

# **Advocacy for People with Speech Disabilities: Emergency Preparedness Resources**

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*January 2015*

*Updated and adapted from article originally published in Therapy Times.*

Kennedy, P. (2011). No One to Speak for Them: Emergency Preparedness Resources for Those with Speech Disabilities. *Therapy Times*, 14, 15.

The ability to communicate is crucial in the event of emergencies, such as a hurricane, flood, fire, trauma, or loss of electricity. Emergency personnel need to be able to interact with the individuals whom they are rescuing; medical personnel need to get accurate information from those who have been injured; displaced persons need to contact loved ones.

At these times, no population is more at risk than those with complex communication needs (CCN) - people who have difficulty communicating as a result of pre-existing disabilities such as cerebral palsy, autism, and cognitive delays. To compensate and interact with others, they utilize augmentative and alternative communication (AAC) techniques like speech-generating devices, sign language, and picture communication displays.

Emergencies pose additional challenges for people with CCN because of the absence of familiar communication partners, loss of electricity to power AAC devices, and the need for low-tech speech technology such as displays with vocabulary that addresses emergency issues. However, these risks can be minimized with forethought, planning, collaboration and teamwork. As a person with cerebral palsy who communicates via a sophisticated speech-generating device, sign language, written messages and gestures, life taught me that lesson when I became a refugee during the Grand Forks, North Dakota flood of 1997.

Flooding had been forecast three months in advance. I had served on Grand Forks' Emergency Preparedness Council for People with Disabilities and entered my name, address, disability, and accommodations in the special needs registry; doing this insured that emergency call centers across the state had my name, location, disability and accommodations on file in the event of any emergency. Because no one expected my neighborhood to be affected, I thought that would be enough.

However, I was not spared! The flood was far worse than anyone expected. The dike was breached on April 19th. I heard the sirens signaling for evacuation around 2:00 a.m., at which point, my neighborhood was completely flooded and I was trapped. Because there was no one in my home who could help me into my chair, I was helpless for about eight hours until a team of emergency responders came by boat, followed by a National Guard truck to rescue me and my assistance dog, Jessie. They barely had enough time to get me in my chair, and to grab my medication and my computer with text-to-speech software before we were evacuated to a makeshift rescue facility, separated from my family and friends.

Despite the disaster and my forced re-location, I continued my efforts at collaboration and teamwork. Once I arrived at the shelter, I saw refugees with CCN who had no means of communicating because their communication supports had been left behind when they were evacuated. While I worked at the shelter to help refugees like myself create basic communication displays on sheets of paper, I knew that more preparation should have been done before the disaster.

After the flood waters receded, I wanted to advocate for my peers who cannot speak, giving them a voice and highlighting the issues and dangers people with complex communication needs face each day. However, I needed to find groups with the same goals. Since 2005, I have worked with the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC), the United States Society for Augmentative and Alternative Communication (USSAAC), the patient-provider communication forum, and local agencies to address this need with forethought, planning, collaboration, and teamwork.

As part of a national effort, the AAC-RERC, people with CCN, clinicians, speech, occupational and physical therapists, vendors, developers, parents and professionals that span the AAC industry have worked to develop resources and materials for individuals with CCN for use before, during, and after natural disasters. These include:

1. A special edition newsletter that highlights the need for action, as well as resources and supports.
2. A webcast featuring my experiences as a refugee and recommendations for people with CCN.
3. Ready-made communication pages for use by people with CCN.
4. A list of resources and tips for communicating with first responders and medical personnel.
5. A symbolized children's story to teach students how to build an emergency kit.

I became involved with AAC-RERC's emergency preparedness initiatives in 2007 after learning that Dr. Sarah Blackstone, an AAC-RERC partner and president of Augmentative Communication Inc. was preparing a special issue of *Augmentative Communication News* that would focus on emergency preparedness. The publication explored disasters, AAC industry relief efforts, tips for communication, refugees' stories, and information regarding efforts of the United States government to address disaster relief issues for people with special needs. This resource is available at [http://www.augcominc.com/newsletters/index.cfm/newsletter\\_3.pdf](http://www.augcominc.com/newsletters/index.cfm/newsletter_3.pdf). When that was completed, Sarah Blackstone and I teamed up with Dr. David McNaughton from Pennsylvania State University to create a webcast entitled, "Disaster Preparedness for People with Complex Communication Needs" for the AAC-RERC website (available at <http://aac-lerc.psu.edu/index.php/webcasts/show/id/12>). The broadcast features the presentation I delivered in New Orleans in 2008 at a conference that addressed disaster relief issues for people with

CCN. In it, I shared my experiences as a refugee and highlighted seven steps anyone can take to insure his/her safety, and illustrated them using my own disaster plan. These include:

**1. Carrying a bag of essential items at all times.** Some people with CCN also have swallow disorders that require dietary modifications to minimize the risk of choking. I am one of them. As a result, I always wear a waterproof backpack that contains modified food, flavored liquids, and a special cup designed to address my issues regarding swallowing liquids. It also contains a printout of my medical information, dietary limitations, insurance cards, a small notebook, pens, emergency contacts, doctors, activities of daily living instructions, charged cell phone, inhalers, and pain medication. Carrying these items meets my needs and enables anyone—including first responders and medical professionals to learn quickly about my communication abilities, dietary needs, as well as my normal activities and accommodations. They can then perform any needed assessments quickly.

**2. Making an emergency kit.** I keep a Go-Bag in a closet near an exit. It includes a change of clothes, copies of communication interfaces, medication, medical supplies, animal carrier, and food and pet food in resealable, watertight containers. That way, if I ever need to be evacuated again, my family and I are as ready as we can be.

**3. Contacting the local emergency department.** When I move to a new area and emergency management doesn't have a registry, I call the police department and emergency responders. I let them know a person with physical disabilities and complex communication needs lives at my address.

**4. Creating a personal disaster plans that identifies and addresses hazards specific to each person and situation.** I've developed a disaster plan with my network of family and friends, so I don't have to rely on emergency responders to rescue me unless absolutely necessary. I am at risk because I currently live in Bismarck, North Dakota in a third floor apartment. Snowfall, road closures and fires pose a huge risk for me. To minimize all of these, I moved into an apartment that is literally right next to the fire station. The roads are cleared on my street before any others in the city. And, if there's a fire in my building, they can see it from the station. Everyone involved in my immediate care—those I live with, my emergency contacts, caseworkers and attendants—all know my communication techniques, unique medical and emergency protocols and the location of associated supplies and escape routes. When/if there is an emergency, a list of people who need to be called and things that need to be done so I can communicate in any new environment is available (e.g., pack my speech device with its cord in the case and bring my backup paper communication displays.)

**5. Being aware of potential disasters.** Because I have lived in multiple flood-prone regions, I have learned to monitor weather watches and warnings online.

**6. Having someone call during risky conditions.** When a watch or warning is issued, somebody calls me on a regular basis to see that I am safe.

**7. Being prepared to evacuate.** When flood watches or warnings are issued, I make every effort to be in my wheelchair and with someone who knows me.

The AAC-RERC recognized the need for downloadable ready-made communication boards with core vocabulary for emergencies. Therefore, Dr. Diane N. Bryen, professor emerita, Temple University coordinated groups of volunteers to develop *Communication 4 ALL*, symbolized sets of communication boards available in multiple languages. Bryen worked with adults with CCN and first responders in teams. They created and revised lists of words that they would need in the event of a disaster. Gradually, the teams reached consensus on a key set of vocabulary items. Bryen then created the communication boards. The sets are available in English, Spanish and Haitian Creole languages and downloadable from:

- <http://www.temple.edu/instituteondisabilities/aacvocabulary/e4all/EprepPictureAid.pdf> (English version),
- <http://www.temple.edu/instituteondisabilities/aacvocabulary/e4all/EprepPictureAidES.pdf> (Spanish version) and
- <http://www.temple.edu/instituteondisabilities/aacvocabulary/e4all/EprepPictureAidCREOLE02010.pdf> (Haitian Creole).

The AAC-RERC collaborators took a similar approach and developed three in-depth guides to address specific areas of concern for people who use AAC. The first, *"Emergency Communication for People Who Have Limited Speech"* provides a step-by-step guide for developing personal disaster plans with questions to help identify an individual's unique needs and hazards. The second, *"Emergency Communication for Emergency Response Personnel"* educates medical professionals about those who utilize alternative communication strategies and facilitates interaction. It contains a series of commands and questions for the communication partner to perform, such as, "Listen and watch carefully," and, "Show me how you say 'NO.'" The third guide encourages adults to advocate for emergency preparedness on behalf of those who have communication disabilities in their own communities. These resources are available on the web at <http://aac-lerc.psu.edu/index.php/pages/show/id/4>.

Finally, the AAC-RERC and I felt it was important to create resources that educate children about disaster readiness. As a result, I forged a partnership with Sarah Blackstone, Pat Ourand, former USSAAC President, Theresa Tanchak, Education Consultant at Region 4 Education Service Center in Houston, Texas and News-2-You, a publishing company that produces symbol-based publications for use in special education classrooms. Jacquie Clark and Allison Shumaker from News-2-You also enabled me to write, *"Billy Builds a Kit,"* a symbol-based story designed to teach the importance of emergency preparedness issues for people with CCN. It can be downloaded from <http://aac-lerc.psu.edu/index.php/files/serve/id/38> (English

text) and [http://aac-rerc.psu.edu/documents/billy\\_builds\\_a\\_kit\\_supported.pdf](http://aac-rerc.psu.edu/documents/billy_builds_a_kit_supported.pdf) (symbol supported text).

Preparing for emergencies and natural disasters is crucial for adults and children. Those who have difficulty communicating as a result of pre-existing disabilities are especially at risk because of the potential loss of familiar communication partners, communication displays, and speech-generating devices that require electricity. However, the risks can be minimized with forethought, planning, collaboration and teamwork.

Working with the staff and partners at Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC), the patient-provider communication Forum, United States Society for Augmentative and Alternative Communication (USSAAC), News-2-You, and the Pennsylvania State University, I have worked to develop multiple materials to address the need: a special edition newsletter that highlights the issue with a call to action, a webcast featuring my experiences as a refugee, ready-made communication pages, a list of resources and tips for communicating with first responders and medical personnel a symbolated children's story to teach students how to build an emergency kit. Communities need to educate people, build networks, and share information. People with complex communication needs need to use their speech technology and become advocates. Please check out these resources and do everything possible to prepare!