

Emergency Preparedness for People with Disabilities and Other Special Needs: Another Look After Katrina

by Carl T. Cameron. Ph.D.

During more than ten years that the Inclusive Preparedness Center has been in operation, the 9/11 catastrophe and the Florida hurricanes of 2004 have caused emergency professionals and all the rest of us to review emergency preparedness for ourselves, our families, our communities and our nation. But as is typical of most events, they fade from our attention and fairly quickly are replaced by new events and our day-to-day responsibilities. It became quite obvious during the events in New Orleans and the rest of the Gulf Coast that we still have much to do if we are going to be truly prepared to protect the most vulnerable citizens of our great nation.

The very visible suffering in New Orleans reminds us that emergency preparedness and response plans must consider persons with disabilities and other special needs. If preparedness in New Orleans was typical of the rest of the nation, then persons with "special needs" have not been sufficiently included in the ongoing discussions of how to shelter and evacuate large numbers of residents of an area. We all, not just emergency professionals, must think more comprehensively to prepare better for incidents of national significance.

During the attack on the World Trade Towers and the Pentagon, it was painfully obvious that most organizations were ill prepared to provide the needed support for employees and other users of their facilities. Stories emerged of how people with disabilities attempted to evacuate from the buildings. In some cases, individuals acted heroically to help people with disabilities escape, but in other cases no options were available.

Now there are similar stories coming from the Gulf Coast of individual acts of heroism and extraordinary efforts by advocacy groups and special needs service organizations to provide critical services. These groups and organizations are responding to individuals and needs that the Red Cross, FEMA and the military are not sufficiently prepared to deal with in their response activities.

One major difference between 9-11 and Hurricane Katrina is the media's ongoing access to many individuals who are the most vulnerable, have the least resources, and are the least mobile. With so many evacuees, the recovery phase takes on a new meaning. By some estimates, Katrina may have disrupted the lives of as many as 250,000 individuals with pre-existing special needs, and may cause many new disabilities and special needs.

Who are people with "special needs"?

People with special needs include a wide variety of individuals who are identified by a variety of names - people who use wheel chairs, people who are blind or visually impaired, people who are deaf or severely hard of hearing, people with severe emotional impairments, people with severe intellectual impairments, people with medically related needs such as diabetics, individuals with seizure disorders, and many others who require individualized assistance. Individuals with disabilities are persons who have physical or mental impairments that limit major life activities, have an ongoing or chronic condition, or even if they don't have such a condition, are regarded by the community as being disabled. And this doesn't necessarily include the ever-enlarging group of senior citizens who have newly recognized special needs, such as Alzheimer's and related memory disorders.

In addition, in recent years we have started to recognize the special needs in emergencies of large numbers of individuals who do not speak or understand English, or whose cultural roots have not prepared them to react well to emergencies. When you start to consider the number of people who may have special needs, it may at first seem overwhelming to try to include these individuals in your emergency planning.

This article is addressed to both local emergency professionals and special needs/disability service and advocacy organizations. Its purpose is to identify key issues and action options related to inclusion of individuals with disabilities in emergency planning processes; and to identify related

information and support required to help individuals with disabilities participate fully in planning.

First, some salient facts about people with special needs in emergencies and the current state of emergency planning with respect to them.

People with disabilities -

Are not now sufficiently included in emergency planning, and little, if any, communication exists between planners and the disability community,

Have a wide variety of communication, support and health needs that differentiate them from persons without disabilities, and

Tend to live in low income areas that include areas at higher risk for emergencies and lack critical infrastructure

The requirements of Federal law reflect our growing awareness of the requirements of basic human decency with respect to the most vulnerable among us. Good sense and the law press us all to do a better job of extending to all Americans our common protections in times of danger and our shared supports for a full life in normal times.

What are the legal requirements to serve people with disabilities and other special needs?

The major Federal legislation that impacts on services to individuals with disabilities is the Americans with Disabilities Act (ADA). The ADA prohibits discrimination against people with disabilities, forbids exclusion from services or activities available to the general public, and requires equal access. The requirements of the ADA need to be taken into consideration when developing emergency planning and when implementing response and recovery efforts. In the aftermath of Katrina, special needs advocacy groups and individuals with disabilities across the country are likely to take renewed interest in how well they are included in preparedness efforts

Individuals with disabilities who believe they have been discriminated against because of their disabilities and been denied access to services may begin a series of steps to obtain those services. A person with a disability may file a complaint with the U.S. Department of Justice (DOJ), which is followed by an investigation, mediation, litigation or a DOJ or individual suit. The result is a compliance agreement, and possible fines and penalties. Taking new steps to make preparedness truly effective and inclusive is clearly preferable for reasons of effectiveness and human decency.

The Presidential order

A year ago, Presidential Order 13347 (July 22, 2004) was issued to ensure that the Federal Government appropriately supports safety and security for individuals with disabilities in situations involving disasters, including earthquakes, tornadoes, fires, floods, hurricanes, and acts of terrorism. It shall be the policy of the United States that executive departments and agencies of the Federal Government (a)consider, in their emergency preparedness planning the unique needs of agency employees with disabilities and individuals with disabilities whom the agency serves; (b) encourage, including through the provision of technical assistance, as appropriate, consideration of the unique needs of employees and individuals with disabilities served by State, local, and tribal governments and private organizations and individuals in emergency preparedness planning: and (c) facilitate cooperation among Federal, State, local, and tribal governments and private organizations and individuals in the implementation of emergency preparedness plans as they relate to individuals with disabilities.

What can local emergency planners do?

You obviously cannot guarantee that everything will go well before, during, and after a major emergency or that all people with special needs will receive all the help they need. But there are specific actions that local emergency planning agencies can take to ensure that individuals with disabilities are included in the planning process. Most of these actions are simple, and easy to integrate into existing planning.

Action #1: Include people with disabilities in the planning process

There are literally hundreds of organizations in the United States that are comprised of people with disabilities who are advocates for themselves and their organization. Almost any of the organizations like the Centers for Independent Living, the Governor's Committees on People with Disabilities, the State Councils on Developmental Disabilities, or the National Organization on Disabilities, are able to assist you in locating appropriate individuals to participate in your planning process. The National Rehabilitation Information Center (NARIC) has a web site (www.naric.com) and a toll free number (800.346.2742) that can provide a wide range of contacts.

Once you have identified individuals with disabilities, make sure that your meeting facilities are accessible, and that accommodations are available. Depending on who is involved, accommodations may include sign language interpreters, electronic copies of handouts, accessible restrooms, or

locations for individuals to use personal assistive computer equipment. It is not usually necessary or possible to provide accommodations for all possible needs, so try to ask participants beforehand what support, if any, they will need. In most cases, an individual with a disability already has their own supports in place, and you may not need to make any accommodations; providing accommodation may be as simple as removing a chair or relocating a table so a person who uses a wheelchair can join others sitting around a conference table.

It is a good idea to select representatives who are able to represent the interests of people who have different types of disabilities. There are many organizations that focus on disabilities in general, not specifically on one disabling condition. But ways should be found to include all who want to participate.

Action #2: Include disability specific procedures

For most communities, local and state emergency plans already exist. Your first step is to review the existing plan and how it addresses the special needs in emergencies of people with disabilities. The review process should include members of your community who have disabilities. They will suggest what accommodations are necessary and what is the most direct and effective way to ensure appropriate services. If you can arrange it, draft a set of proposed changes and disseminate them for comment to a broader audience of individuals with disabilities and special needs advocacy groups in your community. People with disabilities live with accessibility issues every day, and have developed some easy and cost effective ways of making sure they have access. For additional information, see www.disabilitypreparedness.org for a list of helpful information sources. Such outreach may seem difficult if you are not already in touch with disability advocacy groups, but it can be done and it is the right thing to do. The suffering and loss from Katrina may convince all parties in other locations that they have to find ways to get together to prepare together. Investing in preparedness reduces suffering in the event, and the need for dangerous rescues.

Action #3: Train response personnel

Training response personnel should include how to assist individuals with disabilities during emergencies. A few simple principles will reduce stress in emergencies for both response personnel and individuals with disabilities. When providing this training, it is extremely valuable to use individuals with disabilities as trainers. They have concrete, practical knowledge. Individuals with disabilities don't always agree on the right way to provide accessibility services (they are human beings, just

like the rest of us), so be prepared for some debate; stay focused on finding solutions.

There are very few materials available to use for information and training purposes, but the Red Cross (1998) has developed some materials on natural disaster sheltering and evacuation, and the planning guide, *Emergency Planning for People with Disabilities and Other Special Needs* (Disability Preparedness Center, 2004), offers assistance in training personnel to deal with issues such as:

- Evacuating and transporting
- Lifting or carrying people with disabilities
- Assistance animals
- Communication
- Dealing with highly emotional people
- Using appropriate language

Action #4: Provide pro-active information

Like everyone else, getting information prior to an emergency offers one of the most cost effective and useful alternatives for ensuring the safety of the community. The major problem is that almost all information is limited to print materials or broadcast on the radio or TV. It is most important to remember that people with special needs can't always hear the radio or TV, see printed materials, or understand them if they can see them. Materials need to be prepared in alternative formats such as large print. audio tapes, or on a CD-ROM that a home computer can read aloud. You should be able to secure the assistance of existing disability organizations and their in-house publications to distribute materials even more effectively - because they know where people with disabilities live. Share with other jurisdictions the materials you develop.

Action #5: Consider a special needs listing

Finally, if feasible, involve disability organizations in developing listings of individuals with special needs in your community. They probably already keep track of the people they work with who live independently, live with their family, in group homes, in assisted living, or in other types of living arrangements. You could also ask government agencies and private employers how many employees have special emergency needs. When you start looking around, there are a lot more people with disabilities living in your community than you may think now. And guess what, because people with disabilities tend to have less income, you will find a higher concentration of residents with special needs working and living in less desirable and often more hazardous areas: industrial areas that house chemical plants and other hazardous facilities, and in lower income housing areas. And often in areas most prone to flooding.

In densely populated urban areas it may not be feasible for emergency management agencies to keep a special needs listing up to date. But in response to Katrina, disability advocacy groups and service organizations may find themselves keeping track of people with special needs and working with them to be prepared for emergencies. Emergency professionals should be prepared themselves to help these organizations with that important task.

Conclusion

Skimping on preparedness to direct funds elsewhere has been shown on the Gulf Coast to have sometimes disastrous consequences. Katrina has been extremely expensive in damage to lives, to the economy, and to our sense of ourselves as a civilized society. If, as a society, we find new ways to prepare and protect those who cannot protect themselves, then even the most successful and self-reliant among us will benefit. In our times, being able to take pride in America requires preparedness that does not leave the most vulnerable among us to take their chances when danger strikes. The right preparedness will reduce the need for heroic self-sacrifice by responders endangering themselves to rescue the most vulnerable.

About the Author

Dr. Carl T. Cameron founded the Inclusive Preparedness Center in 1998. He is a nationally known education professional in the area of employment and community living for people with disabilities.



He has been recognized as a program developer, researcher. teacher. author and presenter throughout the United States. Dr. Cameron is well known as a media and training expert, including as a producer of satellite video teleconferences. videotape training and interactive video productions. He currently is developing education and training materials focused on persons with special needs, preparedness. emergency determination, community living and employment for persons with disabilities.



www.inclusivepreparedness.org

The Inclusive Preparedness Center (IPC) works to ensure that all individuals are included in the development and implementation of plans for protection from both natural and man-made emergencies. In almost all emergency planning, whether for evacuation or sheltering during natural disasters, attacks of terrorism, or industrial or highway accidents, the communication, transportation and medical needs of persons with disabilities or other special populations have not been taken into consideration.

IPC provides resources to assist local emergency planning organizations in developing plans that include provisions for people who need specialized communication. transportation. and supports. In many cases, it is communication with individuals with disabilities that is most important to successful emergency planning and response from initial warnings and specific directions on how to shelter or evacuate, to what personal items (like medicines and life supports) evacuees should take with them. Responders also need to know how to communicate effectively with individuals who are deaf, have limited intellectual capacity or are easily upset, fearful or disturbed by emergency situations.

The Center cooperates with federal, State and local agencies that are responsible for emergency plannina and management, including Environmental Protection Agency, Federal Emergency Management Agency, Department of Transportation, and others. The Center's services also available businesses. to private corporations and other organizations.

A wide variety of resources are available from the Center, including print and multi-media materials, bibliographical references, training materials and packages for training professionals on-site or through distance education. Customized technical assistance is available for organizations that are evaluating and/or revising their emergency planning or procedures.

Or more information, contact DPC @202.338.7158 x201, or ctcameron @inclusivepreparedness.org