

Disaster Preparedness for People on the Autism Spectrum and their Supporters

horse**ns**ense

Wisdom Shared
by Autistics
Already Winning
the Race of Life

Recent disasters require a call for action!

The Tsunami of 2004 in Indonesia. Earthquakes. Hurricane Katrina in 2005. These life-shattering natural disasters have spurred individuals, groups and governments around the world to take a deeper interest in disaster preparedness. Within the global autism community, the same is true. These unfortunate events have resulted in new attention being given to educate and prepare people on the autism spectrum and their supporters to handle these and other natural disasters.

For the past year I, along with Brenda Smith Myles and other colleagues, have been involved with an international movement to better prepare people with disabilities for potential disasters. Organized by Hiroshi Kawamura, the first meeting of the International Workshop on Disaster Preparedness of Persons with Disabilities occurred at a United Nations conference in Kobe, Japan in January of 2005. My contribution was to present ideas on helping people with autism prepare for disasters. Work continued in this area as I was then invited to present the material at the United Nations-sponsored World Society on Information Systems conference in Tunis, Tunisia, which was held in November, 2005. I returned to Japan this past January to present my findings from the previous year and working with other professionals, discuss possible options for the future.

In-Roads to Preparedness Using Universal Design

Two important revelations came out of my background research in this area. The first is that many of the ideas relevant to disaster preparedness for the ASD population are already being used and materials already exist that can propel education and awareness.

It was surprising to learn that nothing new has to be invented in order to prepare people with autism for disaster. Everything we need is already available. Examples include various intervention programs and approaches such as PowerCards, developed by Elisa Gagnon, technology such as vibrating cell phones that provide multi-sensory awareness, as well as educational pamphlets, stickers and awareness cards developed by groups such as the Autism Society of America and Unlocking Autism.



By
Stephen Shore

The second revelation is that materials developed for people with autism are useful on a more global scale for preparing larger segments of the population without disabilities. This concept is known as “universal design.” Just like fully-abled people use a ramp built for people in wheelchairs to enter a building, materials that offer visual representations of actions to take in the event of a disaster are perfect for assisting non-English speaking people, young children, the elderly, etc.

By using materials that already exist, and combining those with new materials applicable to people of all abilities, we assure greater overall preparation for natural and manmade disasters.

A Possible Scenario

A vicious storm has just blown through your area and the power has gone out. You look out your door to find trees and power lines strewn across the road. Some buildings have broken windows and doors. You venture outside and hear soft moaning coming from the house across the street.

Your yells of “Anybody home? Anybody need some help” are met with silence, save for that moaning sound. Following your ears you happen across a young teenage girl gently rocking back and forth, flipping pages of a book with the speed of a person shuffling cards. Certainly she’s not reading the text as she continues to emit an unearthly “eeeeeee” sound.

Outside you hear an announcement: everyone is to evacuate their homes and head to the basement of the local public school before the next thunderstorm cell arrives with possible tornadoes. Your assurance to the girl, “Come along, everything is going to be all right”, is met with no response. You repeat yourself a few times, each a little louder. Still no response. She doesn’t even look at you. You wonder if she is in shock or hearing impaired.

You hear a strong gust of wind. “No more fooling around” you think to yourself. Quickly and without warning you neatly scoop the girl up to carry her with you to shelter and safety. The last rational thought you remember having before racing out the house towards safety was “I may have well just picked up a wild cougar.”

To the well-meaning neighbor, friend or stranger who doesn’t recognize the characteristics of autism, it may well have seemed the child acted like a frightened animal. One of the major characteristics of people on the autism spectrum is sensory distortions which are often combined with an exaggerated startle response. Add to this, difficulties people with autism have in experiencing change and their various communication challenges. Without advance preparedness - or at minimum, visual aids that alert a stranger that autism is present - a rescue attempt can escalate to a potentially dangerous situation of its own.



Materials developed for people with autism are useful on a more global scale.

A comprehensive disaster preparedness program for people with autism will have two components: 1) the use of visual materials to alert on-the-spot responders that autism is present and that offer practical advice for helping these individuals and 2) advance preparedness in the form of training for the child or adult on the spectrum in the event of a natural disaster, and education and awareness of first responders. Both components are discussed below.

Ideas for On-the-Spot Assistance During a Natural Disaster

Natural disasters can often occur with little advance warning. Once they strike, a person with autism is likely to encounter highly chaotic situations involving a vast number of strangers. In all likelihood, the person with autism will ‘shut down’, or revert to self-stimulatory behavior that is calming, such as rocking, or repeating words or phrases. It is important, therefore, to prepare the environment in which the child or adult may be found, i.e., their home, apartment, or room, with visual materials aimed at identifying a person with autism and educating a potential first responder. To be effective, these materials must be understood immediately or take no more than five to ten seconds to read.

Identification and Education

The Autism Society of America has created an easy to comprehend sticker that has almost instantaneous recognition that a person with autism is present. The universal warning symbol



plus potential reactions of someone with autism are described. Find the sticker online at www.Autism-Society.org.

Another identification sticker has been developed by Bill Davis, author of the excellent book, *Dangerous Encounters - Avoiding Perilous Situations with Autism: A Streetwise Guide for All Emergency Responders, Retailers and Parents*. He is a representative of, Unlocking Autism, and his decal is available through them, www.UnlockingAutism.org.



Additional information about a person with autism can be shared via a two-sided business card such as the one developed by the Autism Society of America. One side of the card offers nine major characteristics of the disorder, such as “may not understand what you say”, “may engage in repetitive behaviors”, “may act upset for no apparent reason”, and “may be unable to speak or speaks with difficulty.” It also offers a special caveat to the first responder: “For law enforcement or medical emergency personnel: This individual may not understand the law, know right from wrong, or know the consequences of his or her actions.” The second side of this card includes helpful hints for interacting with a person on the autism spectrum such as:

- Use concrete terms
- Allow time for responses
- Do not attempt to physically block self-stimulatory behavior

Other Visual, Picture-based Tools

Most individuals on the autism spectrum benefit from visual communication tools. As stress escalates, the ability to process verbal information declines. Picture-based instructions and alerts can be highly useful during emergency situations. Fortunately, the technology to do this is already available and a wide range of materials already exist that can help first-responders and the person with autism.

Diagnosed with “strong autistic tendencies,” nonverbal until four and recommended for institutionalization, Stephen Shore is completing a doctorate at Boston University focusing on helping people with autism develop their capacities to the fullest extent possible. Presenting and consulting internationally, Stephen is president emeritus for the Asperger’s Association of New England and serves as board member for several other similar organizations. More about Stephen can be found at www.autismasperger.net.

Visual schedules that depict the actions a person with autism should take in the event of emergency can be posted in the home or the child’s room. A wide range of picture symbols to create these visual instructions are available. One product, “Boardmaker” contains a database of over 3,000 pictures (available through the Mayer-Johnson company website www.mayer-johnson.com). A variety of free symbols are available on



the Internet. These visual instructions serve a two-fold purpose: they can help the individual with autism stay calm and know what to do, and alert first-responders that the child or adult may need extra time and/or assistance in order to comprehend instructions.

Pictures such as these have already been adopted for assistive communication devices, such as the Dynavox™. By also adapting them for PDA’s, cell phones, or other electronic devices, they become useful not only for people with autism and Asperger’s, but any person with visual ability.



The materials described above can be useful in times of immediate, impending disaster, when there is no time to educate responders about autism. In the next issue of the Digest, we’ll continue with helpful advice for advance pre-

Disaster Preparedness for People on the Autism Spectrum and their Supporters

Part 2

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In the last issue of the Digest we opened the topic of disaster preparedness for people on the autism spectrum by offering some ideas for providing on-the-spot assistance to people on the autism spectrum and first responders during natural and manmade disasters. Visual aides such as stickers, awareness cards and pamphlets can not only alert first responders that a person has autism, but can help them with easy, quick education on how to effectively interact with this population when danger is imminent. As discussed, these already-existing materials can help not only people with autism but other groups of individuals with limited English or speaking capabilities.

However helpful these materials can be, a truly effective disaster preparedness program will be proactive in providing education, awareness and preparedness of people with autism and their supporters **BEFORE** disasters strike. Why bother with advance preparation? Dennis Debbaudt, nationally renowned emergency preparedness expert, likens disaster preparation to wearing a seatbelt in an automobile. You almost never need the restraint that seatbelt provides. However, in the case of an accident or emergency situation, when you *do* need it, you *really* need it.

Proactive Education of People with Autism and their Supporters

A complete disaster preparedness program will follow a two-pronged path: education of the person(s) with autism and their immediate family or caregivers, and education of first-responders, such as policemen, firefighters, emergency medical providers, and other community members who may come in contact with people on the spectrum during disaster situations. The good news is that various materials and programs already exist that can help in this education and awareness, as outlined below.



By
Stephen Shore

In conjunction with Dennis Debbaudt and one of their national Board members, Ruth Elaine Hane, the Autism Society of America has produced a handy tip sheet that is a good starting point for disaster preparedness for both individuals on the spectrum and their families. Entitled “Disaster Preparedness Tips for Our Families” the two-page flyer is part of the ASA’s “Safe & Sound” Initiative. It provides basic tips, such as “Practice Calm”, “Prepare for Immediate Needs Before Disaster” and “Prepare for Needs in Your Home Now...” along with numerous practical, do-it-now type ideas, such as those listed below.



Disaster Preparedness Tips for our Families

PREPARE FOR IMMEDIATE NEEDS BEFORE DISASTER

- Wearing a medical alert tag or bracelet to identify your disability may help in case of emergency.
- Have a disaster supplies kit on hand you can use at home or in an evacuation setting. Kits should include:
 1. Flashlight with extra batteries
 2. Portable, battery-operated radio and extra batteries

Full document available at www.autism-society.org

(Find additional helpful materials at the ASA website, www.autism-society.org. Dennis Debbaudt is author of the book, *Autism, Advocates, and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders*, and offers helpful information at his website, <http://www.autismriskmanagement.com/>)

Another avenue for educating people on the autism spectrum who have more advanced verbal and reasoning ability is through the use of PowerCards. Power Cards were developed

by Elisa Gagnon, author of *PowerCards: Using Special Interests to Motivate Children and Youth with Asperger Syndrome and Autism* (2001). PowerCards are useful for working with people with Asperger’s Syndrome (AS) and high-functioning autism (HFA) because they capitalize on two strengths often found in this population: having a special interest and identifying with a “hero” involved with that special interest.

For example, suppose a child with Asperger Syndrome has a special interest in flying and wants to become a pilot. Using the strategy suggested by author Gagnon, a power card could be developed that incorporates a picture of a pilot the child knows and/or admires (for instance, Chuck Yeager), coupled with recommendations from this pilot on what to do in the case of a severe weather alarm.

Brenda Smith Myles, in her book *The Hidden Curriculum* (2004), offers another excellent technique that takes into account the logical and visual strengths that are characteristic of people with AS/HFA. Called SOCCSS (Situations-Options-Consequences-Choices-Strategies-Simulation (SOCCSS), the technique is useful for identifying problems the individual may encounter and devising an action plan the person can then follow.

Looking to the Future

We have explored just a few of the already-existing materials, strategies and interventions that can be used or easily adapted for use in the notification and education of people with autism and their supporters for disaster preparedness. The next step will be to enhance these existing tools in ways that make accessibility easier and more aligned with the needs of people on the spectrum.

Finding ways to employ existing tools using as many senses as possible will, in all likelihood, promote their use both within and outside the disability population. For example, the hard of hearing might not perceive an audible warning siren, but could easily respond if given a device that vibrates to signal a warning. The vibrating technology already exists in cell phones. For people who are blind, disaster preparedness educational material can be placed in other formats such as DAISY, a program analogous to talking books for the Windows platform. The materials discussed in this article, along with many more that exist, could be adapted to electronic devices such as a PDA, computer, or cell phone.

Disaster preparedness education needs to become a priority in our homes and our schools. These materials are only effective if they are **used** in educating people with autism, their families, and community responders. This involves *everyone* assuming responsibility for teaching and educating others about people with autism spectrum disorders. In the event of a disaster, even a little effort, a little education, a little awareness can easily be the difference between a life and death outcome. Don’t wait

Pilot Chuck Yeager wants you to remember to choose one of the following ways to help calm yourself when the severe weather alarm sounds.

1. Take 5 deep breaths exhaling slowly after each breath.
2. Close your eyes and slowly count from 1 to 20.
3. Go to the basement of your home or other emergency shelter.
4. Wait until someone tells you it is safe to come out.



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for 'someone else' to educate your child, your family, or your community. **Be proactive.**

Finally, by acknowledging and extending considerations for people with autism and other differences when developing warning, identification, and educational materials we move closer to bringing to life the concept that *everyone* benefits from our efforts – large and small - in disaster preparedness.

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Resources

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AS APPEARED IN

March - April and May June 2006 Issues

Since 1999, offering practical information and strategies to improve the lives of children and adults with autism spectrum disorders.

www.autismdigest.com

A Future Horizons publication