Resources Promote Emergency Preparedness and Improved Safety for People with Autism Spectrum Disorder

By Dawn Brasch, Autism Society of Minnesota (AuSM) Senator Director of Operations and Kelly Thomalla, AuSM Director of Communications

Autism spectrum disorder (ASD) is the fastest growing developmental disability in the United States. More people than ever before are being diagnosed with ASD; the Centers for Disease Control estimates that one in 88 has been diagnosed with ASD, and autism diagnoses are increasing at the rate of 10 to 17 percent per year.

Autism, Asperger’s Syndrome and Pervasive Developmental Disorder - not otherwise specified, are included on the autism spectrum. Autism usually develops before three years of age, yet there is an increase in adults getting diagnosed. Individuals affected by ASD have three common features to varying degrees: disordered social skills, disordered communication skills and repetitive or obsessive behavior.

The hallmark symptom of autism is impaired social skills. Individuals with autism may fail to respond to their name and often avoid eye contact with people. They have difficulty interpreting what others are thinking or feeling because they don’t understand social cues provided by tone of voice or facial expressions and they don’t watch other people’s faces to pick up on these cues.

The impact of having a child with autism is great for families and for the community. Because of the need for lifelong parental, school and societal support, education and awareness are the keys to creating a safe environment for individuals with ASD.

Experts estimate that as many as 25 percent of children with autism may never develop verbal language skills, and even the most high functioning, mildly impacted individuals with ASD may have difficulty communicating when subjected to the stress and anxiety of an emergency event or encounter. As they become adults, many are vulnerable but may look and act violent.

Public Safety Officials Frequently Are Sought For Assistance

It is not uncommon for public safety officials, 911 operators, law enforcement, EMS and fire to receive emergency calls about someone acting “weird,” “argumentative,” “drunk,” “high” or “psychotic.” This situation may be an overreaction or misunderstanding by someone who does not understand ASD and is reporting behaviors of a person with ASD.

Families and caregivers may seek emergency assistance when the behavior of the individual with ASD escalates beyond the ability of the family member or caregiver to manage. Concern may be for the emotional or physical well being of the individual with ASD or threat of injury or harm to others. Intervention is influenced by how well first responders understand ASD and the needs of the family members, caregivers and the community.

A Personal Story: Teen with Autism has Meltdown, Seeks Out Local Police for Help

What began as a simple argument between two siblings in August 2012 escalated into a situation involving the Carver County Police Department.

Jake, a 19-year-old individual with ASD came home to find his sister using the family’s computer. Annoyed because he wanted to use it, he told her to move. She said she was using the computer and he said, “No, you’re not.”

Unable to control his emotions, Jake grabbed a chair and smashed it down and then went after his sister, picking her up and repeatedly hitting her. When she wiggled away from him, he chased her, throwing photo frames and anything else he could grab in her direction.

Jake’s mom, Dawn, watched the situation unfold, unable to get Jake’s attention to attempt to calm him down. “Even if I could have gotten him to look at me, he would not have heard me,”
she said. “Jake was filled with anxiety and not in control.”

His sister locked herself in her bedroom and Jake ran barefoot out of the house into a thunderstorm. Dawn called the local Crisis Unit – her goal being to find Jake. The Crisis Unit said they could not help, stating that Jake needed to learn the consequences of his behavior. Unnerved by this response, Dawn called Jake’s social worker; the social worker called the Carver County Police Department.

A police deputy was sent to Dawn’s house where Dawn explained to the deputy that Jake has autism, a cognitive delay that prevents Jake from understanding the consequences of his outbursts. The police deputy, unfamiliar with autism, discussed pressing charges against Jake because of the assault on his sister.

While Dawn talked with the deputy in her home, Jake was at the Carver County Police Department, his set destination when he ran out in his rage. “I’ve always taught Jake that when he feels out of control that he should take a break and go talk to someone,” Dawn said. “He sought the police for help.”

Choosing the local police department as his place to escape, Jake entered the building saying, “I need to talk to somebody. I need help.” He proceeded to relay the details of the occurrence to police officers. Officers explained to Jake that what he did was assault and that he could go to jail. Jake nodded in what appeared to be understanding.

After calls between Dawn’s house and the police station, Jake was driven home. Jake’s sister went to a friend’s house before Jake returned, noting that she did not want to press charges against her brother because Jake didn’t understand what he was doing and would not be safe in a jail cell.

When Jake arrived home, his officer escort told Dawn that Jake was very honest and respectful when recounting what had happened. “Jake is not malicious,” Dawn said. “He will tell the truth because he does not understand the consequences.”

Dawn asked Jake if he knows what a crime is. Jake said, “No.” Dawn asked Jake if he knows what it means to be charged with a crime. Jake said, “No.” The officer he spoke with at the station was shocked as Jake nodded his head “yes” when he asked Jake those questions earlier in the evening. Dawn said Jake likely was shutting down, agreeing to what he was hearing because he didn’t understand.

Having used the 5-Point Scale to help explain his emotions since he was younger, Jake immediately related to Dawn that what happened that night was a five, meaning a crisis or the

**HealthEast Transportation**
**Emergency Vehicle Services**
- Quality Installations
- Certified Technicians
- Whelen Distributor
- Custom Emergency Vehicle Conversions
- Certified Panasonic Arbitrator Installation Center
- GPS Tracking and Vehicle Monitoring System Installs
- Bait Car Installs and System Service

For more information, contact Ken Larsen at 651-232-5893. HealthEast Medical Transportation | 799 Reaney Ave., St Paul, MN 55106
most heightened stage of anxiety. Jake noted that it was a five and it was against the law. Dawn explained the use of the 5-Point Scale to the officers.

Because of the social worker’s intervention, Dawn’s explanation of Jake’s diagnosis and the education of the officers that evening, it was decided that Jake is vulnerable and did not understand the consequences of his actions that night; being arrested would serve no purpose other than to put him at great risk. The county attorney was convinced that charges should not be filed.

Emergency Situations Can Have Added Challenges
Imagine the challenge a firefighter faces with extra locks and bars on windows and doors and Plexiglas instead of glass windows – common safety precautions for households with children with ASD.

Another danger is the child who refuses to come out from under the bed or runs back into a fire out of fear and anxiety, despite the rescuer’s best efforts to get that child to safety.

Individuals on the spectrum can be very literal. In the scenario of a person with ASD being given Miranda warnings, when asked if he wants to, “waive his right to an attorney,” he may simply wave his right hand at the police officer or prosecutor.

Emergency Preparedness Program for Families and First Responders
Recognizing that awareness and education are necessary to avoid unfortunate incidents and ensure safe encounters between public safety officials and individuals with ASD, AuSM created the Emergency Preparedness Program. Available on the AuSM website, www.ausm.org, this program’s free tool kits help individuals with ASD, families, caregivers, educators and public safety officers better prepare for and respond to emergencies.

The Emergency Preparedness Program includes two audience-specific kits available for download:

Family Emergency Preparedness Kit
Designed for individuals with ASD, families and caregivers, this kit provides tools and resources to plan, prepare and effectively handle emergency situations. Kit components include:

- Autism Awareness Information – Six Actions to Prepare
- Emergency Preparedness Videos (show how children with ASD handle common emergency situations)
- Children’s Book – Awesome Heroes
- 5-Point Scale Emergency App

First Responder Emergency Preparedness Kit
Designed for first responders, 911 dispatchers, EMTs, hospital personnel, law enforcement, fire fighters, service providers, legal professionals and community leaders, this kit includes:

- Autism Awareness Training – Workshops (offered at your location)
- Public Safety Education Series – Six Actions to Prepare
- Emergency Preparedness Videos (show how children with ASD handle common emergency situations)
- Children’s Book – Awesome Heroes (for school tours, community events, etc.)
- 5-Point Scale Emergency App (encourage families to use the free download from iTunes)

Awesome Heroes Children’s Book
This children’s book was designed to show real scenarios that are common to children with ASD and how first responders, children and their supports (family, educators, community) respond. Although this book highlights children with autism, it is a tool to help all children be safe in emergency situations, to become heroes.

Illustrations bring the stories to life as they depict common behaviors children with ASD display when in emergency situations (e.g. hands over ears when fire alarm goes off versus leaving). Readers can download a safety plan and a Hero certificate from the AuSM website.

Emergency Preparedness App
The 5-Point Scale is a tool used by educators throughout Minnesota to teach appropriate behaviors to children with ASD. The Governor’s Council on Developmental Disabilities and AuSM created a 5-Point Scale Emergency app that helps individuals with ASD communicate with first responders and others in emergency situations. The app, which is available for download free of charge on
iTunes, can be customized to the specific situation of an individual or family. Public safety officials should become familiar with the 5-Point Scale Emergency app as it may be presented to a responder upon arrival at the emergency scene.

Recently the 5-Point Scale app was awarded the Digital Government Achievement Award in the Government-to-Citizen category.

Reach for Your Resources – Increase Education and Awareness

Public safety officials are encouraged to use the resources available from the Autism Society of Minnesota (AuSM) for their safety and for those they are saving. The resources increase awareness of the unique safety risks to persons with ASD, explain the characteristics and behaviors of persons with ASD, and educate about the appropriate steps to take to better ensure safety and avoidance of unfortunate incidents.

(Established in 1971, the Autism Society of Minnesota (AuSM) is a self-funded, local organization committed to education, advocacy and support designed to enhance the lives of those affected by autism from birth through retirement. The Autism Society of Minnesota is located at 2380 Wycliff Street, Suite 102, St. Paul, Minn., 651.647.1083. www.ausm.org)

---

1 Centers for Disease Control and Prevention, http://www.cdc.gov/features/CountingAutism/
2 National Human Genome Research Institute, http://www.genome.gov/25522099
4 National Human Genome Research Institute, http://www.genome.gov/25522099

---

This article has been reprinted with the permission of the Minnesota Chiefs of Police Association.