

Upfront



On August 29, 2005, a Category 5 hurricane approached the Gulf Coast of the United States clocking winds up to 185 mph. Too few heeded the evacuation alert, and many found they were unable to leave. When hurricane Katrina blasted ashore, it left behind a devastating storm surge in Mississippi and levee breaks in New Orleans. Because local, state and federal agencies were overwhelmed, underprepared, and in some cases, poorly led, that natural disaster became a complex humanitarian emergency (CHE).

The world watched, horrified. People with disabilities, elders and medically fragile individuals were left behind, overlooked and mistreated. In fact, individuals with mobility, sensory, cognitive, psychiatric, language and speech impairments, the very young, the elderly and those with medical conditions have always suffered enormously during natural and human-imposed disasters, waiting to be evacuated or rescued, not hearing alerts, not able to call for help, unable to move, separated from caregivers or simply ignored or forgotten.

This issue of *ACN* is a call to action. The needs of people who rely on AAC are NOT being considered in the best of disaster preparedness plans. Anywhere! Just call your local emergency preparedness agency. Ask them, "Do you have a plan or protocol for people who are unable to speak so others can understand

them? for people who rely on augmentative and alternative communication (AAC)?" The right answer is not "Huh?"

Then, go to the next important step. Ask yourself, "Do I have a plan?" "Do the people I care about have a plan?" Odds are that you, like me, care about a substantial number of people who rely on AAC.

No one likes to think about CHEs. No one expects to be involved in one, but everyone should be prepared. Encourage yourself, your family and others to prepare.

A call to action

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Complex Humanitarian Emergencies (CHEs)



World disasters and humanitarian emergencies: Unheard voices with Anne Warrick

In today's world, global communication can inform us within hours of disasters and the humanitarian emergencies that arise thereafter. The Internet, television and radio report each unfortunate event, showing us pictures of devastation and human suffering. These immediate reports are followed by day-to-day descriptions of relief operations, rescue missions, the efforts and amazing resilience of people who have been affected by earthquakes, war, floods, draughts,

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bombs, shootings, hurricanes, fires, industrial accidents and so on.

We hear worldwide outpourings of sympathy and support. Then, the

media move on to other topics, taking away the world's attention just as the long-term recovery process begins.

Complex humanitarian emergencies (CHE) usually involve a cross section of the population: men, women and children across the age span, both able-bodied people and those with disabilities. Sometimes people are given warning, which can lessen the impact in a disaster. When warnings are late, absent or unheeded, however, or when the CHE becomes chronic, the casualties can be enormous.

While no one can be truly

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prepared for the consequences of human-induced or natural disasters or CHEs, some individuals, communities, regions and nations do acknowledge their unique vulnerabilities and understand that emergencies will happen. While some countries have resources to support disaster preparedness, rescue, relief and recovery, others have none, and international help is requested. But all individuals and community-based entities, whether corporate, faith-based, governmental, non-profit, *etc.* can plan and prepare.

Communication is key

It is well documented and understood by the United Nations, the World Health Organization and agencies at all levels of government that everyone has a right to communicate. Less well documented and lacking in specifics by organizations worldwide, however, is an understanding that ‘everyone’

includes people with disabilities. While accommodations and plans for CHEs may exist for people with motor, hearing, vision impairments and medical issues, it is rare to find information about accommodations for people whose speech is severely impaired and who rely on manual signs, gestures, communication displays, books, speech generating devices, *etc.*—known as AAC—during CHEs. This is true despite widespread recognition that communication is a basic human right and elemental for survival.

Rescue and relief workers understand that good communication is essential in CHEs. Also, laws in some countries, *e.g.*, the United States, require that the needs of ALL people, including those with disabilities, be addressed. This includes people who rely on AAC.

A vulnerable group

People with complex communication needs (CCN) are among the

most vulnerable individuals. They experience discrimination and are at high risk for abuse—physical, emotional and sexual—in everyday situations and in CHEs, no matter where they live. Catriona Gunn, the director of the Communication Project Group based in South Australia, has worked with people in many CHE situations. She reports:

- Workers in relief organizations may believe that individuals with CCN are unable to accurately answer questions relating to their physical, emotional and intellectual condition; so they do not ask.
- Workers may turn people with CCN away or ignore even their basic needs because they are unable to understand them.
- Workers may assume that all disabilities are a result of the immediate disaster and require hospitalization.
- Workers may separate people with CCN from family members and others they rely on to communicate.¹

Preparation and training for workers

Rescue and relief workers and medical personnel face enormous challenges. It is essential they get the training and guidance they need to do their jobs effectively and efficiently. This includes anticipating and solving communication problems. Captain Bruce Cleveland, a Clinical Military Social Worker deployed to Sri Lanka after the 2005 Asian tsunami with the Canadian Forces Disaster Assistance Response Team (DART), writes of his team’s preparation for their relief and rescue mission:

Immediately upon the arrival of our advance team, the process of identifying competent translators and interpreters began for the various elements of our team to use—this was key to our impending work. In some cases, the government of Sri Lanka was able to assist in identifying these persons.

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I recently attended a conference on Emergency Preparedness and People with Disabilities in Washington, D.C. [See **Governmental.**] Only one speaker mentioned people with severe speech impairments. No one used the term augmentative and alternative communication (AAC). The AAC community needs to change this.

USSAAC’s Gulf Coast relief project

In September, 2005, USSAAC began working with Meher Banajee, an AAC professional from New Orleans, to support people who rely on AAC who were affected by that year’s hurricane season. In February, 2008, USSAAC will host an AAC emergency preparedness meeting and the AAC and

All That Jazz Conference in New Orleans. These events are aimed at rebuilding AAC capacity along the Gulf Coast and drawing attention to AAC issues in CHE at the local, regional, national and international levels.

What can you do? Find out whether emergency preparedness plans and policies in your community consider the needs of people who rely on AAC. If not, do something to make that happen. This issue can help you. Finally—be safe.

*Sarah W. Blackstone, Ph.D.,
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Due to the language barriers, however, the decision was made not to attempt to engage in one-on-one therapeutic counseling since many of the nuances of the different local dialects and languages could be missed or lost in translation. However, I did many psycho-educational presentations to groups (via interpreter) relating to grief, loss, physiological and emotional responses to stress. I also took one of our publications on the subject of responding to critical incidents and had that translated into Tamil and Sinhalese.²

Trainers need to provide access to good information, tools and other resources, like simple and inexpensive communication displays, explanations and demonstrations about how to use these tools and how to support people with CCN, including those who rely on AAC. For example,

1. Generic communication displays. Generic communication displays are used in hospitals, emergency rooms and ambulances, as well as in war zones and CHEs. To see examples designed for use in Afghanistan, Iraq, hospitals, etc., go to www.kwikpoint.com. See also a generic display being used in hospitals, ambulances and as part of emergency preparedness at www.eadasociates.com.

Workers in CHEs need to know how to communicate with anyone they encounter. This includes people who have difficulty communicating because of trauma, illness, severe pain, cognitive limitations, psychiatric problems, their age, as well as because of confusion or language/dialectical differences. Workers also need to know how to communicate with people with severe speech/language impairments who rely on AAC. For them, communication displays with pictures, words, letters and icons make communication possible. These tools and strategies decrease frustration and increase the efficiency and effectiveness of information exchange. Frontline workers have neither the materials, the ability, nor the time to create these displays.

2. Personal communication displays and speech generating devices (SGDs). Emergency personnel and relief workers need to know that some people always rely on communication boards or books with symbols, words or pictures, letter boards or speech generating

devices (SGDs). Many also use gestures, writing, manual signs and their impaired speech. Just as canes, guide dogs, hearing aids, wheelchairs and medications should not be left behind, AAC tools and strategies should remain with these individuals.

3. Yes/no responses. Rescue and relief workers should know (1) how to ask “yes” “no” questions so individuals can easily respond, (2) how to teach someone with CCN to use a “yes” “no” signal and (3) how to provide an alternate response option (e.g., I don’t know; Do over; I don’t understand.)

4. Gestures and impaired speech. Many people rely on gestures and impaired speech with their family and familiar communication partners. This includes almost all small children and some people with dementia, autism, Down syndrome, verbal apraxia, multiple sclerosis, aphasia and amyotrophic lateral sclerosis. It is essential that these individuals not be separated from those who can understand them.

Nancy Christie, past Executive Director of the International Society for Augmentative and Alternative Communication (ISAAC), noted:

People with complex communication needs—in the ISAAC sense—rely on family and friends to communicate. Often simple signing is developed within the family. If those close to them are lost, their communication system is lost. They have to rely on the kindness and patience of someone new to attempt to understand their needs—often unavailable in a crisis.³

Curb cuts to effective communication

Many people without mobility impairments use curb cuts to cross the street. Communication displays can serve as “curb cuts” to more efficient and effective communication during CHE situations. Graphic displays offer avenues to communication for people who speak different languages, as well as to those with psychiatric disorders, cognitive issues and speech and language impairments. These simple tools can save lives and decrease frustration. They can also increase the efficiency

of workers who are trying to help survivors. Generic communication boards/displays with appropriate vocabulary can increase the safety and well-being of many—including people who rely on AAC.

In some areas, relief workers have developed an awareness of AAC strategies and how they can solve communication difficulties. In Israel, for example, Judy Seligman-Wine explained that during the first Gulf War, AAC strategies enabled some children to talk about their experiences:

Because children had vocabulary depicted by words, hand-drawn pictures, pictures from newspapers to express their feelings and experiences, several returned to school, after being at home for a month, with poignant stories to share.⁴

Michal Nir, another AAC Consultant in Israel, said that during the second Gulf war, he received numerous and urgent requests about vocabulary from staff at various facilities. He was able to provide help using email and the telephone.⁴

Making a difference

As a community, we have a responsibility to make the efficacy and applicability of AAC known widely. We need to:

1. Raise awareness about the needs of people who rely on AAC in potential CHE situations in local communities.
2. Make sure the needs of people who rely on AAC are considered and addressed in disaster preparation planning, in trainings and during drills.
3. Encourage people who rely on AAC to be involved actively in disaster planning and training activities and to participate in drills.
4. Encourage people who rely on AAC, their family members and others who care about them to prepare a Go-Bag and create a network of support in case of a CHE. [See next article.]
5. Help people to “self identify” with emergency preparedness personnel and registries in their area. 

Perspective: Person with CCN



Next time, I'll be ready with Pamela Kennedy

In nearly everyone's life, pivotal moments can cause one to re-examine past decisions, take action and alter course. April 19, 1997 was one such time for Pamela Kennedy. Today, she is involved in USSAAC's Gulf Recovery Initiative and serves on the *All That Jazz* planning committee. This is her story.

Almost everyone living in the Red River region knew Grand Forks, North Dakota was going to flood. In February, the city began building a dike, developing action plans and fostering community disaster networks. I served on planning committees and was well known by emergency management personnel and our mayor, Pat Owens. I thought that where I lived was safe, so I didn't personally prepare. As a result, I suffered.

The dike was breached on April 19, 1997 at about 2:00 a.m. When the sirens awoke me, I was terrified because no one was there to get me up. As a result, I was stuck in bed until 10:00 the next morning when my personal assistant came via boat. We barely had enough time to get me in my wheelchair, grab my medications, my computer with text-to-speech software and Jessie, my golden retriever assistance dog, before the National Guard arrived in a truck. Because my vital evacuation information was in the Special Needs Registry, the rescue team knew about Jessie and me even though we'd never met. Thankfully, my personal assistant told them I could communicate by writing, indicate "yes" and "no" by traditional means and use text-to-speech software, manual signs and gestures.

When we left my home, the water was more than four feet deep.

I was horrified as we maneuvered through the flooded streets. My anxiety increased exponentially when I was told I couldn't be evacuated to the same shelter as my friends and family because of my complex communication needs. Someone enlightened me:

We set up a makeshift nursing home at the army base's elementary school in the special education room. It's too noisy for us to put people with speech impairments anywhere else. Besides, we don't want to separate you from Jessie.

Until that moment, I hadn't considered myself to be disabled. The waves of grief that washed over my soul seemed far more destructive than the flood waters around me. Suddenly, losing my possessions didn't seem so painful. I wanted only one thing—to be with my friends and family.

The shelter

When we got to the shelter, I was whisked away to the tiny special education classroom. A soldier explained:

I know it's cramped, but unfortunately you and Jessie will have to share it with one other person like yourself. We hope to get a cot in here so you two can take turns sleeping. We're sharing the generators with other shelters to conserve electricity. We'll work out a schedule to plug in your laptop, but you won't be able to use your computer voice during peak hours. Did you bring anything else to communicate with, like a notebook or board?

I slowly shook my head no.

I'll see if we can find something for you to write with. Until then, can you and Jess hang tight?

I nodded.

Being segregated from my friends and family magnified my sense of loss and helplessness. Yet, I forced myself to remember I wasn't trapped anymore. After all,



Pamela Kennedy

I could send Jessie for someone if I needed help.

Within the next three hours, another refugee joined me. A cot was brought to us. I now had a legal pad and pen which I could use to communicate with the soldiers. I wrote, "Thank you for rescuing me and bringing me the legal pad!"

The soldier replied, "You're welcome. Do you think you'll be able to sleep on the cot?"

I sighed and wrote, "No, it's too low to the ground. I can't transfer to it. I'll have to recline in my wheelchair."

He answered, "Well, at least you'll be able to eat some of the lovely school cafeteria food."

I smiled and nodded. He was trying to cheer me up, so I didn't mention that I had a swallowing disorder and could tolerate only soft, mushy foods.

Talking to my bunkmate was difficult without my computer because he couldn't understand my signs and gestures or read my notes. I wished I had grabbed some paper communication boards with symbols. This would have enabled me to communicate more easily with him and saved my shrinking supply of paper.

The hours were very lonely. I felt naked and vulnerable without my speech software and paper communication boards because these interfaces are an extension of my body. I longed for those visual representa-

tions of myself because I wanted to feel intact.

A friend

Sometime that evening, there was a knock on the door. “Hello, it’s Mayor Pat. May I come in to see you?” The door opened and a look of shock registered on her face. “Pam and Jessie! What are you guys doing in here?” She turned to the soldier at her side:

Major, we need to put this girl to work! She doesn’t need to be shut up in here all the time. We need another person to help maintain the registry on the night shift. She can type, and it will get her out of here for a few hours.

I worked in the office at night keeping data on evacuees so our families could find us. Those were also the hours I was allowed to plug in my laptop. During the day, I had to go back to the special education room. In those hours, I slept and created paper boards so I could communicate with my bunkmate. We were there only four days before people in Mandan and Bismarck took us in temporarily. To me, however, it seemed like a lifetime, because I wasn’t able to get out of my wheelchair at all.

Lessons learned

As a result of that experience, I’ve taken measures to prevent being unprepared for an emergency:

1. I always wear a waterproof fanny pack that contains a printout of my medical information, insurance cards, paper communication boards, accommodations requirements, emergency contacts, doctors, activities of daily living instructions, charged cell phone, inhalers and pain medication.
2. I keep a Go-Bag in a closet near an exit. It includes a change of clothes, copies of communication interfaces, medication, medical supplies, food and dog food in resealable, watertight containers. That way, if I ever need to be evacuated again, we are as ready as we can be.

3. 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 complex communication needs lives at my address.

4. I’ve developed a personal 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.

5. Because I have lived in multiple flood-prone regions, I have learned to monitor weather watches and warnings online.

6. When a watch or warning is issued, somebody calls me to see that I’m OK.

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

Hopefully, I’ll never have to execute my evacuation plan. Meanwhile, I take comfort in knowing that I have made every effort to prepare. While in that refugee shelter, I promised myself that I would do whatever I could to help other people with CCN who are displaced by a disaster. Today I’ve rolled up my sleeves and am working on USAAC’s Gulf Relief project. 

been on duty since the storm hit and has only been able to get through to me a few times. He is a strong man, but he just sobs every time he calls. The police department is flooded; their generators are destroyed; there is no phone service with the exception of intermittent cell phone service. People were calling for help and the rescuers could not get to them.

We have temporary shelter, but I can’t take the boys to just any place.

One month later, she and the children were still looking for housing. She wrote:

Hi. My name is Susan Cunningham. I found your email address on a site that FEMA directed me to. Our home was flooded by Katrina’s storm surge. Though it still stands, there are times when I wish that it did not. Dealing with how to repair it and make it safe for our six children, all adopted and three with special needs, is just overwhelming.

Our most immediate need is temporary housing. We are staying with relatives. Our six-year-old son, Ron, has cerebral palsy and is dependent on a wheelchair for mobility. We desperately need an accessible home to rent for several months in order to properly care for our children. We need a place where we can have temporary ramps, hospital beds, etc.

A week later, she tried again:

I know everyone has difficulties, but caring for six children under these conditions, two with multiple medical needs and one

in a wheelchair, is more difficult than can be described. Surely there is help available. How do we find it? I talked to a FEMA community relations liaison here on the Coast yesterday. She said it would probably be two months before we got any type of housing.

This time she got a response from a FEMA representative:

Dear Susan, As of today, there are over two hundred, three-person teams of installers working twelve hours a day, seven days a week, to get people into travel trailers and mobile homes. It is estimated we have 35,000 to 45,000 families who need housing.

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Perspective: Family



A Gulf family’s Odyssey with Susan Cunningham

When hurricane Katrina demolished their home in 2005, Susan Cunningham and her husband had six adopted children, three with disabilities. Ron, who was six at the time, has cerebral palsy and had just gotten his first speech generating device (SGD). Susan shares some of her email from that time and some recent reflections.

On September 1, Susan sent the following email to a case worker:

Our entire town is devastated. We have sustained substantial damage to our home and its contents due to the 25 foot storm surge. I have evacuated to Pensacola, Florida with my six children. My husband is a police officer on the coast and could not leave. He has

Perspective: Family, Cont. from page 5

Conservatively, it is estimated that 15 to 20 percent of that total need ADA accessible housing. That's between 5,000 and 9,000 families. For families not on a priority list, perhaps 35,000 or more, the wait could be measured in months, rather than days or weeks...and that's just in Mississippi. Please know everyone here in FEMA and MEMA is doing all they can.

Susan's family finally moved into temporary housing almost three months after the storm. Ultimately, they did rebuild their home.

Today, the Cunninghams have nine children. To accommodate their growing family, they have moved to a larger home farther away from the coast. Susan reflects:

The biggest lesson I learned was that we must be tenacious in our search for help and information. I now have a list of agencies, organizations and individual people who can help in the event of a disaster. I continue to work on our evacuation plan. It is difficult to find the space to take all of the things that my children need because we have so much equipment.

When Katrina hit, I was so worried about Ron's device getting damaged or stolen, I didn't take it with us. Luckily, it survived. Now, I have a box I pack it in whenever we travel. The mount and switch for his device also can go with him, attached to his wheelchair. Both were destroyed in the storm and US-SAAC replaced them in 2005.

We always take Ron and our other children's communication needs into account when we consider evacuation destinations. We have lots of low-tech displays. Sadly, there aren't many people with the knowledge or initiative to communicate with my boys unless I'm there to "prod" them along nicely. This is true even in the medical community. Ron can't verbalize, but he understands everything that is said around him. I have to constantly remind people of that.

Susan concludes:

I don't think we will ever find the 'before Katrina' normal, but that's okay. We are stronger, more prepared people. We will move forward and impact our world positively.



Perspective: Educator



Rebuilding an infrastructure with Tim Morse

When hurricane Katrina devastated the Gulf Coast of Mississippi, Tim Morse was an Assistant Director of Special Education in the Harrison County School District, one of the state's largest school districts.

The process of reopening the schools was more complicated than one might expect. Administrators understood that parents needed their children to be in school during the day so they could begin to rebuild their homes and lives. They also had to make sure buildings were safe and that professional and support staff were available to work.

School districts faced a loss of personnel, damage to schools and enrollment issues after the hurricane, as they scrambled to reopen and serve the needs of children and families. Dr. Morse reflects:

Initially, we had no way to know the status of our school district's special education teachers and related services personnel. While the Director of Special Education did her best to contact everybody shortly after the storm, we simply did not know each person's status. As it turned out, some special education teachers, instructional assistants and related services personnel left the area immediately and didn't return. Their homes were destroyed, and they had better support networks elsewhere.

We had a serious personnel shortage that lasted about one year. In addition to fewer staff, we had few substitutes. Our primary source of substitute teachers and instructional assistants was a local company that typically had hundreds of people available on a daily basis. Their numbers had dwindled to less than 30.

From a managerial standpoint, we had to balance our employees' work obligations with their need to attend to personal recovery efforts. Initially, we instituted a very liberal leave policy so staff could take off for an hour or

two during the day to deal with insurance and related matters. We also tried to cover classrooms so teachers could attend to personal matters *via* the telephone. Even so, given the extent of the personal and property loss many had experienced, a number of staff ended up taking personal leave to deal with their problems. This further compounded and complicated our severe personnel shortages.

Fortunately, we were not hardest hit and most of our schools came through the storm without receiving significant damage. We did lose one school completely along with its records, some of which had no electronic backups, so we had to create new records for some students. We also had significant damage to two self-contained special education classrooms where several students who rely on AAC were enrolled. Fortunately for us, volunteer agencies from outside the area adopted these classrooms and worked with our teachers to provide support and materials.

Opening the schools

No one really knew which students would return and what to expect when the schools reopened. Local districts instituted an open enrollment policy, which enabled families affected by the storm to enroll their children wherever it was most convenient. District administrators speculated about where students might enroll and what impact this would have on our district's ability to employ personnel. The early days were a scramble:

One school district took the lead and announced they would start classes five weeks after the storm; other districts quickly announced similar re-start dates. Our district was one of the first to reopen. About 80 percent of our students returned on the first day of class. While we had developed clearly defined criteria to determine appropriate placements for all returning special education students, that plan quickly unraveled as we accepted—almost at a moment's notice—new students who enrolled. We were constantly reconfiguring our classrooms to best meet student needs.



Many buildings were destroyed along Mississippi's inland coastline. Hundreds were killed, more than a hundred thousand were left homeless and more than one million were affected. Aerial shot from <http://www.photosfromkatrina.com/>

The intense emotional angst of our returning students, staff and administrators was palpable. I distinctly remember my first day back to work, five weeks after the storm: Looking around the room, I observed that quite a number of my colleagues looked five years older. On the other hand, I was amazed at the ability of people to come together and overcome difficult circumstances.

The recovery process

Hurricane Katrina devastated the Mississippi Gulf region in a matter of hours, but recovery and rebuilding is ongoing still. Dealing with state and federal disaster support programs, like Federal Emergency Management Agency (FEMA), can be both challenging and frustrating.

While struggling to get back to our pre-storm routines, school administrators and teachers were dealing with FEMA, which proved to be especially difficult because of government red tape and our lack of experience with this agency. For example, we expended a great deal of time and effort (that could have been used more appropriately) putting together lists for FEMA of materials our teachers needed to educate our students. In the end, this did not result in any of the monies we had expected.

Looking ahead

Rebuilding and recovering after a disaster can offer an opportunity to share lessons learned with others. Dr. Morse has several suggestions:

1. Develop an emergency preparedness plan. If evacuation is necessary, every-

one needs to know where to go.

2. Develop a solid local AAC infrastructure. It is much easier to repair or even rebuild an infrastructure that was in place than to try to start something new after a disaster.

3. Prepare documentation. Make sure there is a clear description of how each student communicates. Ideally, disaster and relief-related vocabulary should be available on communication displays.

4. Reach out. Encourage families to prepare and provide them with guid-

ance about Go-Bags, networking, self-identifying registries, and so on.

5. Network! Immediately following an emergency, you need trusted friends and colleagues to help you in the recovery phase.

6. Avoid profiteers. Beware. Not all offers of help are well intentioned. Contacts that are made through reputable organizations, such as USSAAC, will prove to be invaluable during the disaster recovery phase.

7. Build-in redundancies. For instance, within a school make sure that most teachers and administrators know something about AAC. Then, someone can carry on.

According to Dr. Morse, there were some 'silver linings':

In some situations where entire schools or classrooms were destroyed, the replacement modules are actually much nicer than the classrooms that existed prior to the storm. Also, a neighboring district, which literally was almost wiped off the face of this earth by the storm, recently received \$1 million from a major U.S. corporation to establish a preschool program. 

Governmental



Some "need to knows"

On January 8-9, 2008, a *Disability and Special Needs Technical Assistance Conference—Emergency preparedness, response and recovery* was held in Washington, D.C., hosted by the National Organization on Disability's Emergency Preparedness Initiative [www.nod.gov]. This event brought together speakers and attendees from multiple federal, state and local agencies, practitioners, policy makers, first responders, vendors, 'first-timers' and experts.

Some topics were aimed at helping participants advocate for people

with disabilities. Other speakers discussed the complexity of emergency preparedness, rescue, relief and long-term recovery issues,

highlighting logistical, financial, organizational and political issues. Presentations about laws and public policies that mandate planning for people with disabilities were particularly helpful.^{5,6} Another important topic area was the importance of building strength and cooperation within our communities through the involvement of people with disabilities at every level. Many pointed out that unless the disability community participates, their needs are not likely to be understood or met. [See Table I. on page 8 for additional information.] 

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Table I. CHE related information for the AAC community

<p>1. Emergency preparedness, rescue, relief and recovery is a very complex area. It involves preparation, notification, evacuation and transportation, sheltering, first aid and medical services, temporary lodging and housing, transition back to the community, clean up, incident management, emotional and counseling needs, and so on.</p>	<p>6. First responders, relief workers, medical personnel and counselors may not be trained to anticipate and accommodate the needs of people with disabilities. Trainings for workers should include strategies for working with people who have CCNs and who rely on AAC techniques, aids and devices.</p>
<p>2. Plans and procedures are disaster specific—floods, hurricanes, droughts, tornados/downbursts, earthquakes, fire, severe weather (heat and cold), hazardous materials incidents, terrorist attacks, war, etc. A good resource is the <i>Emergency Readiness Wheel for People with Disabilities</i>. Go to www.eadassociates.com.</p>	<p>7. Many regions now have special-needs* registries. Registries identify the location of individuals who require assistance and the types of assistance they may require. All information is private and protected. *The term "special needs" was challenged because 25% of the population typically require 'special' accommodations during CHEs.</p>
<p>3. The communication needs of people who rely on AAC are often not acknowledged, considered or addressed. Lists of auxiliary aids and services rarely mention communication boards/displays, communication books or speech generating devices (SGDs). Even so, they do include sign language interpreters, use of video relay service, teletypewriters (TTYs), pen and paper to facilitate exchange of notes, message boards, written materials in Braille, large print, and people to assist in reading and filling out forms. [Shouldn't it be easy to change this?]</p>	<p>8. ADA Guidelines are available for sheltering. Some guidelines are specific for particular types of disabilities. The unique needs of people who rely on AAC (e.g., communication displays/books, speech generating devices or familiar communication partners) are not noted at this time. These guidelines do address important issues related to inclusion, integration, self-determination, equal access and physical access.</p>
<p>4. Communication, networking and coordination among agencies, entities and individuals are key to success but very challenging to accomplish.</p>	<p>9. People with disabilities are often not involved in emergency planning, preparation and training exercises or drills. They should be. So should their aides, personal assistants and/or family members.</p>
<p>5. U.S. laws require that the needs of ALL people with disabilities be addressed in disasters.⁵ (1) Executive Order 13347, signed by President Bush in July 2004. (2) Titles I, II and III of the Americans with Disabilities Act (ADA). See ADA guide for state and local governments at www.ada.gov/emergencyprepguide.htm (3) Section 504 of the 1973 Rehabilitation Act</p>	<p>10. Personal and community networks are key components of emergency preparedness, relief and long-term recovery. Centers for independent living, faith-based groups, non-profit agencies, etc., play critical roles. People who rely on AAC and their supporters should work with these local groups to make sure individuals who rely on AAC are safe and their needs are being considered.</p>

Resources

A sincere and hearty thanks to my co-authors and to others cited in this issue for sharing their experiences, expertise and research skills. All share a strong commitment to changing the way things are in emergency preparedness for people with disabilities who rely on AAC. All hope others will also see this unmet need and move this agenda forward. *SB*

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