



Individuals with Autism Spectrum Disorder and Preparation for Emergencies

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The need for First Responders, including fire fighters, police, and medical emergency personnel to understand autism spectrum disorders has become a high priority concern for many individuals who care about children and adults with ASD. Agencies, including IRCA, have picked up the mantra and are charging forward to meet this important challenge. The expected outcome of having knowledgeable responders is that individuals with ASD will be supported with dignity and understanding in emergency situations.

Training First Responders is an Important Step, But Only the First Step

While everyone may feel better once emergency personnel in their local community have been trained, the problem is not totally resolved. Parents will also need to look at how they can best prepare their child to provide information to emergency personnel, in case the parent is not available or is unable to provide support or information. Preparation will vary by child and will depend on his or her ability to actively respond to questions.

Step Two: Provision of Information for Responders Which Requires Minimal to No Effort from the Person with ASD

Information that requires minimal or no effort from the person with ASD falls into two categories: information carried by or on the individual with ASD and that which is available in various locations that the First Responders might find on their own as they search for information.

Information Carried by the Individual

Basic information should be available in print form so that every individual with ASD can take, at least, a limited albeit passive role in interaction with First Responders. Even if a child can talk, there is no guarantee that he or she will be able or willing to interact in an unfamiliar or stressful situation. Each individual with ASD should carry a laminated card that provides his or her name, age, blood type, diagnosis, and contact information. If possible and practical, keep an updated list of medications and dosage levels on the card, as well. If medication is chronically changing, then it may be safer to not have the information available than to provide inaccurate information. The person with ASD will need to be taught to give the card to a fireman, policeman, or emergency responder upon request or to anyone else who asks for his name and identification information. An emergency situation is not a time for the person with ASD to refuse because the First Responder does not look like the pictured ones that were part of his or her previous training. Parents will need to vary the phrases that might be used to request identification and teach the same response of a handover of the card to all requests. Parents may want to elicit neighbors, other family members, and particularly strangers to the child (but friends of the parents) to provide opportunities for the child to practice handing over the identification information. Sample elicitation phrases are included in the Table 1.

Table 1. Examples of Name Elicitation

What's your name?
Name, please.
Who are you?
Can you tell me your name, please?
(Invent others, as needed)

A medical ID bracelet, a neck ID tag or a neck document pouch could list some amount of information, if this is the preferred approach. One must always consider the safety of these options, however, vs. the possibility of the individual getting the neck apparel stuck on something. Although the bracelet or pouch COULD be worn by the child 24/7, the biggest hurdle might be getting him or her to wear it and then, since the identification system is so much a part of the individual's apparel, get him or her to show it upon request. Of course, with either the laminated card or the identification tag, or pouch, opportunities abound to forget the system, to take it off, or to lose the system; this, however, should not be a deterrent to the consideration that each child have some emergency identification system.

Information Left for First Responders to Find

Another option is to leave a copy of relevant information in a plastic sleeve attached to the sun visors or in the glove compartments of the family vehicles that transport the child. That way, in case of a car accident, more important information would be available than what might be carried on the child's person. Information might include the names of doctors, medications, special challenges and suggestions for management and alternative emergency phone numbers and contacts. The latter might include information about sound sensitivity and the suggestion of no sirens, if possible. Consider a bumper sticker that says "Child with autism on board" as a means of alerting First Responders to look for additional information.

Duplicate sets of emergency information should also be available in the house, at school, at the daycare, and in the homes of other family members who provide informal respite services. Consider putting a decal on the front door or front window to alert a First Responder to the presence of a child with ASD. The elderly often have a decal on their refrigerator indicating that their important emergency information is located inside the refrigerator in a plastic bag. Consider a similar strategy for your household.

Step Three: Provision of Elicited or Active Information by the Person with ASD for the First Responder

Once Step Two emergency supports have been put into place, then attention needs to be given to potential opportunities for the person with ASD to engage in active or elicited information sharing with First Responders. Step Three will not be appropriate for all individuals with ASD, especially those with significant cognitive challenges. The Sample Topic Emergency Board that is included in this article covers a variety of situations. It allows a child to initiate information or to respond to the questions of others. Obviously, it is limited since it is generic and made to specific dimensions. A parent does not need to use all or any of the vocabulary shown; he or she may want to add additional or customized vocabulary or may want to use a different layout or alternate organizational format. The clipart pictures were taken from Microsoft Office On-Line; one does not need to use special software to do a design of a support communication system.

To use a topic board, the child with ASD would point to the pictures to construct anything from a single word sentence to a multi-word sentence to a series of short sentences. The child could initiate a report or could use the board to respond to the questions of others. (See Table 2 for potential examples.) First Responders could use the board in the same fashion by pointing to key words to back up their questions or to reassure the child. As everyone

who is familiar with children with ASD knows, the visual often overrides the auditory, particularly when the child is under stress. (See Table 3 for potential examples.)

Table 2. Possible Example Utterances Generated from the Sample Emergency Topic Board Include the Following (the list may provide ideas for family practice):

- "Call Grandma Luke; Mom hurt."
- "Call ambulance; Dad hurt."
- "Call police. Man hit Mrs. Jones."
- "Call fire department."
- "Boy break."(gesture for window); "Steal."
- "Man touch me. Park."
- "Man scare me."
- "Man hurt. Man gun. I scared."
- "Boy show drugs."
- "I see accident."
- "Call 911. Lisa hurt."
- "Snowball" (cat) "accident."
- "Man angry; hurt Sebastian." (dog)
- "I afraid outside".
- "I afraid school. Boy hit me. Call teacher."
- "I confused. See angry man."
- "Real, not TV. Man hit man. Angry. Call police."

Table 3 Use of Visual Backup for Key Words by First Responders

- Where's your **Mom** (points to picture of Mom)?
- Who else is in the car (points to various family member's pictures)?
- **Mom** is **hurt**; the **ambulance** will take her to the hospital. You will ride in the police car with me. We will follow the ambulance (points to key words).
- Did you see the **accident** (points to picture of accident)?

The **Sample Emergency Topic Board** is multi-purpose. It allows for a child to report in a limited fashion about others having medical emergencies, exposure to drugs or weapons, assault, molestation, robbery, vandalism, animal cruelty, and other acts of aggression. Someone would need to ask follow-up questions and "yes," "no," or "I don't know" could be used. Or, one might use an alphabet if one were added to the backside of the topic board. If a child could spell, he or she could share more detailed information. One does not need to make a topic board that is this versatile, however. It depends upon what best suits the age, abilities, and environment of the specific child.

While one hopes that a given child never has need to use an emergency topic board, preparing a board is only a first step. The child has to be familiar with the concept of speaking via the board, know the vocabulary available and know how to use the communication system. If topic boards on other subjects are used as prompts for the child who can talk and as communication displays for the child who can not talk or who has limited skills, the knowledge of how to use it should transfer. Use an organizational pattern for an emergency communication display that is similar to that used for the other topic boards or speech generating device pages that are part of the individual's

current communication repertoire. The topic board that appears in this article is organized according to a layout called the Fitzgerald Key. It has columns of words for people, verbs or actions, objects, feelings, places, and some miscellaneous words. Speak to the school speech language pathologist for assistance in developing a customized board appropriate for your child. Modify it as your child develops more sophisticated communication skills or as environmental circumstances require the addition of new vocabulary (e.g., the presence of drugs at school).

While the notion of talking on the emergency topic board should transfer if it is similar to other familiar topic displays, the student will still need to know ahead of time that an emergency version exists. Depending on the age of the child and his or her comprehension ability, the use might be discussed and some utterances demonstrated or practiced. Instead of extensive rote practice, parents may want to help their child understand what might constitute an emergency situation that could directly or indirectly involve him or her or some other familiar person. Consider generating a list of situations and let him know that copies of the emergency board or display page will be available in the house and car for emergency situations only.

Parents may want to do other things to help the child understand and cope with emergencies. Reading books or pamphlets, watching specific videos or TV shows that give concrete information may be helpful. *Fireman Sam* on PBS Kids Sprout is a good example of simple positive exposure to First Responders. Certain children's books can offer understanding and encouragement that might help in a real situation. For example, the book *Shy Charles* by Rosemary Wells tells the tale of a character who won't talk to people outside of his family, yet when his elderly babysitter collapses, he calls to get help. Once there is some real understanding of emergencies and expected behavior, then practice could be very helpful. Without real understanding, the child is apt to learn a routine that may not be triggered during a real emergency situation because a First Responder lacks knowledge about the precise cue words needed to activate the routine.

With children on the autism spectrum representing so much diversity, this article can not be specific enough to provide suggestions that will apply to all situations. Instead, the purpose has been to raise awareness of families to consider the possibility of First Responders needing information from your child. Many families are very resourceful and may be willing to share ideas through listserves or through parent groups of how they have successfully approached this particular problem.

Wells, R. (1992). *Shy Charles*. New York: Dial Books for Young Readers.

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Sample Emergency Topic Board

Michael me 	Grandma Luke 	call 	Police Dept 	afraid 	school 
Mom 	Mrs. Jones (neighbor) 	see show 	Fire Dept. 	hurt 	park 
Dad 	boy girl 	hit 	ambulance 	angry 	outside 
Lisa (sister) 	man 	break 	gun knife 	confused 	home 
Sebastian (dog) 	woman 	touch 	drugs 	real. not TV 	YES NO
Snowball (cat) 	teacher 	steal 	accident 	911	I don't know 

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