

• BY PATTI MURPHY

Emergency Communication: A Unique Work in Progress for Those with Disabilities

Clear communication in the best of human circumstances is often a work in progress, a goal yet to be attained. Efforts to make it happen in an emergency may be thwarted by the shock and distress of people involved or the need to get to a safe place fast. Unique complications may arise for people with limited, if any, natural speech and who are reliant on augmentative and alternative communication (AAC) tools and strategies as their voice. As many in the AAC and disability advocacy communities have learned through unfortunate events spanning the past decade, finding appropriate help in a catastrophic situation - or offering it - requires careful planning.

Significant gaps remain in community emergency preparedness for populations with special needs in the four years since Hurricane Katrina, according to an August 12th *Washington Times* article summarizing a report by the National Council on Disability to be released this year. Its message echoes that of “Saving Lives: Emergency Planning for People with Disabilities,” a similar report the council published in 2005 and based on post-9/11 research on the accessibility of emergency preparations across disability groups. “All too often in emergency situations the legitimate concerns of people with disabilities are overlooked or swept aside,” said the authors of that report, which focuses on matters such as local registries identifying people requiring special transportation

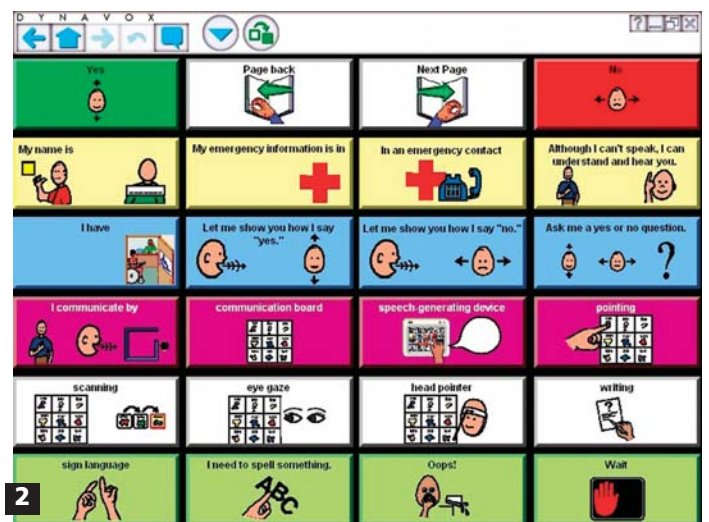
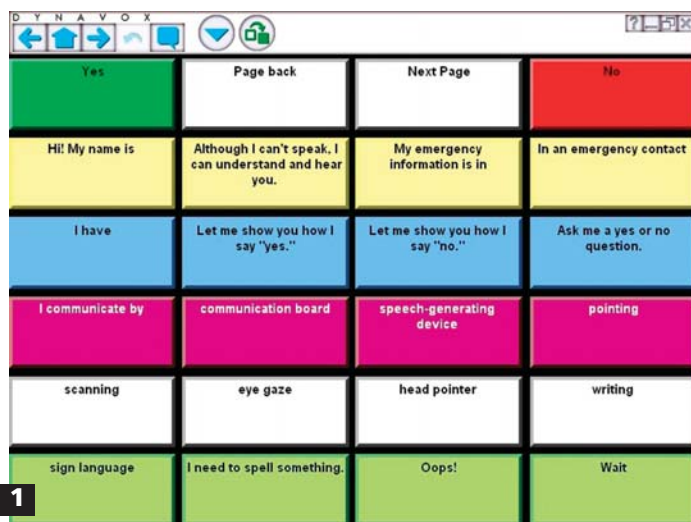
and evacuation assistance, alert systems for those with hearing or visual impairment, evacuation and relocation procedures, and mitigation of damaging effects. While there is no direct reference to AAC in the 2005 document, it cites the need to ensure that communication is possible during emergencies for individuals with speech, hearing or visual limitations. The *Times* article notes that the council, in its 2009 report, recommended improvements ensuring safe transport of assistive equipment and allocation of recovery funding for replacement of damaged equipment. For many individuals, that could mean an electronic speech communication device.

Finding a sound voice in chaos

Pam Kennedy, 37, who has such a device mounted on her wheelchair, remembers April 19, 1997 vividly. That night, the newly built dam in Grand Forks, North Dakota, where she lived at the time, broke in a ravishing flood. The community had hoped to avoid such an incident by constructing the dam and to avert disastrous consequences of anticipated flooding by putting an action plan in place.

Awakened at 2 a.m. by sirens, Kennedy, who cannot speak or walk due to the effects of cerebral palsy, wondered and worried for nine hours how she would reach safety. Then, in the late morning, her aide came. After helping Kennedy transfer to her wheelchair,

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People without the ability to speak must have a way to tell others how to communicate with them in emergencies, like these communication displays above that Pam Kennedy created. Text-based or symbol-based vocabulary may be used, depending on the literacy level of the conversation partners.

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they scrambled to gather Kennedy's service dog Jessie, medications, and laptop computer with text-to-speech software that served as her primary means of communication. She used it to create and print paper communication displays that allowed her to express herself more easily and fully than writing notes with paper and pencil a rescue worker gave her initially.

Kennedy, who now lives in Carrollton, Georgia, shared her experience at the "AAC and All That Jazz" conference held in New Orleans in 2008 as part of the post-Katrina restoration effort. Spearheaded by the United States Society for Augmentative and Alternative Communication, the event aimed to raise awareness of issues that people with complex communication needs must deal with when disaster hits and encourage development of proactive safety plans. In her presentation, Kennedy recounted her arrival in a National Guard truck at an emergency shelter set up in a special education classroom at a school.

"Until that moment, I didn't consider myself to be that disabled," Kennedy said using a DynaVox V speech communication device, the type she currently uses. "The waves of grief that washed over my soul seemed far more destructive than the flood waters around me. Suddenly, the possibility of losing my possessions didn't seem as painful anymore. The only thing I wanted was to be with my friends and family."

She took one of her shelter mates, a young man also lacking verbal communication abilities, under her wing, and made a symbol-based communication display for him because she saw that he could not read her text-based display. Pointing to the symbols, he conveyed that he felt sad and frightened because the flood badly damaged his home. Though his display did not include a symbol for "I'm sorry," Kennedy typed out the phrase and hoped he sensed empathy in the expression on her face.

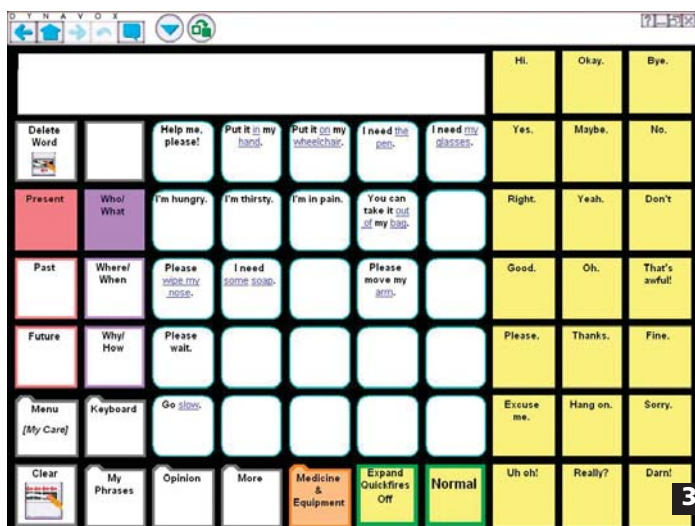
Fast forward to 2001, when Kennedy had a seizure and went by ambulance to a hospital emergency room in Carrollton, where she could not find an empathetic listener. Nor did she have the fanny pack containing her backup communication displays with her. Once coherent, she learned from the conversation around her that despite repeated attempts to express herself through gestures, staff thought she was probably deaf, perhaps mentally retarded. Fortunately, Kennedy said a friend who later called the hospital looking for her helped clarify the situation.

Experience serves as Kennedy's reminder always to keep the fanny pack (which also includes a charged cell phone, an inhaler, pain medication, medical information, insurance cards and other necessities for emergencies) handy.

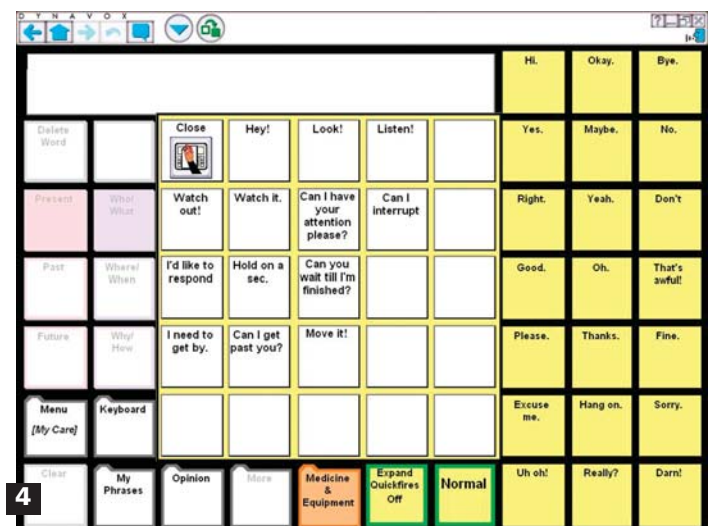
A similar "go bag" is one of three minimal requirements of a personal emergency plan for anybody with complex communication needs, says Meher Banajee, Ph.D, CCC-SLP, a speech-language pathologist and assistant professor in the communication disorders department at the Louisiana State University Health Sciences Center in New Orleans. Two others mentioned in a presentation she gave to the American Speech-Language-Hearing Association and the Rehabilitation Engineering and Assistive Technology Society of North America are contact information for support team members (at least three, if possible) and AAC tools. The latter includes laminated paper communication displays and written instructions for emergency response teams on how to communicate with the person at all times.

Acknowledging that Katrina has prompted increased vigilance, Banajee said it is wise for individuals with complex communication needs to have a plan A, B, and C ready for emergencies. Given that disasters tend to unfold at a rapid pace and leave people scattered in various directions, depending on one strategy or person for help may be unwise.

"If there's any way you can look after yourself, you need to do



Speech communication technology is helpful in an emergency, putting age-appropriate vocabulary within easy reach for those who cannot speak.



The InterAACt language framework of the Xpress and other DynaVox devices, for example, has capabilities for adapting words and phrases to virtually any situation instantaneously. Sample vocabulary is shown above.



Pam Kennedy and her service dog Jessie stuck together during the flood of 1997 in Grand Forks, North Dakota, strengthening their bond of trust.

that,” she said. “If your caregiver doesn’t show up, then what?”

Banajee said she and colleagues on the “All That Jazz” organizing committee have found that Katrina has highlighted the value of electronic speech communication devices in emergencies and motivated more people to consider acquiring one. Yet that does not minimize the consensus in the AAC community that good solutions require more than a single piece of technology, however urgent the need to communicate.

What to say and how to say it

Encountering someone using AAC in an emergency situation is no different than being with someone speaking a foreign language, said Robyn Landau, M.S., CCC-SLP, a speech-language pathologist at the Shield Institute, a day rehabilitation program for adults with developmental disabilities and mental retardation who live in the New York City metropolitan area. If you wonder what they’re thinking, or how you can help them, what you see can be as telling as anything you might hear.

“It’s usually written all over their face,” Landau said. “Facial expressions are universal.” Time constraints imposed by an emergency, she said, need not diminish sensitivity. It is important to communicate directly with the person with the disability as quickly as possible instead of through a third party.

New ways of thinking about emergency preparedness and its entwinement with communication have evolved since 9/11, Landau said, “unfortunately or fortunately. I’m not sure which.”

Soon after, she and clients who use AAC technology began putting extra thought into programming their devices with vocabulary for unexpected occurrences in their lives as well as to help them vent concerns relevant to the World Trade Center terrorist attacks. “I added what happened that day to everyone’s device to allow everyone to talk about it, because that was all everybody talking about,” she said. New single-word vocabulary included the names of New York City Mayor

Rudy Giuliani, President George W. Bush, hijackers, memorial service, war, TV, and newspapers. The sentences “Airplane flew into buildings,” “Twin towers fell down,” and “Many people died and were hurt” provided a way to recap the sequence of events.

One woman expressed relief that her brother, who worked in one of the towers, was not there during the attacks because he went to get breakfast. She told her story using verbal approximations and symbol buttons already programmed on the dynamic touch screen of her DynaVox DynaMyte 3100 device, including one for his name. Landau encouraged her use of both methods. “She couldn’t stop smiling and kept saying, ‘He OK.’”

Later, she joined other consumers in expanding the 9/11 vocabulary on their devices with words such as fire, accident, bus, and car, and referred to it to discuss an electrical fire at the Shield and other emergencies they experienced or witnessed. The Northeast Blackout of 2003 reminded them to keep low-tech communication tools within reach in case a device cannot be charged. Coping without such tools is usually not an issue, thanks in part to a standard Shield practice Landau described. “Nobody would get a device without having a manual communication book first.”

Kennedy recommends white lettering and symbols on a black background to promote good visibility, particularly for communication partners who are not familiar with manual displays. She has a separate display with vocabulary pertinent to Jessie, the golden retriever that assists her.

Everyday influences

Mobility and living arrangements influence the interdependence of AAC use and routine personal safety. Sometimes it is more efficient for a person who is ambulatory to walk across a room and tug on someone’s shirt than to loudly utter a cry for help through an AAC device, said Kim Ingram, M.Ed. CCC-SLP, a speech-language pathologist at Austin State Supported Living Center, where residents are usually accompanied by staff. Voice-output technology may be most helpful at night or in private moments. “If a fire started in the room and you had no way to tell anyone, it could be a problem,” she said.

Preprogrammed messages for emergency purposes benefit not just the person using the device. “My biggest concern is that something would happen to the spouse and the patient would not have a way to contact emergency services,” said Meredith Sullivan, MBA, MS, CCC-SLP, whose patients in the speech-language pathology department she manages at Bay Health Medical Center in Dover, Delaware are generally elderly. One advantage of devices such as the new DynaVox Xpress, she said, is that that text and graphics on its screen of the pocket-sized device are easy to read, complementing its clear speech-output and supplying tools needed to create a succinct call for help.

A woman with another DynaVox device felt more secure, for example, because of a message for placing 911 calls when her husband was at work. It simply said, “This is an emergency. This is not a prank call. Please help me.” •

Patti Murphy writes for DynaVox Mayer-Johnson.