

AAC-RERC Webcast Series
**Disaster Preparedness for Persons with Complex Communication Needs:
A Personal Perspective**

Pamela Kennedy

Slide 1: The AAC RERC Webcast Series

Slide 2: New Orleans, 2005

In 2005, Hurricane Katrina brought massive flooding to the Gulf Region. Many lives were lost, and many communities destroyed.

The impact of this disaster was felt acutely by people throughout the Gulf region, however the consequences were especially severe for individuals with disabilities, including those with complex communication needs. Being unable to communicate during a disaster is life threatening. This catastrophe reminds us that any emergency situation, whether it be a flood, a fire, an earthquake, a tornado, ice-storm or the loss of electrical power, puts people with complex communication needs at risk. In many cases it can threaten their ability to survive. To avoid a catastrophe, you need to prepare in advance.

Slide 3: Disaster Preparedness for Persons with Complex Communication Needs: A Personal Perspective

Pamela Kennedy, is an individual with complex communication needs who uses augmentative and alternative communication to interact with others. She served on the USSAAC planning committee for “AAC and All that Jazz”, attended that conference, and the first ever Emergency Planning meeting of professionals, people who rely on AAC, and Emergency Preparedness personnel in New Orleans in February 2008. This webcast is taken from her presentations to Emergency Preparedness personnel, AAC practitioners, manufacturers, and administrators.

Slide 4: Pamela Kennedy Introduction

Good morning ladies and gentleman. Mere words cannot possibly express how honored I feel to begin our conversation concerning emergency preparedness and disaster relief issues specifically related to people with complex communication needs.

Slide 5: Pamela Kennedy

I'm Pamela Kennedy, a very active member of the augmentative and alternative communication field and community. I work for the Rehabilitation Engineering Research Center on Communication Enhancement as a participant of the Writers Brigade project.

Slide 6: USSAAC

I'm a member of the United States Society for Augmentative and Alternative Communication, commonly called USSAAC.

Slide 7: Video

To get our discussion started, please allow me to relate my own experience as a refugee. In nearly everyone's life, there are pivotal moments that causes one to re-examine decisions, take

action and alter the course of his or her life. April 19, 1997 happens to be one of those moments in my life.

Slide 8: Preparation

Almost everyone living in the Red River region knew Grand Forks, North Dakota was going to flood at least two full months in advance, myself included. Therefore the city began building a dike and developing action plans and community networks before disaster struck.

Slide 9: Committees

I served on some planning committees and was well known by Emergency Management and Pat Owens, the mayor. However, I thought the area in which I lived was safe. Therefore, I didn't prepare. As a result, I suffered.

Slide 10: The Dike Breaks

The dike was breached on April 19, 1997 in the middle of the night about 2:00 a.m. When the sirens awoke me, I was terrified because there wasn't anyone there who could get me up. As a result, I was stuck in bed until 10:00 or 11:00 that morning until my aide came via boat with the National Guard in a truck 15 minutes behind her. We barely had enough time to get me in my chair, grab my medication, computer with text-to-speech software...

Slide 11: Jessie

...and Golden Retriever Assistance Dog, Jessie before the Guard arrived.

Because my vital evacuation information was in the registry, the rescue team knew who Jessie and I were even though none of us had met. Thankfully, my assistant told them I could communicate by writing, indicating yes and no by traditional means, text-to-speech software, sign language and gestures.

Slide 12: The flood

By the time we left, the water was more than four feet deep, so everybody took me to the entrance with high concrete steps and loaded me on the truck from the top step.

Slide 13: The flood

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. When I asked what shelter I would be in, someone replied 'The makeshift nursing home we set up 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.'

Slide 14: The flood

Until that moment, I didn't consider myself to be that disabled. 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.

Slide 15: Grief

I had just enough time to see the tears and anxiety that etched people's faces before Jessie and I were whisked away to the tiny special education room. From that moment forward, I vowed to do whatever I could to assist those who are in need. I remember it like it was yesterday. There was barely enough space for four child sized desks and one for the teacher. I wondered, 'How am I going to cope with this?'

Slide 16: Jessie

And ran my hand along Jessie's silky fur for comfort. I thought, 'I'm not alone. I have Jess.' The soldier standing beside me said, 'I know it's crammed with some of the desks, 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 the other shelters. That means we'll have 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 in the meantime. 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, I could send Jessie for someone if I needed help.

Slide 17: Video

"Within the next three hours, another refugee joined me. A cot was brought to us. And, I had a legal pad and pen so I could communicate with the soldiers. " 'One of first things I said to the soldiers was, '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 said, '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.

Slide 18: Video

He was trying to cheer me up, so I didn't mention that I had a swallow disorder and could only tolerate soft, mushy foods. I would compensate for it myself. However, talking to my bunkmate was difficult without my computer because he couldn't sign or read well. I wished I had grabbed some paper communication pages with symbols on them. This would have enabled me to communicate more easily, and save my shrinking supply of paper. The hours between visits were very lonely.

Slide 19: Video

I felt naked and vulnerable when I couldn't use my speech software or paper boards because my interfaces felt like an extension of my body. I longed to see those visual representations of myself because I wanted to feel intact.

Slide 20: The Mayor

Sometime that evening, there was a knock on the door. 'Hello, it's Mayor Pat. May I come into see you?' The door opened, 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.'

Slide 21: Video

I worked in the office at night keeping data on all of the 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 boards so I could communicate with my bunkmate. I plan to show them to you in a moment.

Slide 22: Emergency Preparedness

I was only in the shelter for four days, before someone found people in Mandan and Bismarck to take us in temporarily. Still, that seemed like a lifetime to me because I wasn't able to get out of my wheelchair at all. As a result of those experiences, I've taken measures in an effort to prevent being unprepared for an emergency. I encourage you to do the same.

Slide 23: Keep a fanny pack of essential items with you at all times

1. I always wear a waterproof fanny pack that contains a print out of my medical information, insurance cards, paper communication boards, accommodations, emergency contacts, doctors, activities of daily living, charged cell phone, inhalers and pain medication.

Slide 24: Make an emergency kit

2. I keep changes of clothes, copies of communication interfaces, medication, medical supplies, food and dog food in watertight containers in closets near an exit. That way if I ever need to be evacuated again, I am as ready as I can be.

Slide 25: Contact Emergency Departments

3. When I move to a new area, if Emergency Management doesn't have a registry, I call the police department and emergency responders to let them know a person with complex communication needs lives at the following address.

Slide 26: Create a personal disaster plan

4. I've developed a personal disaster plan that my network of family and friends know about, so I don't have to rely on emergency responders to rescue me unless absolutely necessary.

Slide 27: Keep aware of potential disasters

5. Because I've lived in multiple flood prone regions, I log on to the National Weather Services' website for the most accurate and up-to-date weather watches and warnings in my area.

Slide 28: Have someone call you

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

Slide 29: Be prepared to evacuate

7. When flood watches or warnings are issued, I make every effort to be in my wheelchair and with someone so it isn't so difficult to rescue me.

Slide 30: Emergency preparation

Hopefully, I'll never have to institute my evacuation plan. If I ever do, I'll take comfort in knowing I made every effort to prepare.

Slide 31: AAC and All that Jazz

And, I haven't forgotten the promise I made to myself in that refugee shelter. That's why I asked Sarah Blackstone if I could lend a hand with the "AAC and All That Jazz" Conference. I want to help make the AAC Restore and Rebuilt Project a continuing success. We are not replacing AAC technologies; we are restoring families and communities and rebuilding lives! Networks only function properly if they remain connected. Even after the conference, I hope to remain involved. To me, doesn't matter that I wasn't displaced in New Orleans. That's just geography. My heart can't read a map! So, I've rolled up my sleeves and I'm in it for the long haul, willing to share whatever I can -- including my boards.

Slide 32: Paper communication systems

Paper was rationed. As a result, I was limited to four pages. Because the signed alphabet was my first language, I've always preferred interfaces that contain text and no symbols. However, my bunkmate needed symbols. So, I created both types. I tried several grid configurations on my computer with my bunkmate and the soldiers. Finally, I settled on an evenly spaced grid with 70 congruent squares on a single page. When talking to an unfamiliar partner with paper communication boards, I've found that utilizing a black background works best because the squares are more visible to him or her.

Slide 33: Communication displays

Now, let me explain them...My pages were text based and displayed the alphabet and core phrases. Because of this, they didn't require as much context as symbol based boards. The squares on my first page featured the letters of the alphabet,

Slide 34: Communication displays

all single digit numbers, key phrases and objects in the room. This provided convenience, speed and the ability to compose novel messages without adding pages. My core vocabulary included words like: yes, no, need, want, basic pronouns, Jessie, help, seizure, please, thanks, hi, bye, blanket, pillow, paper, pen, eat, drink, soup, sandwich, computer, and the phrase 'I can't eat that.'

Slide 35: Communication displays

The last phrase was essential. The stress of being displaced made my swallowing disorder much worse. To avoid having a food fight with myself, maximize my ability to swallow and reduce my risk of choking, I resorted to having someone feed me. In doing so, I reduced my fatigue and likelihood of seizures.

Slide 36: Communication displays

The boxes on my second page contained related, color coded clusters of words and phrases that might be used in combination. In the section containing my vital information I listed my name, disability, and strengths. I made sure I could tell them I understood them and to feel free to ask questions when necessary. The next cluster allowed me to state if I was experiencing

headaches, seizures, dizziness, nausea, swelling, or double vision. This was critical because the water supply might have become toxic as a result of the sewage and gas leaks in the city.

Slide 37: Video

Because I was unable to use the cot, I had to stay in my chair for four days! As you can imagine, I was in terrible pain and extremely spastic. When I asked for something to relieve it, I had to communicate exactly where I hurt. Naturally, I created appropriate squares. However, I usually prefaced my answer by rolling my eyes and spelling the word 'everywhere.' Finally, I reserved one cluster to communicate Jessie's needs and to inquire about updates when I was in the office at night. Doing that enabled me to ask if my family had called, and if access roads were still flooded. My heart always pounded when I pointed to the phrase, 'Any refugees found homes since I was on last?'

Slide 38: Communication displays

Then, I focused on my roommate's pages. My first priority was to lessen his anxiety. Every time I used my AAC, his gestures and vocalization became exaggerated. Unfortunately, when I showed him text based boards, he became frustrated. So, I loaded common color core symbol sets that depicted the actual concepts on my PC. I watched his reactions when he saw each square. Gradually, he told me which ones he recognized! He knew the symbols for bed, chair, blanket, yes, no, wait, help, want, toilet, drink, eat, sandwich, soup, soda, done, home, basic emotions, good, bad, past, present, and future. I was elated! By the end of our first day, I created a page of squares that contained groups of related words: foods, objects in the room, body parts, and essential pronouns, and prepositions. I also added the symbols for soldier and flood.

Slide 39: Thank you

When I handed the page to him, he pointed to 'thank you.' I replied. His responses is seared into my memory.

Slide 40: Messages

He looked out the window and pointed to: 'present, I, home, flood bad. I sad, afraid.' My heart sunk.

Slide 41: Messages

Because I had friends who communicated similarly, I understood that he had said, 'My house flooded badly. I wish it was over. I'm so frightened and sad.'

Slide 42: Messages

I choked back the tears, put my hand on his arm and pointed. 'Yes. You, I sad. Present, flood bad.' He indicated, 'present, I want family, friends Past, flood, bad, done.'

Slide 43: Messages

I didn't have his symbol to indicate I was sorry, so I typed it and hoped my expression conveyed the compassion and empathy I felt. We sat in companionable silence. Sometime later, he indicated, 'Thank you.' I smiled and responded, 'You're welcome.'

Slide 44: Communication displays

The following day, we looked through my symbol archive again. Knowing he could construct complex responses, I hoped he knew more of them so we could talk about many more subjects. As we clicked through them, I realized that I didn't have most of the pictures in his sets. I compiled the few we had identified and constructed his interface. I took solace in the fact his first page contained enough vocabulary so he could tell our caregivers when he wanted something to eat and drink or to go to bed.

Slide 45: Messages

He could also say, 'Soldiers, men, women, loud. I head hurt. I want medicine.'

Slide 46: Messages

And, 'more toilet stink. I sick.' In other words. "The stench of raw sewage is making me nauseated."

Slide 47: Messages

We used the second page when we were alone because it held key temporal indicators, such as: "who," 'what,' 'where,' 'when,' why,' and 'how.' By doing so, he was able to articulate more complex thoughts like: 'I afraid when I go home.'" "How bad flood my home question.'" I knew he had said I'm afraid to go home. How badly is my house flooded? I also added symbols so we could attempt to engage in small talk. However, without more extensive vocabulary and environmental context it was difficult to ascertain which ones he was referring to. Still I'm glad we had the opportunity to meet and be there for each other when we needed it most.

Slide 48: Video

The four days I spent in the shelter changed my perspective on human suffering. Today, when I hear of an emergency on the news, my heart still pounds in my chest as I wait to hear its toll on families and communities. Thank you allowing me to share my story with you. I really enjoyed doing so and hope you did as well.

Slide 49: "All that Jazz"

Nearly a year has passed since I gave the preceding presentation and to the completion of this webcast. I am delighted to say that conference participants did establish a dialogue. This allowed us to achieve our goals and outcomes while we were in New Orleans. The original purpose of the AAC and All That Jazz conference was to rebuild capacity, restore AAC services, and focus on brightening the future along the gulf for people with complex communication needs. As the AAC Action Corps organized the event, we also decide to launch USSAAC's Restore and Rebuild Project.

Slide 50: Continuing Work

Thanks to those efforts, AAC and All That Jazz has become a network of people rallying to respond to the needs of people with CCN worldwide and to raise awareness regarding the need for emergency preparedness.

Slide 51: Thanks to...

I would like to express a very heartfelt thank you to USSAAC, all ATJ Committee members, sponsors, and contributors. You were the backbone of AAC and All That Jazz. We could not have accomplished so much without you. And finally, I am deeply grateful to David McNaughton, Sarah Blackstone, Sarah Douglas, and Pennsylvania State University for their collaboration on this webcast. I couldn't have done it without you. Thank you for allowing me to stand on your shoulders.

Slide 52: Additional Resources

If you would like to learn more, or become involved, please go to USSAAC.ORG and AAC-RERC.COM, or you may email me at pdkennedy416@gmail.com. Thank you, I look forward to hearing from you.