of legal, moral and ethical issues which impede the criminal justice system. A more team-oriented system to address these issues has come about through Crisis Intervention Team Training (CIT), a 40-hour training program being implemented throughout the country aimed at improving relationships between mental health systems and law enforcement. Mental Health First Aid classes are also available, which can be geared towards law enforcement officers and offer a short, basic overview of the needs and concerns of people with mental illness. Gaps remain, however, for people with developmental disabilities. First, these programs are concerned with addressing mental illness, a different cognitive issue. Second and equally important, most programs of this type address crisis settings, providing immediate, concrete information for de-escalating potentially dangerous situations. Unquestionably, these are serious concerns for law enforcement, but the need to build trusting relationships within the community must be addressed. Training and education beyond crisis intervention needed to be developed.

In an effort to address this need, The Arc of the US created the National Center on Criminal Justice and Disability, which you can learn more about by visiting www.thearc.org/NCCJD. Five pilot training sites have been chosen to implement a training program called “Pathways to Justice,” and they include: The Arc of Maryland, The Arc of the Midlands, The Arc of New Jersey, The Arc of Pikes Peak and The Arc of Spokane. This comprehensive training program, now in the process of being rolled out, seeks to

Jessica S. Oppenheim, Esq.

see Pathways on page 22

Logan from page 11

real time is much more effective than trying to teach a skill then working to apply it. In addition we work on the foundation of using Core Language to start, and ProxTalker created our Core language tags for us so our students can engage quickly and efficiently using Core words regardless of the content.

This significantly increases the number of times students get to communicate with each other which is paramount to becoming an active communicator and not someone that just identifies vocabulary words. Additionally, since the device can be used for some instructional tasks such as math and spelling and sentence generation, pre-literacy skills for left to right orientation etc., it is very handy for reinforcement and teaching skills within the instructional setting. The ProxTalker does this in a very UDL (Universal Design for Learning) way: the tactile component of using the tags with the voice output for the auditory feedback and the picture symbol for the visual the information and content is accessible to all learning styles.”

In 2014, STEPS Center for Excellence in Autism in Cleveland, OH carried out a case study trial with students looking at the effects communication had on stereotypic behaviors, the results of which were published in the Journal on Technology and Persons with Disabilities in 2014. The trial results reflect that for both students there was a decrease in motor stereotypic with the use of the ProxTalker using modified communication training protocol alongside an increase in mastered communication exchange phases. Excitingly there was also an increase in independent communicative intent. Based on the results of the studies and further successes the team at STEPS have produced a training manual called Approach to Comprehensive Communication Training with the ProxTalker which is available along with the ProxTalker for trial or purchase at www.LoganTech.com.

Logan’s journey continues to be arduous but he now has a voice both with his ProxTalker and Alt Chat tablet device. He fluctuates between the two depending on how much sensory support he appears to need. There is no other device like the ProxTalker which offers 4 modes of sensory support: visual, auditory, tactile and verbal. It is the ideal diving board for verbal communication and may be the bridge some children need to progress to a more demanding device. We are excited to see what the future holds for the ProxTalker and the LoganTech ProxPAD choice maker which was developed using the same technology and launched to support individuals with greater visual and physical limitations in early 2013. Together the ProxTalker and ProxPAD open doors to communication and learning for individuals who need multi-sensory support to access communication.

To learn more or arrange a trial of either device, please contact LoganTech at (866) 962-0966 or visit www.LoganTech.com.
Direct Access Application Revolutionizes Service Delivery for People with Disabilities

By Tristan Stovall
Special Citizens Futures Unlimited

You need a job. You need a home that provides support. You want to be involved in your community. You want all of these things yet the system that is in place before you is arduous to navigate and often leaves you feeling discouraged.

TOUCH (Therapeutic Outreach Uniting Community Health) was created with your needs in mind. TOUCH is a web-based application for people with disabilities, families, parents, advocates and professionals that allows you to sign up and have direct access to service providers close to where you live, provides an aggregate employment search engine that connects you directly with employers and exposure to recreation and community events hosted by the providers that you are interested in learning more about.

Finding sufficient employment and/or housing is difficult for anyone and can be particularly challenging to those with intellectual and developmental disabilities. The TOUCH web-based platform is free and accessible to everyone and will enable people receiving services, their families, friends and advocates to log on and search all of the provider and employment opportunities available to them, allowing them to self-direct their services by referring themselves for the opportunity, provided they have successfully gone through NYS OPWDD’s Front Door.

TOUCH was designed by Special Citizens Futures Unlimited (SCFU), a non-profit organization that has been supporting adults and children with Autism for forty years. “Giving people with developmental and intellectual disabilities the ability to self-direct the course of their lives is imperative and it is our hope and vision that TOUCH will become a national model for our industry,” says Jessica Zufall, CEO of SCFU.

TOUCH enlisted the support of Gerry Libertelli, Managing Partner of Agnostech Systems, to develop the highly complex TOUCH application.

Gerry Libertelli is a veteran entrepreneur and Internet developer with roots in Online Service Delivery dating back to the start-up of the industry. Libertelli began his career at Charles Schwab and Company where he played several critical roles in delivering Schwab’s online investing products: StreetSmart and The Equalizer. These products were the first of their kind in the investment industry and were a precursor to Schwab’s eventual success on the Internet. Following his accomplishments at Schwab, Libertelli formed G. Triad Development Corporation in 1995. Under his leadership, G. Triad became the Internet development services firm of choice for enterprise and dot-coms alike. G. Triad delivered some of the most comprehensive Web applications in operation today, including such revolutionary projects as SmartMoney.com and Simon and Schuster’s Simonsays.com, ToysRUs.com, Dow Jones University and several award winning applications. Libertelli has been an active supporter of eGovernment initiatives around the country and frequently gives his time to municipalities interested in bringing local government to the Internet.

“TOUCH streamlines the way people with developmental and intellectual disabilities get the services they need. It is my hope that it becomes a tool for better connections across the services landscape. It creates an environment that ensures people find information that has for so long been buried to them. All providers have to do is use it, and it will unlock many direct access obstacles. Agnostech Systems is proud to have built this framework and hope it serves to further the goal of Direct Access for everyone,” says, Gerry Libertelli.

TOUCH has experienced great success since its release in the spring of 2015 and has been working diligently to create enhancements to the application based on feedback from its users. Through the application, people and their families can locate service providers they can begin to engage with, locate employment through our highly efficient partnership with SimplyHired, communicate directly with their Job Coach and attend events that are being hosted by New York State Providers. The application also allows a manner in which students can view their wallets with the college’s telephone numbers to NYIT security which coordinates the re-connection process. In addition, each student has the NYIT security telephone number pre-programmed into his or her cell phone and each team leader has a list of all of the students’ cell phone numbers with them on each and every trip. In preparation for the trip, the travel training faculty reminds the students to bring a fully charged cell phone, charging cables and a backup battery.

One set of skills that many students take for granted are pedestrian skills. This is the second most important topic to cover in a travel training course. Looking both ways while crossing the entire street is a key to staying safe. In large cities pedestrians must cope not only with vehicular traffic, but bicyclists, skateboarders, and rollerbladers as well. Often these modes of transportation are silent and sometimes do not follow the rules of the road. They can appear suddenly from an unexpected direction. Students must be reminded that just because they have the green light and are in a crosswalk, it does not necessarily mean that they are safe to cross the street.

Traveling from page 10

Staying focused and alert are critical to maintaining their personal safety.

After establishing basic safety rules, the travel training curriculum should teach the students how to access information regarding transportation modes at their destination. Using the internet is a basic skill that can open the doors of mass transit to students on the autism spectrum. They can look up routes, fares, schedules, and points of interest along the way. Classroom discussion can revolve around the optimal way to get to a destination. There may be more than one way to get to a place. Choosing the route or mode of transportation can depend upon a number of factors including: time of day; weather conditions; city wide special events like parades or visiting dignitaries, and construction or maintenance of transportation infrastructure.

Preparing the Staff for Escorting the Students on Trips

Being responsible for escorting a large group of students on a trip of any kind can be anxiety provoking for even the most...
Hidden Curriculum from page 4

are shocking but true and for many reasons. Individuals on the spectrum are perfect victims. Again, they don’t understand the “creep factor.” They tend to be rule-governed. We need to be very clear about what rules we are teaching, especially where compliance is concerned. Many individuals with ASD don’t understand the consequences of their actions and can be very literal. Unless they have been taught explicitly, many of those with ASD or don’t want to see our children as sexual beings so we always say, “Not my child.” Parents of the more severely impacted and nonverbal children often feel that someone they know and trust is always with their child, keeping them safe; the bad things must be happening to more independent children who can be on their own. The parents of the more independent and verbal children may think their child will tell them everything; it must be those nonverbal children that all the bad things are happening to. Let me be clear, these skills need to be taught to children and adults across the entire autism spectrum. We ask parents and educators need to realize this and give our kids the skills they need to be safe and toilet training (including the hidden curriculum) is at the top of the list.

Here is the good news: we can teach our kids these skills. Parents have over 70 years of science on how to teach them. There are some really good curricula for teaching sex education to individuals with autism and it’s very important that time is carved out during the school day to teach these life and safety skills. It’s never too early to start, but in reality, most individuals don’t get sex education before high school. Sex has occurred — until after a student has engaged in inappropriate behavior such as touching themselves or someone else or breaking the rules, law, or other parts of the hidden curriculum. As a certified law enforcement instructor, I have trained over 26,000 first responders in autism recognition and response. When I first started, I was training police, then firefighters, and EMS personnel. But as I digged towards and her recently, I find myself training prison guards. I didn’t go looking for this work, prisons and juvenile detention centers have reached out to POAC as individuals with ASD are now entering the prison system for the first time. Prison is not a good place for anyone, but especially not for our population. The first time I received a call from a juvenile detention center with a request for training was a bad day. I asked how it was possible that children with autism could be in detention. The reply was simple; once the sexual line has been crossed, it’s hard to stop the process. Nationally, The Arc is spearheading an initiative, “Movement to Justice” (www.thearc.org/NCCJD), to help advocate for developmentally disabled individuals who have entered the criminal justice system. This is extremely important, but it’s more important to give students with ASD the education and skills needed to avoid these situations.

So where and how do we begin? We start the sex education process in preschool (yes, preschool) with simple discriminations such as the difference between a boy and a girl and “yes” and “no.” We teach young children how to say “no” and we reinforce their use of the word. Eventually we teach that the parts of their bodies that are covered by their bathing suits are not to be touched by others. Again, these skills are so important that time must be dedicated to teaching them with sound teaching techniques and they must be taught to mastery. As children get older, we must get our boys out of sweat pants. Sweat pants can be very helpful in the toilet training process, but once this is achieved, boys need to wear pants with belts like their typically developing peers. Social acceptance is an important reason to do this but more importantly, sweat pants give easy access not only to the other boys, but to be predators as well. They also allow for sensory input that is not appropriate in public situations.

Eventually, we must teach our kids about inappropriate touching - how to avoid being touched and how to tell other people. Here’s what parents and educators must ask themselves every day: “Is this behavior that may be cute at five years old still going to be cute, or socially acceptable, or legal at 15 years old, at 25 years old?” If the answer is no, we must put a stop to it at five. Common examples are hugging, kissing, touching or smelling others. Here is another great piece of advice: Do not tolerate inappropriate touching. Any child with ASD that you wouldn’t tolerate from a typically developing child. We must continue to teach our children the difference between trusted individuals and strangers, and how to recognize danger in the real world and on the internet.

It’s not easy to think about and it can even be embarrassing, but we have to start somewhere and practice makes perfect. Let me leave you with an image. I was on a flight and sitting behind a boy and his mom. I asked the boy if he knew how to use the bathroom and he said yes. I asked him to show me his underwear and he said yes. I asked him why he knew how to use the bathroom and he said, “Because my mom taught me.” I then explained the parts of his body that are covered by his underwear are private parts and think how what I was teaching was not enough. POAC offers free training to parents and educators on all of these safety and sexuality issues. We must give the individuals with ASD themselves the knowledge, skills, and power to recognize and avoid danger and keep themselves safe.

For more information about POAC, please visit www.poac.net.

References


Avonte’s Law from page 13

projected $10 million bill is also requesting tracking devices for individuals with autism and technology to assist law enforcement, first responders, and search-and-rescue teams when an individual is reported missing. While the bill has not only reached the hands of the Senate Committee on the Judiciary, which Senator Schumer is a member of, changes are progressing in New York City because of the help of the Senator.

In 2014, Senator Schumer also went before the New York Department of Education (DOE) requesting that sounding alarms for fire alarms in special education classrooms so incidents like Avonte would not occur again (Evans & Eyewitness News, 2014). While the DOE opposed this policy, the city council unanimously agreed and in August 2014 Mayor Bill DeBlasio signed the policy and gave the DOE a deadline of May 30, 2015 to compile a list of schools that would benefit from sounding alarms (Autism Speaks, 2014). On June 5, 2015, Autism Speaks reported 21,000 door alarms would be installed in 97% of schools assessed in New York by the end of 2015. Small strides are being made in the right direction to provide a greater awareness in the autism community even though there is still much work to be done to get Avonte’s Law established federally.

With 49% of children with ASD wandering away from a safe environment, 24% of those individuals are in danger of drowning and 65% are in danger of experiencing traffic injuries (Anderson et al., 2012). These staggering statistics are not isolated to certain areas. A previous client that Nancy (author) worked with escaped from his home about a year ago to reach his brother. The mother stated that no one heard the child leave, and it was only when she went downstairs and saw the front door wide open that she noticed the child was missing. “I did not know where he could have been. My heart immediately stopped when I saw that front door open” (personal communication, August 8, 2015). She frantically began to look for her child and was unsure of how long he had been missing. After five minutes had passed, what seemed like an eternity for the mother, and she was still unable to locate the child, she called her father that her son was missing and needed help finding him. They began walking down their busy street and eventually saw the missing child almost a block away from the house heading towards her busy intersection. When the grandfather approached the child, he began to act aggressively and persisted that he wanted to go with his brother. Ever since this incident, this mother has done everything she can to ensure the child does not leave the house. However, each day is a different day with the child with autism and anything can happen.

As a community we need to rally together to decrease the likelihood of another child becoming a statistic. The numbers should cause alarm for cities and communities that can work with the implementation of community-based trainings to law enforcement, school officials, first responders and community members we can provide autism awareness. This heightened awareness and planned action will provide a glimmer of hope to countless families who constantly endure fear and worry for their child. Passing Avonte’s Law will create a world where parents will no longer have to fear for the safety of their child at school or among the community. Parents can now reach out to their local leaders, law enforcements and first aid responders of the dangers children with autism can face in the event they wander from a safe environment. When we all advocate for the voices that are often unheard we can change and impact neighborhoods and communities one at a time.

Nancy is from Riverside, CA and Christopher is from Phoenix, AZ. They are both graduate students at the University of Southern California, School of Social Work virtual program. They can be reached at nancy@ucsc.edu and cbenger@usc.edu. They continue to advocate in their respective cities for Avonte’s Law Act of 2015.

References


**Interacting from page 8**

The Value of Video Modeling

To learn these important skills individuals with ASD are likely to need to see different kinds of encounters with the police and practice safe behaviors, repeatedly. Learning through real-life experience, however, is much too risky! For these reasons, video modeling can be an excellent choice for teaching safety skills. Evidence shows that video modeling can be effective for learners across the spectrum, of all ages. Regardless of verbal or cognitive ability, anyone may benefit from video modeling (Reichow & Volkmar, 2010).

Individuals with ASD may already have negative images of police interactions in their heads from news stories, television or movies. The key to video modeling is presenting positive, specific skills to watch and practice. This can create a new “visuafile” to remember and “pull up” if it is ever needed. In fact, after instruction through video modeling, viewers are more likely to remember what to do and say in real situations. Skills learned through video modeling have been found to generalize across different settings and conditions (Bellini & Akullian, 2007).

You can create your own short, simple safety videos using role play and a smart phone. The person with ASD does not have to be the one who is video-taped; research shows that individuals with ASD also respond positively to watching others (Reichow & Volkmar, 2010). You might like to involve siblings or peers to create short video models of 1 to 2 minutes. An other option is using a professional video made expressly for this purpose, such as Be Safe the Movie. Exposure to positive models and the chance to practice or copy the models can help the viewer feel more confident about his or her ability to follow the models when needed (Bandura, 1996a; Bandura, 1996b).

Safety Tools for Self-disclosure

Another tool that parents can use to improve the odds of a positive encounter with police are known as disclosure options. Ask any officer or first responder and they will tell you: the more information they have, the better they can do their job. If police are informed about a person’s disability, they are more likely to choose effective response techniques. Because there are no physical “markers” to alert officers about someone’s autism, you may wish to select a useful tool to share information, enhance communication and improve outcomes.

It can be a great idea to ensure that the person carries or wears some kind of identification to help others understand their exceptional needs. This is especially crucial for those who cannot verbally identify themselves or ask for help.

- Did you know that police and other first responders are trained to check a person’s wrist for medical alert jewelry? Many individuals with ASD could not tolerate old-school medical bracelets, but new materials might make this kind of disclosure tool a viable option. In case of emergency, caregivers may also want to wear medical alert jewelry with a message for first responders such as, “Primary caregiver of non-verbal adult with autism.”
- Safety tools using QR Codes are also becoming popular. A QR code is a two-dimensional bar code that looks like a collection of black and white squares. When a QR Code is scanned using a camera or Smartphone, it connects to a message or data. If I Need Help is one example of a non-profit organization that uses QR Codes IDs for safety purposes. They have created a variety of wearable patches and tags, including shoe tags, which help identify lost individuals and connect first responders to caregivers.
- Some people carry a self-disclosure card in their wallet, providing specific information about their disability, accommodations and caregiver contact information. Be Safe has created a customizable self-disclosure card that goes along with a lesson from the Movie: always ask before presenting a card to police; never reach into a pocket, bag, pants or purse unless the police tell you it’s OK to do so.
- Do you live in a Yellow-Dot state? Many states have adopted this program in which a yellow dot is affixed to the rear window of a car or other vehicle. Should an accident occur, first responders who see the dot will check your glove compartment for the vital information you prepared about yourself (and other information you prepare, including information about your loved one with ASD who may or may not be in the vehicle at the time). This is another way to communicate and help first responders interact with the person with ASD when you are unable to assist.
- Lastly, for verbal individuals, the voice is a powerful safety tool for self-disclosure. Helping a young person understand and accept their disability is one of the most important things anyone can do to promote safety and independence. The individual may need help to develop self-awareness (knowing what they need) and self-advocacy (speaking up for himself, asking for help). Both skills can improve safety in many different situations, including with police.

Relationships Matter

Being afraid of the police can be a real disadvantage when help is needed. Being overly-friendly (touching the police or their equipment) can be equally dangerous, even for someone with a disability. Getting to know local law enforcement officers can be a great way to promote mutual understanding. A good option is to go to the local police station during a calm, quiet time. When the person with ASD meets with officers, it can be a first step in developing a sense of familiarity, balanced with boundaries. Officers get a chance to meet someone with ASD in the community they serve, in advance of any emergency. They can see what the person looks like, hear how he communicates, see how he behaves, notice his sensory sensitivities, and get a sense of a good way to approach and interact with him.

When you visit the station, you may want to ask for the watch commander, the person in charge of the station at the time of the visit. The watch commander is in charge of all calls, and may remember meeting you and your child, teen or adult in the event of a call for help. The community service officer is also a great potential liaison.

Conclusion

Having read this article, hopefully you agree: safe interactions with police are too important to leave to chance! Doing nothing is not an option! Parents and educators can team up to prioritize safety, take advantage of safety tools, create relationships and help ensure that every individual with ASD learns to be safe, now and in the future.

BE SAFE The Movie is a 1-hour DVD that uses video modeling to show viewers how to interact with the police in everyday encounters. Made by and for young adults with Autism Spectrum Disorders and similar conditions, BE SAFE The Movie’s seven episodes demonstrate skills ranging from following instructions to the right to remain silent. Spanish subtitles, English captions.

BE SAFE Teaching Edition includes a specialized Companion Curriculum and BE SAFE The Movie. Seven Lessons matched to each Movie Episode include 300 pages of activities, visual supports and resources on a CD-ROM. Use Curriculum materials together with Movie Episodes to help diverse learners build understanding and safety skills at home, school or community programs. Also available in Spanish, CUíDATE: Guía de Enseñanza.

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www.mhnews-autism.org
Project Lifesaver from page 12

proposed alarm system. The biggest disadvantage is simple - if a caregiver needs GPS then the loved one is already GONE! Why not prevent the loved one from disappearing in the first place? That was my goal! After months of research I contacted Chief Gene Saunders who is the CEO and Founder of Project Lifesaver International.

Project Lifesaver is a program designed to help individuals affected with autism and other developmental disabilities that may wander or get lost. Project Lifesaver uses state-of-the-art technology, employing wristband transmitters to locate wandering and lost children and adults. Project Lifesaver can be found in 48 states and in over 1,000 law enforcement agencies throughout the United States. Individuals who are part of the Project Lifesaver program wear a personalized bracelet that emits a tracking signal. The bracelet serves as a transmitter that produces an automatic tracking signal every second, 24 hours a day. The signal can be tracked on the ground or in the air over several miles. After caregivers call 911, trained police officers are dispatched to the area to begin the search for the missing person using a mobile locator tracking system. Most searches last no longer than 30 minutes. Although Project Lifesaver sounded like a great program it still did not offer what I was truly seeking, a perimeter alarm system and personal locator for my son.

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The Chief’s response instantly changed my life as a parent and as PBA President. Chief Saunders disclosed to me that Project Lifesaver was soon releasing two new products that would help achieve my goals and help thousands of families that may require a personal locator system and perimeter alarm system. These products include the PLI-1000 Personal Locator System and a Perimeter Alarm Protector System.

The PLI-1000 Locator System is the newest radio frequency based tracking system that is available to project members. It is a GPS based device that would locate a wanderer and send an immediate notification. The PLI-1000 was released in the summer of 2015 and the Perimeter Alarm Protector System is expected to be released in November 2015. The PLI-1000 is a portable, mountable device that is programmable to a frequency used by the police department (if enrolled) or can be used by families that live in towns or counties which do not offer Project Lifesaver at their local police department. In the event that a loved one goes missing the caregiver equipped with the PLI-1000 can start the search immediately and notify their local police of the wandering event. The Perimeter Alarm Protector System will be intended to sound an alarm if the invisible fence is broken and should immediately notify the caregiver to locate the loved one before they go missing and return them to safety.

The equipment and device described by Chief Saunders was the perfect opportunity to better protect my son and to bring a great community-based policing program to New Rochelle. Within weeks my son was registered in Project Lifesaver and I was able to purchase my own PLI-1000. Additionally, the New Rochelle PBA was able to raise over $15,000 to buy and donate to the New Rochelle Police Department its own Project Lifesaver search and rescue program. New Rochelle has since become the first police agency within Westchester County, NY to purchase and maintain its own equipment. By becoming a member agency in Project Lifesaver, the New Rochelle Police Department will be able to deploy specially trained police officers to begin searching immediately for an enrolled person who was wandering or in need. The New Rochelle Police Department will also be able to provide search support to the Westchester County Police in other nearby jurisdictions that may have a wandering event.

Additionally with the money raised the New Rochelle Police Department was able to donate qualified families PLI-1000 Perimeter Alarm Protector Systems.

As the parent of a child with autism and as a law enforcement official I am compelled to stress upon any parent or police agency the need for this equipment. If your county or local police does not have Project Lifesaver or a similar program please contact your local law enforcement department. As the parent of a child with autism and as a law enforcement official I am compelled to stress upon any parent or police agency the need for this equipment. If your county or local police does not have Project Lifesaver or a similar program please contact your local law enforcement department.

For any questions about our program or Project Lifesaver please contact Detective Christopher Greco at panrpresident@gmail.com.

Pathways from page 18

enlighten professionals and community members about what “hidden disabilities” are, something often not readily identified and, once identified, difficult to interpret for other parties. The second goal of the training is to create site-specific, holistic solutions to develop ongoing relationships within each community and to work to “institutionalize” training so that new laws and new procedures can be, in turn, modified and professionals come into the work force, important lessons can be passed down. The one-day training, which will be provided by the State’s Pathways to Justice or Disability Response Team, will bring together members of all the relevant professions to review and address one case study. Creators of a comprehensive team is crucial to long term success and must include individuals with developmental disabilities, representing themselves and their own concerns.

While current numbers of criminal defendants who have an intellectual or developmental disability (IDD) is not known, it is generally agreed that persons with IDD represent a disproportionate number of offenders in both the juvenile and adult systems. While approximately 2% to 3% of the general population can be identified as living with a developmental disability, at least 9% of the offender population has been identified as having a developmental disability (Smith, T., Polloway, E.A., Patent, J.R., Beyer, J.F., 2008). A more recent study from Canada places those numbers as high as 40% of the offender population as being identifiable as a person with a developmental disability. (Jones, J., 2007). In the juvenile justice system, though the number of school aged children currently being identified as a person with a IDD is around 9%, nonetheless, close to 32% of all juveniles in the juvenile justice system can be seen as having an IDD. We know unequivocally that individuals with developmental disabilities are grossly overrepresented in the criminal justice system, yet lack of identification and availability of services for those individuals who come into the system creates dangerous circumstances and hampers the ability of professionals to address this problem.

In addition to increased involvement in the criminal justice system as defendants, the rate of violent victimization for people with all disabilities is more than twice the rate for people without disabilities. In this group, people with cognitive disabilities have the highest rate of violent victimization, with violent perpetrators known to them, as caregivers, family and friends. Crimes Against Persons with Disabilities, Summary, May 2015, Bureau of Justice Statistics, U.S. Department of Justice. See also Abuse of People with Developmental Disabilities and Their Families Speak Out, 2012 National Survey on Abuse of People with Disabilities, N. Baladerian, Ph.D., Disability and Abuse Project, www.disabilityandabuse.org.

In this regard backdrop that individuals who live in the community may encounter law enforcement on the streets, may have police officers called into their home in response to a 911 call, be approached in a public place by police officers or ultimately find themselves involved as a suspect or victim in possible criminal activities. As people with I/DD move into the community and take their place as contributing members of society, unencumbered by supervision and guardianship, the possibility of interaction with law enforcement increases. Also, the risk of involvement with criminal justice system.

In considering common characteristics shared by persons with a wide array of developmental or intellectual impairment, the result is often that people with IDD are less likely to acknowledge wrongdoing or admit to wrongdoing. They are more likely to misattribute actions and thus have a higher incidence of delinquent behavior. Law enforcement, people with disabilities and community professionals need to move beyond crisis response and instead create and sustain ongoing relationships. In that way, trust and respect develop. Interpersonal communication is the key to that development. By implementing and supporting a Pathways to Justice Team, the goal is to create a sustained system that allows all community members to feel safe and allows all professionals to do their job effectively.

For more information about The Arc of New Jersey, please visit www.arcnj.org.

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loom large. If person-specific information is clearly advantageous for a responding officer, how can individuals with ASD, families and caregivers provide this actionable intelligence? In a word: disclosure.

Disclosure of persons with ASD’s information is a key element — perhaps the key element — of a personal safety plan. Disclosure in a variety of settings can be simple or complex depending on individual needs and circumstances. While disclosure and what to disclose will always be voluntary, it can provide a higher level of informed response during interactions with law enforcement professionals.

During training, officer and citizen safety and protocol concerns will likely be the focus of officer investments in time, patience, and clear communications can occur. Training does inform officers about the sights and sounds associated with persons with ASD. Yet, asking trained police officers to accurately conduct a field diagnosis of person’s autism may go beyond reasonable expectations. Disclosure will help by taking guesswork off the table of risk.

Police officers include how a physical outpatient might well be related to the ASD person’s sensory dysfunction, inability to deal with interruptions in the daily routine, or emotional lability (being susceptible to change, error, or instability). This often presents itself in individuals with ASD - their emotions can change quickly and they can become upset, scared, or anxious very quickly. They may also be extremely anxious one minute, and then calm the next, or vice versa (Taylor, Meisbøv & Debbaudt, 2009).

Suspicious person reports can include parent or caregiver actions that may be misinterpreted or appear as assault. For example, a father picking up and carrying away his crying child from a store or park may appear to observers as a possible child abduction. Another example would be a caregiver’s actions in trying to calm an adult. Boise Police have identified situations that may result in a 911 call reporting suspicious persons (Debbaudt, 2001). When police do arrive, lack of disclosure and proximity can become a volatile combination.

Aggressive outbursts frequently occur at home, at school or in any community setting. The proximity of most homes and schools adds to the danger of the situation. These aggressive behaviors may be a form of self-stimulation or a sensory reaction to objects and influences in the environment and not a sign of calculated disobedience. The person with autism wants the circumstances to change but does not know how to implement that change. When one adds in the issue of emotionality, this presents a dilemma for the law enforcement officers (Debbaudt, 2013 and Debbaudt & Rothman, 2001).

Independent adults may wander away from homes and caregivers, but the majority of missing persons calls will involve children. Responding officers will be facing a myriad of situations where they may seek rest and comfort unattended, perhaps when using a restroom, taking a call, or caring for a sibling. Keep in mind that the initial call may quickly cut across great distances.

Drowning is a leading cause of death for people with autism (Shavelle, Straus & Pickett, 2001). They may be unusually attracted to water sources and frequently found in or near rivers, lakes, ponds, pools and fountains. The child or adult will all too often seek out and enter into water sources, for example, permanent or seasonal swimming pools, ponds, rivers, streams and lakes. Individuals may also be dangerously attracted to vehicles and wander into traffic or attempt to enter nearby homes or dwellings, wander onto train tracks and elevated places such as rooftops, trees and on or under bridges. They may fatally find false refuge in underbrush, alleys and dumps where they may seek rest and comfort under a mattress, between sofa cushions or inside discarded furniture and appliances. For each of these situations, the first step for families, school officials or other caregivers will be to call 911 immediately upon discovery of a missing child or adult and use the word autism to describe the individual. Resist the temptation to conduct a search before calling 911.

Review, revise and practice your disclosure options at least once a month. Remember the advice from our law enforcement advisors: accurate information will inform their response. Let’s get it to them! Stay safe!

For more information, please contact Dennis Debbaudt at ddip@fast.com or (772) 398-9756 and visit www.autismriskmanagement.com.

References


Training from page 1

on children with intellectual and developmental disabilities, including autism. The Los Angeles Police Department declined receiving this training as they “already have training on mental illness.” I was extremely disappointed. Nothing I could say, such as “autism is not a mental illness,” could convince the training director. Law enforcement who did take the training said it filled an important gap in their preparation to work with people on the spectrum and those with other developmental disabilities.

It is essential for anyone dealing with the public such as law enforcement and first responders to become knowledgeable about autism and the many developmental disabilities including autism. One motto I love is, “when you have met one person with autism...you have met one person with autism!” Everyone is so different! Thus, one can do a training using the usual “here are the differences, here are the similarities” model, yet there is much more to the story. There are unique sensitivities, abilities, methods of communication, styles of communication, and relationship issues among others that demand officer sensitivity. One clear example is that many on the spectrum are literal thinkers. When officers fail to adjust their communication corresponding to this unique and present feature, they may not realize that they are not using expressive language in a way that reflects what they really want to communicate. A good training will help increase their awareness that there is a call of saying “sarcasm, joking, and commands may not be understood in the same way by the listener on the spectrum. They should be aware of the variety of ways in which children and adults with autism communicate, particularly those who are non-verbal.

One parent told me that when her son was 10, he had suddenly disappeared while she was in the kitchen and he had been outside. She immediately went looking for him. Someone had called the fire department on her behalf. She saw a fire truck at a distance and drove to it. When she arrived a police officer was there. She saw a fire engine and he had demanded again that the boy say his name. Being unable to say, “I’m non-verbal,” the officer took his silence as rebellion, or a sign of danger, handcuffed him then struck him in the genitals with his nightstick. One cannot emphasize the awareness on the part of the officer that the autistic little boy had complied 100% with the officer’s demands. And no apology for his disrespectful and unlawful conduct, either.

A recent publication (Teagardin, Dixon, Smith & Granpeesheh, 2012) describes that a training program for law enforcement officers resulted in post-exposure scores above the pre-training scores, but did not result in mastery of the material, which would have hopefully translated to improved performance in the field. Further, the article suggests that a more effective training would include more than watching a 13 minute video, but include more comprehensive information on autism itself, how it may manifest, and most importantly, how officer conduct could change to accommodate the needs of children and adults with autism.

It is for this reason that I advise parents to teach their children “the opposite” of what the generic child is taught. In other words, most children are taught that the police officer is “your friend” and “is there to help you.” While this is true and law enforcement should help if the child becomes lost, for example, as the child ages and becomes an adult, things change. Because of differences in conduct, appearance or use of language, officers may become suspicious when a detainee does not engage in eye contact, sticks to one- or two-word responses, rocks, or vocalizes with the reality of interfacing with law enforcement. While most officers are well-meaning, without training they may misinterpret autistic conduct in a negative manner and move to detain rather than to create a safe interaction with the individual.

It is my hope that proper and vetted training will soon be mandatory for those responding to calls for help. The materials for training exist. Training videos exist. It is the matter of officer training and the population adequately. What will it take? Most likely mandated and funded training statutes will be needed. Currently SB 11 (an act to add Sections 13515.26 and 13515.27 to the Penal Code relating to peace officer training standards), is pending in California to mandate officer training. But, it remains unknown how that training would be conducted.

Meaning, it is essential for parents to be or become aware of the dangers that face their children. For most people, entering into the law enforcement arena as a suspect, is new, brand new territory. It is a matter of self-defense, but an attorney, particularly one familiar with autism and the communication difficulties that can arise. Since many on the spectrum are non-verbal and use alternative and augmentative communication (AAC), it is essential that these methods be viewed by law enforcement as valid strategies, at the level of American Sign Language. They should also be familiar with the Americans with Disabilities Act (ADA) and adhere to the mandates for accommodation detailed therein. Of course parents and individuals on the spectrum should likewise be aware of the ADA and their rights for accommodation if detained or when one is victimized. Adults with autism should be advised to say nothing, as is their right, if detained, until a parent and/or attorney arrive.

The Disability and Abuse Project has addressed these issues over the decades and has developed several products that could be used by any entity. We advocate for those with disabilities to have their rights respected when engaging with protective services and law enforcement agencies. Information about obtaining the law-enforcement training DVD’s and curriculum is available on the project’s website.

In a future article, I will discuss when people with autism are suspects and under investigation by law enforcement, and recommendations for individuals on the spectrum and their family members.

To contact the author send an email to novax@disability-abuse.com or visit www.disabilityandabuse.org.

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Direct Access from page 19
to save jobs of interest, events you would like to attend and to catalogue a cart of providers a person is interested in learning more about. For example, Job Coaches can sign up for TOUCH as a Job Coach user, log into their account, and immediately can start building their roster of users of the TOUCH system. Job Coaches are also encouraged to help their existing followers to sign up for TOUCH so they can all make use of the enhanced Job Coaching features.

The original launch of TOUCH in the spring experienced great success and I am thrilled about the new revisions,” says, Alex DiMaio, TOUCH Coordinator. “We have listened to what you need and what helps you as a person being supported and as a professional, and it is our goal to continue to provide these enhancements to streamline how you have access to the information you need,” he added.

The TOUCH application is the first ever-statewide housing and employment database working directly with state and government agencies to identify housing and employment vacancies directly to the person who will be the recipient of services.

For more information or to become a registered user on TOUCH for free, please visit www.touchnys.org and follow TOUCH on Facebook @TOUCHNYS.
responders in the nature and characteristics of autism will help them to identify autism when they encounter it (Debbaudt & Rothman, 2001).

An individual with autism may not make eye contact, even on request. They may be non-verbal. They may not respond to verbal requests or may simply repeat what is said. These behaviors may be misinterpreted as signs of disrespect toward the officer or as indications of disorientation associated with drug use. It is important for officers to know that these characteristics are part of the disorder, and that language use and social understanding are limited in most individuals on the autism spectrum. It is also important for the officer to realize that a physical struggle being observed is most likely not abuse. They may walk into a situation of restraint, physical fighting, or physical management. Parents may be struggling to prevent elopement or to reduce injury to the individual or to others in the environment.

Individuals with autism often have sensitivities to certain environmental stimuli. These stimuli can increase their agitation. Lights, sounds, and smells might trigger a behavioral escalation. If the person with autism in the situation is sensitive to these triggers, they may react to the sirens, the lights or the radio used by the police.

Messages to First Responders

Many communities are now training first responders to assist people with autism and their families. Below is a list of suggestions that summarizes some of the most common elements of these trainings.

Top 10 List for First Responders

1. Be aware that communication deficits are significant. Many individuals are non-verbal. Many communicate via other means, including sign language, picture systems, or augmentative devices. Many people with autism who are vocal also become less able to express themselves under stress. If possible, it is helpful to get information about the communication modality. This is especially important information for the dispatcher to obtain when the call comes in. In addition, caregivers on the site should be consulted about how the individual communicates.

2. When a person with autism is highly agitated, be or she may not be easy to calm. It may be necessary to focus on de-escalation only for some period of time.

3. Individuals with autism may appear to be non-compliant or disrespectful of authority. In fact, such behavior is sometimes part of the autism spectrum disorder (e.g., failure to make consistent eye contact). It may also be exacerbated by anxiety. Furthermore, they may not understand what is being asked of them.

4. Approaching a person with autism who is agitated in a physically intrusive manner may trigger more of the undesirable behaviors. It is important to be calm and to assist the individual with autism to calm down. It is also important to avoid physically threatening approach behaviors such as finger pointing or an aggressive stance, as this could further escalate the individual.

5. Individuals with autism may not understand the social cues in the situation. They many not, for example, understand the authority of the police or naturally respond to an authority figure present. They also may not comprehend what is being subtly conveyed in body language, as these elements of interaction are often too subtle for them to pick up on.

6. Individuals with autism may not be accurate reporters. They may not answer questions accurately, they may automatically answer yes, or they may repeat the last words heard. They also cannot easily discuss or label abstract concepts or experiences. For example, they may not be able to share information about internal sensations such as pain.

7. Sensory sensitivities may be present in a particular individual and may be increasing agitation. Ask caregivers about whether certain environmental stimuli are an issue for this individual. If they are, consider not using the siren or bright lights.

8. Approach the individual in a non-threatening way and use a calm voice.

9. Be patient – it may take a significant period of time for the individual to calm down.

10. Consider the needs of the family and caregivers present, and assess their need for support, assistance or services.

Summary

Individuals with autism are at high risk for interfacing with law enforcement officials and other first responders. Their behavior patterns place them at risk. Emergencies present as situations involving harm to others due to aggression or risk to the individual with autism because of elopement. First responders must understand the behavioral characteristics of individuals with autism so they do not interpret the individual’s behavior as disrespectful, unresponsive or deliberately uncooperative. Furthermore, they must understand that certain environmental triggers or interaction approaches could make the individual more anxious and agitated. Caregivers can assist in understanding the best ways to approach and communicate with the individual with autism. It is important that first responders be made aware of the unique needs of this vulnerable population.

Mary Jane Weiss, PhD, BCBA-D, is Executive Director of Research, Frank L. Bird, MEd, BCBA, is Chief Clinical Officer, and Jennifer Croner, MSED, BCBA, is Research and Training Coordinator at Melmark.

The mission of Melmark is to serve children, adults and their families affected by a broad range of intellectual disabilities. With program locations in Berwyn, Pennsylvania and Andover, Massachusetts, we provide evidence-based educational, vocational, clinical, residential, healthcare and rehabilitative services, personally designed for each individual in a safe environment of warmth, care and respect. For more information, please visit www.melmark.org and www.melmarkne.org.

References


Free Support Group For Families of Adults with Asperger’s Syndrome and High Functioning Autism

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For more information, visit our website www.FAAHFA.com or contact the facilitators:

Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com

Socialization and Life Skills Group For Asperger’s Syndrome and High Functioning Autistic Adults

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For further information contact the facilitators:

Patricia Rowan, LMSW - (914) 736-7898 | Patrowan@bestweb.net | Susan Cortilet, MS, LMHC - (845) 406-8730 | Susan.cortilet@gmail.com


Westchester Arc

The Gleeson-Israel Gateway Center

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Helping from page 9

Communication Strategies

Individuals with ASD may present with deficits in their understanding of social/pragmatic language and interpreting non-verbal cues. Additionally, they may not understand the law or rules in a given situation. Using a calm tone of voice with neutral facial expression, incorporating a reasonable wait time, avoiding rushed arm movements and gestures, minimizing complex directions, speaking slowly, and repeating questions may increase compliance.

Behavior Management Strategies

First Responders may benefit from being taught common behavior management strategies. Topics may include how to offer behavior specific praise, how to perceive and strategies. Topics may include how to offer training First Responders in how to manage common behavior management questions may increase compliance.

In addition, First Responders may present video models showing individuals with ASD responding successfully to First Responders across multiple situations. In addition, First Responders may consider conducting role plays, providing behavioral feedback, and providing reinforcement for following an emergency protocol.

Similarly for adults, first responders may visit day programs and group homes. They may also hold outreach sessions at firehouses and police stations, which may allow the person with ASD to become accustomed to the associated stimuli of an emergency.

First Responders should be trained and included in developing action plans for different emergency situations with schools, caregivers, and community facilities. First Responders may help to build custom emergency plans for the individual with ASD, including preparing emergency items presented to the individual with ASD once outside the emergency area.

Caregiver Training

Recruiting parents and caregivers most familiar to assist in an emergency situation through a developed plan may be beneficial. ASD-often have a history with their caregivers and their presence can be comforting. Teaching caregivers how to respond and remain calm can help assure the person with ASD that they are safe and secure in a difficult situation.

Understanding the needs of the individual with ASD and the team at all times and refrain from engaging in any personal errands during the trip like shopping. Reminding them to conduct head counts at every transition point helps the team leader keep control of their group. Repeating this basic expectation is essential for student safety and everyone’s enjoyment.

Knowing the profile of a student who is likely to become separated from the group can be important. A student who is unwilling or unable to become a buddy with another student or will not join a group of students is more likely to be lost or separated from the group. Often this is a student who is more comfortable with staff and prefers to be with adults. A second type of student who is likely to become separated from the group includes the student who is highly distractible. This type of student becomes absorbed in all the stimuli of a new environment. Overall, this type of student may become fixated upon shopping, looking for an outlet for charging his or her electronic devices, or searching for his or her favorite fast food outlet. A third type of student who may get separated from the group is the student who has not slept well or eaten well before the trip. This student may fall asleep on a train or bus and miss his or her stop if the team leader is not keeping a keen eye on this type of student.

The group leader on the morning of the trip should provide each team leader with a number of items to ensure that the trip goes smoothly. These items include: (1) a 3” x 5” card with the full names of each of the students on his or her team; (2) a list of all medications; (3) Epi-pens™ for students with severe allergies; (4) A list of staff cell phone numbers on the trip; (5) Train and Metro card tickets for each of team members; (6) Cash, if the students are to practice purchasing tickets from automated machines; (7) An agenda with timelines, objectives, and points of interest/destinations. At the end of the trip or during the group leader should give each team leader an evaluation sheet for each student on his or her team. Team leaders should complete the forms while the trip is fresh in his or her mind. The data from these evaluation sheets are invaluable in planning future classes and trip. It is critical that there is a common theme among the forms. Deficits in the students’ learning can be reviewed in the classroom prior to the next trip.

International Travel Training

Once students have mastered traveling locally using mass transit, they may be interested in traveling internationally. This is a wonderful opportunity for the students to practice their skills and increase their confidence. Students selected to go on international travel training trips should be in good academic and behavioral standing with their program.

Students on international travel training trips must be able to manage their personal possessions especially passports, money, luggage, and medications. One mistake travelers make is that they over-pack. Mini-clinics can be a helpful way to teach students how to pack lightly for internation travel; how to deal with voltage and electronics issues; what to expect at security, customs, and immigration; and the history and culture of the destination.

Having a pot luck dinner with traditional foods from the country the group is traveling to is a nice way students can introduce the traveling companions to each other. During the dinner, the group leader can show a slideshow of the sites the group is about to visit and he or she can include music from that culture. The student to staff ratio on international trips can be slightly higher than beginning travel training classes. This is because students on the international trips are presumably seasoned at traveling with a group and have had previous experience of traveling internationally. The group leader will need to conduct unannounced drills to prepare people with ASD through practicing how to move during an emergency. This type of behavioral rehearsal may result in greater success with following the plan and assist individuals by feeling less overwhelmed by unusual stimuli.

Training, education, and preparation through community outreach are components that are reflected in the guidelines offered by ASD Organizations, Government Agencies, and Charity Response Organizations. Although emergency situations cannot be anticipated, planning for the emergency by training First Responders may allow persons with ASD to experience less stress and anxiety in order to perform successfully.


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