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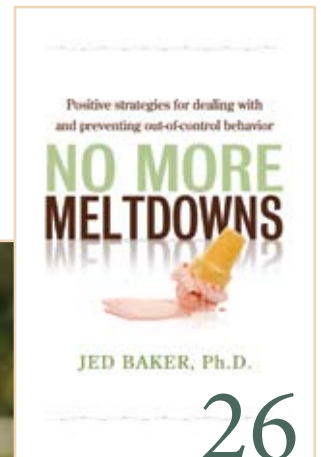
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on the cover

Sam is an energetic three-and-a-half year old, with bright blue eyes and an engaging smile. He loves to run barefoot in the grass and chase butterflies. When he's not on the go or splashing in the bathtub, he loves to sit in his swing and watch Winnie the Pooh.

Cover photo by Barry Lewis, Lewis Photography, Madison, WI





Autism Training for **First Responders**

By Chris Lacey

In June of 2007, a seven-year-old boy with autism named Benjy Heil wandered away from his home in central Wisconsin. Those of us with autistic children of our own held our breath. We watched, waited and prayed as the small community where Benjy lived pulled together a massive search that continued for five days and nights. Benjy's story ends, like too many others, in tragedy. He had drowned in a nearby pond less than a quarter-mile from his home.

With a child of my own prone to wandering, I wondered what more we, as parents, could do to ensure our chil-

dren's safety. If my child was found by a police officer, would that officer realize my child was autistic? And even if he or she did, would that person know what to do?

In an effort to raise awareness in my community, and to lessen the likelihood of my own child becoming a statistic, I contacted my local police, fire, and EMS to inquire if they had received training in autism. They had not, but they were interested.

Over the next few days, I searched for autism training programs in my area only to discover they were almost nonexistent. If I wanted these people

trained, I'd need to do it myself. With no background in police, fire, or EMS, I set out to discover what first responders needed to know most when it came to interacting with children and adults with autism spectrum disorders (ASD). Two issues quickly rose to the top of the list: how to recognize a person with autism and how to communicate with that individual. My professional background in developing training programs told me a simple presentation would not be enough; I needed to both educate and involve these first responders so they could experience autism firsthand.

On a warm, summer night in August, two months after Benjy's tragic passing, a group of 30 paramedics, firefighters, and police officers gathered for my first presentation. It began with an explanation of autism, as well as commonly co-occurring medical conditions. I emphasized that recognition of a child or adult on the autism spectrum encompasses physical, social, communication, and sensory signs and symptoms.

To assist the first responders in remembering what to do when faced with an autistic person, I created a phrase and an acronym: "Our Community CARES."

C – locate a Caregiver. Essential in achieving the best outcome for any person with ASD, caregivers act as translators, communication aids, and a source of comfort for the affected individual.

A – don't make Assumptions. Environments in which autistic children and adults thrive may seem abusive or neglectful to those unfamiliar with the circumstances.

R – Restrict sensory input. This includes lights and sirens.

E – Empathize. Our children truly are doing the best they can in the situation.

S – Secure. A reminder never to leave an autistic individual unattended as they may wander.

Communicating effectively with a person with ASD can be highly challenging. A large segment of the ASD population is nonverbal, or nonverbal under stress, hence first responders

need to be able to modify their means of communication. Following a set of simple interaction guidelines (see sidebar) and limiting sensory input, including the number of people present, could mean the difference between life and death in some cases.

In addition to the challenges associated with communication, our children face a plethora of sensory issues that may seem unusual to neurotypical professionals. Sensitivity to touch, for example, can complicate a medical assessment and challenge how we, as humans, seek to reassure and comfort one another. Stimming – the presence of unusual physical or verbal mannerisms that tend to increase under stress – was also covered. First responders were encouraged to ignore stimming as long as it did not present a threat to the autistic person or others in the immediate area. I also touched on how major life transitions, such as puberty, can throw our kids over the precarious

edge they are so often balanced upon, resulting in aggression and abnormal behaviors often coupled with a lack of understanding of the social inappropriateness of their actions.

Having gained their full attention, I delved into the reasons why first responders may encounter a person with autism or Aspergers, as well as scenarios specific to their jobs as EMTs, firefighters, or police officers (see sidebar). Since persons with autism are seven times more likely to encounter first responders than are their neurotypical peers, this information is especially critical. Search and rescue protocols, including locating and securing sources of water (drowning is the leading cause of accidental death for persons with ASD), was also included in this part of the presentation.

Training, I believe, must be an interactive experience for the information to be fully integrated. Therefore, I

Interaction Suggestions for First Responders

- Speak slowly
- Use five or less words
- Use simple, concrete language
- Give commands or requests one at a time
- Consider other means of communication such as picture boards, sign language, writing information down, offering pen and paper or a computer, demonstrating what is required, singing or whispering the request or instruction (even with adults)



What Parents Can Do



There are many things parents or caregivers can do to keep their children safe. Consider the following:

- equip your child with an autism card or medic alert tag (bracelet, necklace, zipper pull, shoe tag, clothing tag, temporary tattoo, etc.)
- develop a child info sheet (and carry it with you at all times) detailing emergency contact information, medications, communication methods, likes and dislikes, sensory issues, unusual behaviors, and best ways to approach your child
- carry a family picture with you in case your child is separated from you and does not acknowledge you upon return
- use autism alert window decals on your home and car
- place a 911 premise alert on your address to alert first responders to your child's condition
- request a meeting with your police, fire and EMS to introduce your family and discuss your concerns
- alert first responders to aspects of your home environment that may appear odd to someone unfamiliar with your child's special needs
- maintain an "emergency box" filled with items that can be used to calm, redirect or gain your child's compliance in case of an emergency
- request that the community police officer(s) make regular visits to your child's home, school or workplace to develop a relationship with your child

Child safety packets for autistic children are available from Select Autism Merchandise (www.SelectAutismMerchandise.com) and contain the abovementioned products, as well as more information on how to keep your child safe.

If your child wanders/goes missing:

- develop a telephone chain to alert people quickly
- keep child info sheets (updated at least every 6 months) readily available at all times
- maintain a map of all water sources in your immediate area, including lakes, pools, rivers, retention ponds, etc.
- institute a Neighborhood Watch for Wanderers program
- consider investing in a personal tracking device
- inquire if your community has, or can get, Project Lifesaver (www.projectlifesaver.org)

developed over a dozen unique scenarios that would give the first responders a chance to test what they had learned. The large group divided into several small groups, where one person volunteered to be "autistic" while the others performed their duties as first responders. The volunteer was given two forms of medic alert identification and a profile that included their name, age, diagnosis, sensory issues, communication preferences, and level of eye contact. Meanwhile, the first responders were given a packet containing information on the scenario in which

they encountered the autistic individual. The packets also included a picture communication board, pen and paper, laptop computer, and a teddy bear; all of which were available to them to aid in communicating with the autistic individual.

Soon the groups began acting out the carefully constructed scenarios. Volunteers were stimming as instructed, confusing their pronouns, and echoing what was said to them. In turn, first responders proceeded to write instructions on their computers and with pen and paper, try out the communication

boards, and wait patiently for a response, now cognizant of the processing delay that affects so many of our children. When one volunteer covered her ears, a first responder whispered in response. Those working with a profile of my son realized that he would not respond and instead spoke calming words, assuring him they had contacted his parents (after locating the information on his medic alert bracelet) and that his mom and dad would be arriving soon to take him home.

Afterwards, we regrouped to discuss the exercise. Volunteers and responders alike found the experience immensely enlightening. Comments included recognizing the need for increased personal space, struggling with the inability to give comfort through touch, and an increased awareness of looking for medical ID tags. What amazed me most was seeing the participants apply what they had learned from the presentation, improvising in ways I hadn't anticipated to make the scenarios even more realistic.

The presentation concluded with an appeal centered on promoting community partnerships. I encouraged the first responders to get to know the individuals with ASD in their community. Developing a rapport with these individuals and their families now, before an incident occurs, could go a long way in easing future interactions and avoiding harmful mistakes. We also discussed the steps that parents and caregivers can take to keep their children safe and make interactions with first responders more successful (see sidebar). Lastly, I endorsed Project Lifesaver, a radio frequency-based tracking system used by law enforcement to find adults and children prone to wandering; a system that could potentially have saved Benjy's life had it been available to him.

The evening closed with my husband and two sons joining the group. While one of the first responders showed my older son the fire engines, my autistic son ran around the meeting room on his tip-toes, stealing people's keys

Common Behaviors of People with ASD

and soda bottles while humming to himself. He didn't acknowledge anyone in the room other than me, though I'm sure he was aware of them. Bringing my son gave the first responders a chance to see an autistic child as well as to try and interact with him. It gave me the piece of mind that if I should ever need them, they will have met my son and we will be able to work together as a team.

Encounters with first responders are increasingly common as more and more of our children with ASD grow into teens and young adults. Parents can—and should—be proactive in educating their community's fire, police and EMS professionals about ASD. Don't wait for someone else to do it, especially if your child is a runner or is attracted to dangerous places such

Persons with autism or Asperger's Syndrome may not recognize uniforms, badges or emergency vehicles. Alternatively, they may be drawn to them in an obsessive or dangerous way. Turning off lights and sirens, working one-on-one with the autistic individual, and interacting in a smaller, enclosed environment generally leads to the greatest success.

Police: may run toward or away from police officers; may be drawn to shiny objects and reach for a badge or gun; may readily admit to a crime they did not commit; may have an absence of eye contact or odd body language that should not be viewed as an indication of guilt or as suspicious behavior; may have under-developed trunk muscles that could lead to positional asphyxiation and death with chest-down holds.

Fire: may re-enter a burning building due to a lack of awareness of danger; forced entry through locked doors and windows is likely; to move quickly, wrap individual in a blanket.

EMS: often have a high pain threshold; may have an unusual response to pain such as laughing or humming; may have injuries that aren't obvious; may suffer from seizures.

as water or busy highways. Even a simple, informal presentation can go a long way in avoiding the types of misfortune that have befallen too many families already. After all, our children's lives are at stake here, and preventing a tragedy is far better than living through one. 🚒

Chris Lacey is a professional trainer, author, autism advocate and founder of the Autism Alliance for Local Emergency Responder Training (Autism ALERT, Inc.). She lives in south central Wisconsin with her husband and two children. For more information, or to contact Chris, visit her at www.AutismAlert.org.