Disaster Preparedness for People with Disabilities
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1 Introduction
By Karen Janes

The materials in this resource guide provide information on disaster preparedness for people with special needs or disabilities. As a result of the recent natural disasters, such as Hurricane Katrina or the fires in Southern California in 2007, plans for emergency services have been emphasized at the local and state level. Although it is required by law, the needs of people with disabilities is often overlooked during the planning and implementation of emergency strategies. Disaster preparedness plans must consider the needs of people with special needs during evacuation, sheltering and returning home. The following resources serve as a guide for preparing for a disaster for the local government, institutions and individuals with special needs.

In order to be better prepared, everyone must do their part to plan for disasters. The Americans with Disabilities Act prohibits private and public entities to exclude people with disabilities from participation and benefits of any program or activity. It ensures that the needs of people with disabilities are taken into consideration. Just as restaurants must have wheel chair accessibility, emergency shelters must also be accessible for people with disabilities; basic services, such as cots and bathrooms, need to accommodate special needs. This manual includes a guide created by the American Red Cross to inform local governments on requirements for accommodating people with disabilities during times of emergency.

Individuals, with or without disabilities, can decrease the impact of a disaster by taking steps to prepare before an event occurs. A personal disaster plan may be the key to survival. People with disabilities need to be more self reliant in emergencies and have a plan for their own unique circumstances. A fundamental component of an individual's preparation is knowing one's abilities before, during, and after a disaster.

People with complex communication needs should have a personal disaster plan in place in case of emergency. They must have a way to communicate if they are with people who are not familiar with their form of communication. This guide includes a section that addresses the specific needs of individuals who depend on alternative forms of communication to communicate.

There are an abundance of resources for disaster preparedness for people with disabilities that are not covered in this resource guide. If this guide fails to fit your unique need, several resources are available on the Internet. Remember to be prepared. The more prepared you are, the better the outcome before, during, and after a disaster.

2 It's the Law

The Americans with Disabilities Act requires the government, private entities and non-governmental organizations to accommodate the needs of people with disabilities in times of emergencies. It ensures that the needs of people with disabilities are taken into consideration. Information regarding emergency situations to the general public must be effectively communicated to people with special needs. People with disabilities must be able to access and benefit from emergency programs, services, and activities equally with everyone else. They must be provided the same basic services as well as the ability to participate. The following sections identify laws regarding the rights of people with disabilities at all times, and highlight the protection of these rights during times of emergencies.

2.1 Section 504 of the Rehabilitation Act - Nondiscrimination Under Federal Grants and Programs[1]

Sec. 504.(a) No otherwise qualified individual with a disability in the United States, as defined in section 7(20), shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service. The head of each such agency shall promulgate such regulations as may be necessary to carry out the amendments to this section made by the Rehabilitation, Comprehensive Services, and Developmental Disabilities Act of 1978. Copies of any proposed regulation shall be submitted to appropriate authorizing committees of Congress, and such regulations may take effect no earlier than the thirtieth day after the date on which such regulation is so submitted to such committees.

(b) For the purposes of this section, the term "program or activity" means all of the operations of -

(1)(A) a department, agency, special purpose district, or other instrumentality of a State or of a local government; or

(B) the entity of such a State or local government that distributes such assistance and each such department or agency (and each other State or local government entity) to which the assistance is extended, in the case of assistance to a State or local government;

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[1] Section 504 of the Rehabilitation Act. Accessed on January 29 2008 at www.section508.gov/index.cfm?FuseAction=Content&ID=15.

(2)(A) a college, university, or other postsecondary institution, or a public system of higher education; or

(B) A local educational agency (as defined in section 14101 of the Elementary and Secondary Education Act of 1965), system of vocational education, or other school system;

(3)(A) An entire corporation, partnership, or other private organization, or an entire sole proprietorship-

(i) If assistance is extended to such corporation, partnership, private organization, or sole proprietorship as a whole; or

(ii) Which is principally engaged in the business of providing education, health care, housing, social services, or parks and recreation; or

(B) The entire plant or other comparable, geographically separate facility to which Federal financial assistance is extended, in the case of any corporation, partnership, private organization, or sole proprietorship; or

(4) Any other entity which is established by two or more of the entities described in paragraph (1), (2), or (3); any part of which is extended Federal financial assistance.

(c) Small providers are not required by subsection (a) to make significant structural alterations to their existing facilities for the purpose of assuring program accessibility, if alternative means of providing the services are available. The terms used in this subsection shall be construed with reference to the regulations existing on the date of the enactment of this subsection.

(d) The standards used to determine whether this section has been violated in a complaint alleging employment discrimination under this section shall be the standards applied under title I of the Americans with Disabilities Act of 1990 (42 U.S.C. 12111 et seq.) and the provisions of sections 501 through 504, and 510, of the Americans with Disabilities Act of 1990 (42 U.S.C. 12201-12204 and 12210), as such sections relate to employment.
2.1.1.1.1

2.2 ADA Title II: State and Local Government Activities[2]

Title II covers all activities of State and local governments regardless of the government entity's size or receipt of Federal funding. Title II requires that State and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

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[2] Americans with Disabilites Act of 1990 (ADA). Accessed on January 29,2008 at www.fema.gov/oer/reference/ada_1990.shtm

State and local governments are required to follow specific architectural standards in the new construction and alteration of their buildings. They also must relocate programs or otherwise provide access in inaccessible older buildings, and communicate effectively with people who have hearing, vision, or speech disabilities. Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided.

Complaints of title II violations may be filed with the Department of Justice within 180 days of the date of discrimination. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department may bring a lawsuit where it has investigated a matter and has been unable to resolve violations. For more information, contact:

> U.S. Department of Justice
> Civil Rights Division
> 950 Pennsylvania Avenue, N.W.
> Disability Rights Section - NYAV
> Washington, D.C. 20530
>
> www.ada.gov
>
> (800) 514-0301 (voice)
> (800) 514-0383 (TTY)

Title II may also be enforced through private lawsuits in Federal court. It is not necessary to file a complaint with the Department of Justice (DOJ) or any other Federal agency, or to receive a "right-to-sue" letter, before going to court.

The ADA requirements set out in Chapter 7 of the Tool Kit all flow from basic principles embodied in the ADA. These include:

INCLUSION
People with disabilities have the right to participate in all emergency programs, services, and activities provided by governments, private businesses, and nonprofit organizations. A person may not be refused access or participation simply because of a disability.
Example - Notification: When an emergency is imminent, everyone must be notified and receive the information they need to take responsible, appropriate action.

EQUAL ACCESS
People with disabilities must be able to access and benefit from emergency programs, services, and activities equally with everyone else.

Example - Evacuation: People with disabilities, including people who use wheelchairs and scooters for mobility, must have transportation that can safely get them to the right place, even if they cannot travel independently to pick-up areas. Some people need transportation starting from their home. Others need wheelchair-accessible transportation. In addition, like other members of the public, people with disabilities must be able to evacuate with their families or care giver, and take clothing and other personal items they may need in a shelter with them. People with disabilities may need to be transported with oxygen tanks or other medical equipment, service animals, or adaptive equipment that they need to function independently in addition to the clothing and personal items that everyone else needs.

INTEGRATION

Emergency programs, services, and activities typically must be provided in an integrated setting. To provide emergency shelter in an integrated setting, basic support services must be available, such as assistance in wayfinding, eating, dressing, transferring to or from a wheelchair, toileting, and reminders to take medication. Assistance and social/human services must be provided to all individuals through the same application and review process - not separately or after the fact.

Example - General Population Shelters: People who use wheelchairs may not be required to go to a separate shelter from the general population and may not be sent to a different shelter from family members or other people who provide them with support. Shelters need to house people with varied disabilities and provide the supportive services they need to function in that setting. If a person with a disability has a medical condition requiring hospitalization, family members and others who provide support may not be involuntarily separated.

SELF-DETERMINATION

Emergency programs, services, and activities must be provided in a manner that results in an optimal level of functional independence for people with disabilities. People with disabilities have the right to participate in programs designed to serve the general public. Individuals with disabilities are the most knowledgeable people to determine their needs - instead of trying to guess or predict what their needs may be, just ask them.

Example - Emergency Planning and Operations: Emergency planners sometimes assume that they know what will be best for people with disabilities and design evacuation, sheltering, and other emergency programs based on those assumptions. But those assumptions are frequently wrong, since even people with the same type of disability have different abilities and needs. People with disabilities have the right to make choices about the options that will best meet their needs. Like everyone else, in order to make informed choices, people with disabilities need accurate information about their options for emergency preparedness, sheltering in place, evacuation, transportation, sheltering, housing, and participation in other emergency programs.

PHYSICAL ACCESS

Emergency programs, services, and activities must be provided at locations that all people can access, including people who use wheelchairs, scooters, and other mobility

aids and people with limited stamina. People with disabilities must be able to enter and use emergency facilities. Accessible features include parking, drop-off area, entrance and exit, security screening areas, toilet rooms, bathing facilities, sleeping areas, dining facilities, other areas where programs, services, or activities are provided. If a designated emergency facility is not accessible to people with disabilities, it needs to be made accessible, either through permanent or temporary means, or a different facility needs to be chosen.

Reasonable Modifications to Policies, Practices, and Procedures
Rules, policies, practices, and procedures used in emergency programs and emergency facilities may not deny equal access to people with disabilities.

Program and facility operators must make reasonable modifications to rules, policies, practices, and procedures to provide equal access to individuals with disabilities.

Example 1 - Emergency Programs and Facilities: Public transportation and other facilities that provide housing or services during an emergency often have a "no pets" policy. Some have mistakenly applied this policy to exclude service animals such as guide dogs for people who are blind, hearing dogs for people who are deaf, service dogs that pull wheelchairs, assist with balance, or retrieve dropped objects, and other animals that provide assistance to people with physical or mental disabilities.
Example 2 - Shelters: If meals are served in shifts, remember that people with disabilities may take a longer time to eat, and allow them extra time to finish their meal. People with diabetes may need access to food at unscheduled time because of fluctuating blood sugar levels. People with food allergies may require different types of food.

EFFECTIVE COMMUNICATION
People with disabilities must be given the same information that is given to the general population, and they must be notified in an emergency in a way that is understandable to them, and timely. Consider communication formats for those who are blind or have low vision, those who are deaf or hard of hearing, and those with speech, or cognitive disabilities. Auxiliary aids and services must be furnished when necessary to ensure effective communication with people with disabilities. These 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.

No "One Size Fits All"
Individuals with disabilities do not all require the same accommodations and do not all have the same needs. There are many different types of disabilities that affect people in different ways. Emergency planning should consider the needs of people who use mobility aids, people who require portable medical equipment, people who ordinarily rely on personal care attendants, people who use service animals, people who are blind or have low vision, people who are deaf or hard of hearing, people who have a cognitive disability, people with mental illness, and those with other types of disabilities.

Individuals with disabilities require different levels and types of supports. Do not assume that a person with a disability needs assistance or that specific types of assistance will be helpful to all people with the same type of disability. The best way to determine if a person with a disability needs assistance, or if assistance is needed, what type to provide, is to ask that individual what he or she needs.

3   Local Government

One of the most important roles of local government is to protect their citizenry from harm, including helping people prepare for and respond to emergencies. Making local government emergency preparedness and response programs accessible to people with disabilities is a critical part of this responsibility. The Americans with Disabilities Act of 1990 requires that these programs are accessible.

This section is a comprehensive guide for local governments to address the needs of people with disabilities in the disaster preparedness plan. It identifies the critical issues related to people with disabilities during disaster preparedness planning and implementation. Included is the ADA guide for local government, which illustrates steps to take at all phases of a disaster. People with disabilities who have undergone disaster situations designed additional lessons learned. The conclusion of this section includes themes to evaluate the success of the plan post-disaster.

3.1 Key Issues[3]

Based on research from the National Council on Disabilities over the past 3 years in the area of homeland security, as well as Congressional and Executive Branch investigations, a number of key issues are identified as critical and related to people with disabilities. The key issues are as follows:

- People with disabilities frequently encounter barriers to physical plants, communications, and programs in shelters and recovery centers and in other facilities or devices used in connection with disaster operations such as first aid stations, mass feeding areas, portable payphone stations, portable toilets, and temporary housing.

- Many of these barriers are not new. Information and lessons learned arenot shared across agency lines, and thus experience does not enlighten the development of new practices.

- Many accessibility lessons learned during previous disasters are not incorporated in subsequent planning, preparedness, response, and recovery activities.

- People with disabilities are too often left out of preparedness and planning activities. These activities include analyzing and documenting the possibility of an emergency or disaster and the potential consequences or impacts on life and/or property.

- Disaster preparedness and response systems are usually designed for people without disabilities, for whom escape or rescue involves walking, running, driving,

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[3] National Council on Disability Public Consultation May 31, 2007 Homeland Security, Emergency Preparedness, Disaster Relief and Recovery. Accessed January 29, 2008 at www.ncd.gov/newsroom/publications/2007/ncd_consultant_05-31-07.htm

seeing, hearing, and quickly responding to instructions and evacuation announcements.

- Access to emergency public warnings, as well as preparedness and mitigation information and materials, does not adequately include people who cannot depend on sight and hearing to receive their information.

- The strengths and skills of community based organizations (CBOs) serving people with disabilities are not well integrated into the emergency service plans and strategies of local government. Emergency managers need to strengthen their relationships with these organizations by recruiting, encouraging, and providing funding and incentives to CBOs so that they can participate and assist in disaster preparedness and relief.

3.2 An ADA Guide for Local Governments

Making Community Emergency Preparedness and
Response Programs Accessible to People with Disabilities

A police officer uses written notes and hand gestures to tell a man who is deaf to evacuate.

A man using a wheelchair enters a paratransit van provided
so he can evacuate from his home.

A family, including a woman with a service animal, arrives at a shelter.

PLANNING

If you are responsible for your community's emergency planning or response activities, you should involve people with disabilities in identifying needs and evaluating effective emergency management practices. Issues that have the greatest impact on people with disabilities include:

- notification;
- evacuation;
- emergency transportation;
- sheltering;
- access to medications, refrigeration, and back-up power;
- access to their mobility devices or service animals while in transit or at shelters; and
- access to information.

In planning for emergency services, you should consider the needs of people who use mobility aids such as wheelchairs, scooters, walkers, canes or crutches, or people who have limited stamina. Plans also need to include people who use oxygen or respirators, people who are blind or who have low vision, people who are deaf or hard of hearing, people who have a cognitive disability, people with mental illness, and those with other types of disabilities.

Action Step: Planning

Solicit and incorporate input from people with different types of disabilities (e.g. mobility, vision, hearing, cognitive and other disabilities) regarding all phases of your emergency management plan including:

- preparation;
- notification;
- response; and

• clean up.

NOTIFICATION

Many traditional emergency notification methods are not accessible to or usable by people with disabilities. People who are deaf or hard of hearing cannot hear radio, television, sirens, or other audible alerts. Those who are blind or who have low vision may not be aware of visual cues, such as flashing lights. Warning methods should be developed to ensure that all citizens will have the information necessary to make sound decisions and take appropriate, responsible action. Often, using a combination of methods will be more effective than relying on one method alone. For instance, combining visual and audible alerts will reach a greater audience than either method would by itself.

Action Step: Notification

Provide ways to inform people who are deaf or hard of hearing of an impending disaster if you use emergency warning systems such as sirens or other audible alerts.

A police officer uses hand gestures and a printed note to tell a woman who is deaf that she needs to evacuate her home.

When the electric power supply is affected, it may be necessary to use several forms of notification. These might include the use of telephone calls, auto-dialed TTY (teletypewriter) messages, text messaging, E-mails, and even direct door-to-door contact with pre-registered individuals.

A woman who is deaf reads a captioned evacuation notice on her television.

Also, you should consider using open-captioning on local TV stations in addition to incorporating other innovative uses of technology into such procedures, as well as lower-tech options such as dispatching qualified sign language interpreters to assist in broadcasting emergency information provided to the media.

EVACUATION

Individuals with disabilities will face a variety of challenges in evacuating, depending on the nature of the emergency. People with a mobility disability may need assistance leaving a building without a working elevator. Individuals who are blind or who have limited vision may no longer be able to independently use traditional orientation and navigation methods. An individual who is deaf may be trapped somewhere unable to communicate with anyone because the only communication device relies on voice. Procedures should be in place to ensure that people with disabilities can evacuate the physical area in a variety of conditions and with or without assistance.

Action Steps: Evacuation of People with Disabilities

Adopt policies to ensure that your community evacuation plans enable people with disabilities, including those who have mobility, vision, hearing, or cognitive disabilities, mental illness, or other disabilities, to safely self-evacuate or to be evacuated by others. Some communities are instituting voluntary, confidential registries of persons with disabilities who may need individualized evacuation assistance or notification. If you adopt or maintain such a registry, have procedures in place to ensure its voluntariness, guarantee confidentiality controls, and develop a process to update the registry. Also consider how best to publicize its availability. Whether or not a registry is used, your plan should address accessible transportation needs for people who use wheelchairs, scooters, or other mobility aids as well as people who are blind or who have low vision.

A transit bus equipped with a wheelchair lift is used to evacuate individuals and families.

Both public and private transportation may be disrupted due to overcrowding, because of blocked streets and sidewalks, or because the system is not functioning at all. The movement of people during an evacuation is critical, but many people with disabilities cannot use traditional, inaccessible transportation.

Action Steps: Evacuation with Accessible Vehicles

Identify accessible modes of transportation that may be available to help evacuate people with disabilities during an emergency. For instance, some communities have used lift-equipped school or transit buses to evacuate people who use wheelchairs during floods

A lift-equipped school bus is used to evacuate an individual using a wheelchair and her family
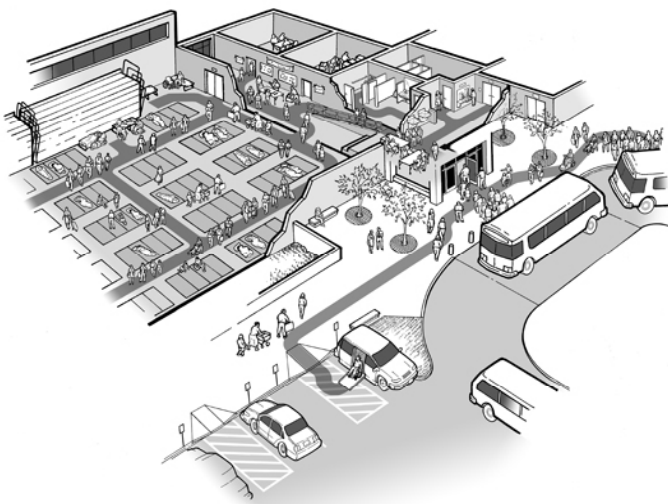
SHELTERING

When disasters occur, people are often provided safe refuge in temporary shelters. Some may be located in schools, office buildings, tents, or other areas. Historically, great attention has been paid to ensuring that those shelters are well stocked with basic

necessities such as food, water, and blankets. But many of these shelters have not been accessible to people with disabilities. Individuals using a wheelchair or scooter have often been able somehow to get to the shelter, only to find no accessible entrance, accessible toilet, or accessible shelter area.

Action Steps: Accessible Shelters

Survey your community's shelters for barriers to access for persons with disabilities. For instance, if you are considering incorporating a particular high school gymnasium into your sheltering plan, early in the process you should examine its parking, the path to the gymnasium, and the toilets serving the gymnasium to make sure they are accessible to people with disabilities. If you find barriers to access, work with the facility's owner to try to get the barriers removed. If you are unable to do so, consider another nearby facility for your community sheltering needs.

A shelter with accessible features including parking, drop-off area, entrance, toilet rooms, and sleeping areas.

Until all of your emergency shelters have accessible parking, exterior routes, entrances, interior routes to the shelter area, and toilet rooms serving the shelter area; you should identify and widely publicize to the public, including persons with disabilities and the organizations that serve them, the locations of the most accessible emergency shelters.

Shelter staff and volunteers are often trained in first aid or other areas critical to the delivery of emergency services, but many have little, if any, familiarity with the needs of people with disabilities. In some instances, people with disabilities have been turned away from shelters because of volunteers' lack of confidence regarding the shelter's ability to meet their needs. Generally, people with disabilities may not be segregated or

told to go to "special" shelters designated for their use. They should ordinarily be allowed to attend the same shelters as their neighbors and coworkers.

Action Steps: Input on Shelter Planning and Staff Training

Invite representatives of group homes and other people with disabilities to meet with you as part of your routine shelter planning. Discuss with them which shelters they would be more likely to use in the event of an emergency and what, if any, disability-related concerns they may have while sheltering. Develop site-specific instructions for your volunteers and staff to address these concerns.
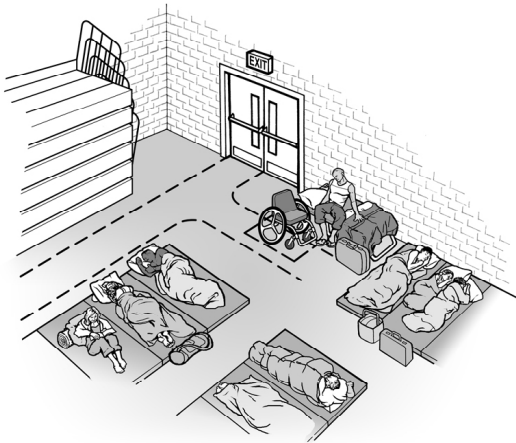
An individual who uses a wheelchair sits on a cot that is placed against a wall. The height of the bed and the wheelchair seat are of similar height making it possible for this person to transfer from the wheelchair to the bed.

Many shelters have a "no pets" policy and some mistakenly apply this policy to exclude service animals such as guide dogs for people who are blind, hearing dogs for people who are deaf, or dogs that pull wheelchairs or retrieve dropped objects. When people with disabilities who use service animals are told that their animals cannot enter the shelter, they are forced to choose between safety and abandoning a highly trained animal that accompanies them everywhere and allows them to function independently.

Action Steps: Service Animals

Adopt procedures to ensure that people with disabilities who use service animals are not separated from their service animals when sheltering during an emergency, even if pets are normally prohibited in shelters. While you cannot unnecessarily segregate persons who use service animals from others, you may consider the potential presence of persons who, for safety or health reasons, should not be with certain types of animals.

A woman has a service animal lying on the floor next to her cot.

Individuals whose disabilities require medications, such as certain types of insulin that require constant refrigeration, may find that many shelters do not provide refrigerators or ice-packed coolers. Individuals who use life support systems and other devices rely on electricity to function and stay alive and, in many cases, may not have access to a generator or other source of electricity within a shelter.

Action Steps: Medications, Refrigeration, and Back-up Power

Ensure that a reasonable number of emergency shelters have back-up generators and a way to keep medications refrigerated (such as a refrigerator or a cooler with ice). These shelters should be made available on a priority basis to people whose disabilities require access to electricity and refrigeration, for example, for using life-sustaining medical devices, providing power to motorized wheelchairs, and preserving certain medications, such as insulin, that require refrigeration. The public should be routinely notified about the location of these shelters. In addition, if you choose to maintain a confidential registry of individuals needing transportation assistance, this registry could also record those who would be in need of particular medications. This will facilitate your planning priorities

A person using a wheelchair picks up medication at the shelter.

People who are deaf or hard of hearing may not have access to audible information routinely made available to people in the temporary shelters. Individuals who are blind or who have low vision will not be able to use printed notices, advisories, or other written information.

Action Steps: Communications

Adopt procedures to provide accessible communication for people who are deaf or hard of hearing and for people with severe speech disabilities. Train staff on the basic procedures for providing accessible communication, including exchanging notes or posting written announcements to go with spoken announcements. Train staff to read printed information, upon request, to persons who are blind or who have low vision.

A shelter worker reads printed information to a woman who is blind.

RETURNING HOME

The needs of individuals with disabilities should be considered, too, when they leave a shelter or are otherwise allowed to return to their home. If a ramp has been destroyed, an individual with a mobility impairment will be unable to get into and out of the house. In case temporary housing is needed past the stay at the shelter, your emergency response plan could identify available physically accessible short-term housing, as well as housing with appropriate communication devices, such as TTY's, to ensure individuals with communication disabilities can communicate with family, friends, and medical professionals.

Action Steps: Planning

Identify temporary accessible housing (such as accessible hotel rooms within the community or in nearby communities) that could be used if people with disabilities

cannot immediately return home after a disaster if, for instance, necessary accessible features such as ramps or electrical systems have been damaged.
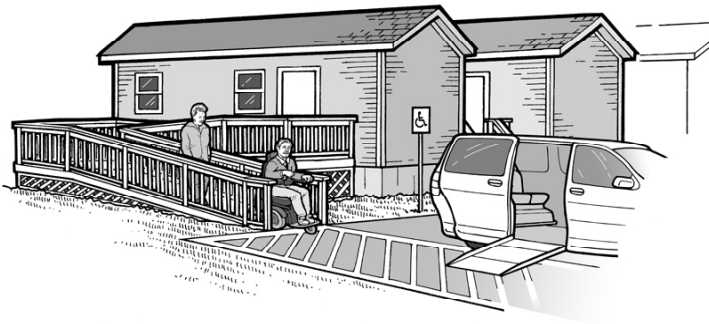
A portable trailer provides temporary accessible housing for an individual who uses a wheelchair and his family. In addition to accessible features inside, the trailer also has an accessible entrance, accessible parking, and the trailer is located on an accessible route to other site features in the mobile home park.

CONTRACTING FOR EMERGENCY SERVICES

Many local governments provide emergency services through contracts with other local governments or private relief organizations. These entities may not fully understand the role they need to play in meeting your obligation to provide accessible emergency services.

Action Steps: Contracting for Emergency Services

Make sure that contracts for emergency services require providers to follow appropriate steps outlined in this document. Review the terms of these contracts on a regular basis to ensure that they continue to meet the accessibility needs of people with disabilities. Provide training to contractors so that they understand how best to coordinate their activities with your overall accessibility plan for emergency services.

3.3 Additional Suggestions from People Who Know

"Disabled People and Disaster Planning" (DP2) was a group of people primarily from Los Angeles County who met during 1996 and 1997 and formulated recommendations to reduce or eliminate problems with accessibility that many disabled people experienced after the Northridge Earthquake of 1994. Within the group were individuals with disabilities and individuals from the disaster planning and response professions.

The website www.citycent.com/dp2/rescue.htm contains the group's recommendations, as well as other information relevant to assisting people with disabilities prepare for and cope with disastrous earthquakes.

TRAINING RESCUE WORKERS

Pre-Disaster Planning

   1. Local police and fire stations should have lists of locations where disabled people live in concentrated numbers such as: senior housing, Section 8 buildings, and board and care facilities. Lists need to be updated annually and shared with field rescue personnel during an emergency.

   2. If police and fire departments decide to have registries of disabled people, both the departments and the people on the registry need to understand the limitations of a registry:

      a) it only helps people who are home at the time of the disaster,
      b) it does not identify any disabled person who visits or works in the area at the time of the disaster, and
      c) it is always out of date.

Training for Rescue Service During an Emergency

   1. Train personnel to regard a disabled person as the best expert in his or her disability and to ask a disabled person for advice before lifting or moving that person.

   2. Train personnel to take extra time when communicating with people who are deaf, hearing impaired, or speech impaired.

   3. Train personnel to never separate a disabled person from his or her assistive aids: wheelchairs, canes, hearing aids, medications, special diet food, urinary supplies, etc. Also, a service animal, usually a dog, is an assistive aid used by some blind, deaf and mobility impaired people.

   4. Train personnel to realize that a disabled person's equipment may not be working after a disaster occurs, or it may be insufficient for emergency circumstances.

   5. Train personnel to realize that a disaster may temporarily confuse service animals and they may not be able to help their owners as effectively as before the disaster.

   6. Train rescue workers to know that some individuals with emotional and developmental disabilities may be too unsettled to respond appropriately to instructions and directions, such as a public address announcement to evacuate a building. Some disabled individuals may need to be in a quiet place for a while to regain their composure; others may even try to hide from rescue workers.

   7. Train personnel to realize that some individuals with significant mental or learning disabilities might not understand the significance of "Keep Out" signs and barricade tape.

3.4 MANAGING SHELTERS

- Recommendations on making emergency shelters more accessible:
- Some cots should be available that are high enough for mobility impaired people to use comfortably and safely.
- Be prepared to provide extra food and water to disabled people with service guide animals.
- In neighborhoods where familiar landmarks are altered or missing due to an earthquake, some visually impaired people may need personal assistance to travel about.
- Some people are non-vocal but still capable of thinking and making their needs known. Shelter staff need to be aware, patient and creative.
- Avoid using outdoor areas that are muddy, sandy, or covered by thick grass.
- Shelter personnel should know how to use the California Relay Service to make and receive phone calls with hearing and speech impaired individuals.
- Permit people with mobility impairments the option of going to the head of long lines.
- Train staff to realize that some people have the physical ability to ride buses, but do not have the cognitive ability to learn new routes established because of a disaster.
- Train staff to know how to contact disability agencies, such as sign interpreter agencies and agencies that help families with at-risk infants with disabilities.
- Train staff to realize that some service animals may temporarily not be able to provide their owners with service as fully effective as before the disaster.
- Train staff about the difference between the medical model and the independence model of disability. Train staff not to see a disabled person as only a person needing medical services.
- Shelters should have telephone books for the local area.
- Shelters should have information about transportation resources and disability service agencies.
- Disabled people and out-of-area emergency volunteers should not have to vie for hotel accommodations.
- Portable telephones should be ordered that have volume controls.
- Public phone stations need power sockets nearby to supply power to portable TDDs used by deaf, hearing impaired, and speech impaired people.
- Train staff to know that even normal amounts of background noise may prevent a person with a hearing impairment from understanding spoken directions and instructions.
- Train staff to know that some disabilities may give a person the appearance of intoxication.
- Train staff to know that some disabilities in certain circumstances leads to disruptive behaviors; and to how to respond appropriately when such behaviors occur.

- In the early days after a disaster, locations of shelters need to be well publicized so that family and friends can search more effectively for disabled people and vice versa.
- Stock writing tablets and pencils for hearing impaired people to use.
- At the accessible entrance to a shelter, have signage providing information about features of the shelter that is less than fully accessible.
- Insure that the shelter's address is clearly visible from the nearby street.
- The approach to outdoor toilets is free of stones, rubble, steps, tree roots, mud, and loose sand.
- Stock simple tools and patch kits for repairing flat tires on wheelchairs.
- Establish contact with local agencies that supply personal care attendants for people with disabilities.
- Train staff to realize the large number of hard of hearing people and their needs.
- All shelters need information boards with notices about announcements that disabled people may not hear or where not present when the announcements were made.

3.5 Best Practice Themes for Evaluation[4]

The following themes can be used as guidance in your reaction and response to this call for best practices information.

1. How people with disabilities were provided with information about the severity of the emergency caused by the disaster or emergency, how to prepare for it, and how to evacuate.

2. Individual assistance (such as personal attendants, sign language interpreters, readers, and service animals) that was made available to people with disabilities during and after the emergency.

3. Assistive devices (such as wheelchairs, walkers, canes, crutches, speech enabled or Braille note takers, pagers, closed captioning, TTYs, hearing aids, and batteries) that people with disabilities were able to keep with them during or after the disaster or emergency; assistive devices people were not able to keep; and, assistive devices that were replaced.

4. Whether accessible temporary housing or shelter was offered to people with disabilities.

5. Whether accessible transportation was provided to people with disabilities when evacuating during the disaster or emergency, receiving food and water, and reaching

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[4] National Council on Disability Public Consultation May 31, 2007 Homeland Security, Emergency Preparedness, Disaster Relief and Recovery. Accessed January 29, 2008 at www.ncd.gov/newsroom/publications/2007/ncd_consultant_05-31-07.htm

temporary shelters or housing. Whether people who use assistive devices were able to keep them during such transport.

6. Medical and mental health treatment, such as emergency care, counseling or medication, that were offered to people with disabilities. The types of accessibility problems that arose.

7. Schools that offered accommodations to students with disabilities affected or dislocated as a result of the disaster or emergency.

8. Types of temporary or permanent employment opportunities that were offered to people with disabilities.

9. Government services (such as Social Security, Medicare, Medicaid, subsidized housing, food vouchers, or any other government assistance) that were, and continue to be, made available to people with disabilities.

10. The immediate, short-term, and long-term aid provided by private, civic, faith-based, advocacy organizations or other groups to people with disabilities.

3.6 Key Tips To Enhancing Accessibility

If you keep the following key points in mind, you will take substantial steps forward on meeting the needs of people with disabilities within emergency preparedness situations.

1. In the area of contracting, if a city contracts with another entity, public or private (like the Red Cross, for example), the city still has an obligation to ensure that programs are accessible. As mentioned earlier, these other entities may have independent obligations under the ADA or Section 504 of the Rehabilitation Act.

2. With regard to planning, people with disabilities and organizations that represent them should be involved in the planning process for emergency preparedness, and their views should be solicited on a regular basis.

3. In terms of notification, public entities must ensure that emergency management policies and procedures address the needs of people with disabilities. For instance, where a city warns citizens of an emergency by sirens or other audible alerts such as police cruiser bullhorns, it is likely that people who are deaf or hard of hearing will be excluded to a significant degree. To address this issue, some cities are developing systems using phone calls, auto-dialed TTY messages, and e-mails to pre-registered individuals. Other methods include providing real-time open captioning on television programming or dispatching sign language interpreters to television studios to assist in broadcasting important emergency-related news information.

4. With evacuations, public entities must establish evacuation procedures to accommodate people with disabilities, including those who use wheelchairs or other

mobility devices, those who are blind or who have low vision, and those who have cognitive disabilities, and enable them to safely evacuate under trying conditions. Some communities are establishing voluntary, confidential registries of individuals who may need assistance. It is critical to establish procedures that ensure voluntariness and confidentiality, that provide a process for continually updating the registry, and that promote the widest possible awareness and participation.

5. Regarding emergency shelters, they historically have been supplied with the basic necessities of food, water, and blankets. Now they must adopt a more sophisticated and comprehensive approach to ensure accessibility to people with disabilities.

6. Turning to the accessibility of buildings, these facilities must provide an accessible route to an accessible entrance and accessible restrooms. If they have phones, TTY's should be provided. If not all shelters are physically accessible, let the community know which ones are. It is important to survey existing shelters and make them more accessible, both within a physical and programmatic sense.

7. There is the important policy question concerning service animals. A shelter cannot turn away someone who comes with a service animal because of a "no pets" rule. Adjustments may need to be made within the shelter for those who for health or safety reasons cannot be near them.

8. The particular medical needs of people with disabilities must be addressed. Emergency officials must consider the needs of individuals who use electricity to power life-sustaining devices or who use medication require refrigeration. There should be at least one shelter with a backup generator. Even though a city may have a "special needs" shelter with a wide range of specialized services, most people with disabilities do not require these services and should not be turned away from their neighborhood shelter or segregated in particular shelters or parts of shelters.

9. With respect to post-evacuation or temporary housing, if a city provides temporary housing for victims of disasters, it should include accessible units within the range of choices offered (e.g., hotels with accessible rooms.)

The Civil Rights Division issued Chapter 7 of the Tool Kit to address this knowledge gap. In the chapter, we discuss how the requirements of the ADA apply to the various aspects of emergency management, from planning and preparedness, to notification, evacuation, and sheltering and, finally, to recovery and remediation. We provide a checklist for evaluating the accessibility of shelters. We also provide a checklist for use in evaluating the ADA compliance of policies and procedures.

Throughout Chapter 7, we identify certain key steps to meeting the needs of people with disabilities in emergencies:

(1) Emergency planners and managers must have basic working knowledge of the accessibility and nondiscrimination requirements applicable under the ADA;

(2) Emergency planners and managers must know the demographics of the population of people with disabilities who live in their community and the types of disabilities these people have;

(3) Emergency planners and managers must involve people with different types of disabilities in identifying disability-related needs in communication, transportation, accommodations, supportive services, equipment, and supplies that residents and visitors with disabilities will need during an emergency: and

(4) Emergency managers and planners must identify and publicize the resources their community will have available and ready to use when an emergency strikes to meet the needs of residents and visitors with disabilities.

4   Disaster Preparedness for People With Disabilities

Although the government has the responsibility for the disaster preparedness plan, individuals should also be prepared for emergencies. People with disabilities should have an individual disaster preparedness plan that accommodates their unique needs. Your own self-reliance will improve your personal experience during all phases of a disaster.

This section identifies the steps necessary for designing a comprehensive individual disaster preparedness plan, checklists to ensure you have addressed your personal needs, and components of a "go-bag" which may be vital to your survival.

4.1 Personal Disaster Preparation

How well you prepare and how much you practice before a disaster occurs will determine how successfully you deal with and recover from disasters. Your personal disaster preparation is a continuing process. It helps you and your network identify, get, develop, manage, and maintain the information and resources you will need to deal with a disaster when it happens.

Prepare yourself based on the capabilities and limitations you believe you will have after the disaster. Also keep in mind that your usual ways of support and assistance may not be available to you for some time during an evacuation and after the disaster has occurred.

Make a personal disaster plan. This will help you organize information you will need and activities you will do during and after a disaster. Key items in a personal disaster plan are described below. Keep copies of your disaster plan in your disaster supplies kit, car, wallet (behind driver's license or primary identification card), wheelchair pack or at work, etc. Also, share your disaster plan with your network.

4.1.1.1.1 Emergency Information List
Make an emergency information list that you and your network can use. This list will let others know whom to call if they find you unconscious, unable to speak, or if they need to help you evacuate quickly. Besides emergency out-of-town contacts, your list should include the names and numbers of everyone in your network.

Ask a relative or friend who lives more than 100 miles away from you to be your "contact person. " Keep in mind that a caller is more likely to connect with a long-distance number outside the disaster area than with a local number within it. In fact, all family members in a disaster area should call the contact person and give their location and condition. Once this is done, have the contact person give messages to your other friends and relatives who live outside the disaster area. This will help reduce calling into and out of the affected area once the phones are working.

If you have a communication disability, make sure your emergency information list notes the best way to communicate with you. This may be by writing notes, pointing to letters, words, or pictures, or finding a quiet place.

4.1.1.1.2 Medical Information List

Complete a medical information list that you and your network can use. The list should have information about your medical providers. Also include the names of medications you take and their dosages, when you take a medication, the condition for which you take a medication, the name of the doctor who prescribed it, and the doctor's phone number. It is important to record any adaptive equipment you use, your allergies and sensitivities, and communication or cognitive difficulties you may have. Keep this list attached to your emergency information list (described above).

Attach copies of health insurance cards and related information to the medical information list. Keep at least a seven-day supply of essential medications with you at all times. Work with your doctor(s) to get extra supplies of medications and extra copies of prescriptions. Talk with your doctor or pharmacist about what you should do if you do not have enough medicine after a disaster and cannot immediately get what you need. Be sure you ask about the shelf life of your medications and the temperatures at which they should be stored. Determine how often you should replace stored medication. This helps ensure that a medicine's effectiveness does not weaken because of long storage time.

Note: If you take medications (such as methadone, chemotherapy, or radiation therapy) administered to you by a clinic or hospital, ask your provider how you should prepare for a disruption caused by a disaster.

4.2 What You Can Do to Prepare for a Disaster

- Earthquake: Identify a sturdy table or desk to get under in each room. This is important because while the earth is shaking, the movement of the ground will probably make it difficult or impossible for you to move any distance. If you cannot safely get under a desk or table, move near an inside wall of the building and cover your head and neck as best you can. Decide how you will get there when the earthquake begins. Lock your wheels if you are in a wheelchair. In bed, pull the sheets and blankets over you and use your pillow to cover and protect your head and neck.
- Tornado: The lowest floor or below-ground area of your home or workplace is safest. If there is no basement or you cannot get there, choose a room without windows, such as a bathroom or closet. Identify where this safe place is and how you would get there.
- Hurricane or flood: If local officials have not told you to leave the area, stay upstairs and in the middle of the building, away from windows. Avoid going to the lowest floor because hurricanes often cause flooding. If you are Blind or visually impaired, use a long cane in areas where debris may have fallen or furniture may

have shifted. This is recommended even if you do not usually use a cane indoors.

For information about how to prepare for disasters that are specific to your area, contact your local Red Cross chapter.

- Keep your service animals with you in a safe place at home, or take them with you to a shelter.
- Install at least one smoke detector on each level of your home, outside sleeping areas. If you are Deaf or have hearing loss, install a system that has flashing strobe lights to get your attention. If you have battery-operated detectors, replace batteries at least once a year, such as on your birthday, New Year's Day, etc. Test smoke detectors once a month by pushing the test button.
- Find the location of main utility cutoff valves and switches in your home. Learn how and when to disconnect them during an emergency. Try to do this yourself (do not practice shutting off the gas). If you cannot practice alone, arrange for your network to help. Turnoff utilities only if local officials tell you to do so or if you believe there is an immediate threat to life. For example, if you smell gas, see or hear sparking wires, or see water gushing from broken pipes, you should turn off utilities immediately. If you turn gas off, only a professional should turn it back on. If you cannot use the proper tools to turn utilities off at the main valves or switches, turn off the valves under sinks and by the stove. Also turn off all electrical switches in every room. Be sure that the members of your network know the following information:

  - Where to find each utility shutoff valve.
  - How to turn off each utility.
  - Whether you have the proper tools and where they are located, or if your network members need to bring tools with them.

- Identify as many exits as possible from each room and from the building you are in. Be sure to include the windows as exits.
- Make a floor plan of your home. You may want your network to assist you with it. Include your primary escape routes. On the floor plan, mark the rooms where you spend a lot of time. Also, mark where your disaster supplies kit is located. Give a copy of the floor plan to your network. This will help them find you and your supplies, if necessary.
- When traveling, know the types of disasters that threaten the area you will be visiting. Let the hotel or motel front desk know of your possible needs in case of an emergency. Describe the type of help you may need. Remember to let your network members know your travel plans: when you will leave and when you will return.
- Prepare an evacuation plan before a disaster happens.
- If you have to leave your home or workplace, you may need someone's help to evacuate safely, especially down stairwells. If you need assistance during an emergency and your network is not available, find helpers and tell them about

your condition. Give them instructions on what you need and how they can help you evacuate.

- Practice using different ways out of a building, especially if you are above the first floor in a building with many stories. Remember, the elevator may not work or should not be used. Decide what type of equipment you may need for assistance during an evacuation. If you cannot use stairs, talk with your network about how you should be evacuated. They may want to take the Red Cross First Responder course or other training. This can teach them the proper and safe way to lift and carry you without injuring you or themselves.
- If you need devices for an emergency escape, think about your physical capabilities before making a purchase. Store devices nearby, where you can get to them easily. This may mean having more than one emergency escape device available.
- Advocate for yourself. Practice how to quickly explain to people the best way to guide or move you and your adaptive equipment, safely and rapidly.

Be ready to give brief, clear, and specific instructions and directions to rescue personnel, either orally or in writing. For example, say or write these instructions:

- "Please take my--
  - Oxygen tank.
  - Wheelchair.
  - Gamma globulin from the freezer.
  - Insulin from the refrigerator.
  - Communication device from under the bed. "

- "Please do not straighten my knees. They are fused in a bent position. "
- "I have had a brain injury. Please write down all important instructions and information. "
- "I am Blind/visually impaired. Please let me grasp your arm firmly. "
- "I am Deaf. Please write things down for me. "

- When needed, ask for an accommodation from disaster response personnel. For example, let a responder or relief worker know if you cannot wait in lines for long periods for items like water, food, and disaster relief assistance. Practice how to explain clearly and briefly why you need this assistance. You may also want to write the explanation down ahead of time.
- Keep your automobile fuel tank more than half full at all times. Also, stock your vehicle with a small disaster supplies kit. If you do not drive, talk with your network about how you will leave the area if the authorities advise an evacuation. In some communities, local government agencies offer transportation for persons needing assistance during an evacuation. Ask your local emergency management office if these services are available in your area for persons with your disability.
- Become familiar with the emergency or disaster/evacuation plan for your office, school, or any other location where you spend a lot of time. If the current plan does not make arrangements for people with disabilities, make sure the

management at these sites knows your needs. Be sure that you are included in the overall plan for safety and evacuation of the building.

- Choose an alternate place to stay, such as with friends, family, or at a hotel or motel outside your area if you have been told to leave your home. You may have enough early warning time (as with a slow-rising flood or hurricane) to leave before the disaster occurs. This is especially important if you live in a mobile home or trailer. Find out if there are predesignated shelters in your area and where they are.
- Have a care plan for your pet. Plan for the care of your pets if you have to evacuate your home. Pets, unlike service animals, will not be allowed into emergency shelters. So, it is best to decide now where you will take your pet if you must leave. Contact your local Red Cross chapter or Humane Society for more information.
- Have a care plan for your service animal. Service animals are allowed in hotels or motels and Red Cross shelters. However, these places cannot care for your animal. When you leave your home, remember to take a collar, harness, identification tags, records of vaccinations, medications, and food for your service animal with you.

4.3 Conduct an "Ability Self -Assessment"[5]

Evaluate your capabilities, limitations and needs, as well as your surroundings to determine what type of help you will need in an emergency.

1. Will you be able to independently shut off the necessary utilities (gas, water, electricity)?

    * Do you know where shut-off valves are? Can you get to them?

    * Can you find and use the right wrench to turn those handles?

2. Can you operate a fire extinguisher?

    * Have you practiced?

    * Will extended handles make these items usable for you?

3. Will you be able to carry your evacuation kit?

    * What do you need to do, in order to carry it; how much can you carry regularly; do you have duplicates at other locations?

4. Have you moved or secured large objects that might block your escape path?

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[5] Accessed February 4, 2008 at www.preparenow.org/eqtips.html

5. Write instructions for the following (keep a copy with you and share a copy with your personal support network):

a. How to turn off utilities; color-code or label these for quick identification.

   * Main gas valve, located next to the meter - blue; Electrical power circuit breaker box - red; and Main water valve - green.

   * If you have a reduced or limited sense of smell, alert your personal support network to check gas leaks.

b. How to operate and safely move your essential equipment. Consider attaching simple to read and understand instructions to your equipment.

c. How to safely transport you if you need to be carried, and include any areas of vulnerability.

d. How to provide personal assistance services.

   * Remind anyone who assists you to practice strict cleanliness and keep fingers out of mouth. With limited water and increased health hazards, the possibility of infection increases. Keep a supply of latex gloves in your emergency supply kit and ask people assisting you with personal hygiene to use them.

   * List all personal care assistance needs (dressing, bathing, etc.) with instructions on how best to assist you.

   * Make a map of where to find medications, aids and supplies. Share with your personal support network.

e. How Will You Evacuate. Be aware of barriers and possible hazards to a clear path of exit. Change what you are able to change (clear obstacles from aisles; secure large, heavy items such as bookcases that may fall to block your path). Plan alternate exit paths.

4.4 Communication: Practice Assertiveness Skills

Take charge and practice how to quickly explain to people how to move your mobility aids or how to move you safely and rapidly. Be prepared to give clear, specific and concise instructions and directions to rescue personnel, i.e., "take my oxygen tank," "take my wheelchair," "take my gamma globulin from the freezer," "take my insulin from the refrigerator," "take my communication device from under the bed." Practice giving these instructions with the least amount of words in the least amount of time. For example: the traditional "fire fighter's carry" may be hazardous for some people with some respiratory weakness. You need to be able to give brief instructions regarding how to move you.

Be prepared to request an accommodation from disaster personnel. For example, if you are unable to wait in long lines for extended periods of time, for such items as water, food, and disaster relief applications, practice clearly and concisely explaining why you cannot wait in the line.

4.5 Ready Kit and Go Bag

A Ready Kit is a supply of items that you will need if you should have to shelter in place, or rely on your own resources for a few days. A Go Bag has fewer items, but they are the most essential items to take with you in case you must evacuate quickly. See the N.O.D. guide, "Prepare Yourself: Disaster Readiness Tips for People with Disabilities," for a list of suggested supplies. The American Red Cross also has a comprehensive checklist of supplies.

Here are a few items of particular interest to people with sensory disabilities:
• Pad of paper with pens or pencils for writing notes
• Extra batteries for tape recorders, portable TTYs, etc.
• Extra pair of dark glasses, if medically required
• Folding mobility cane
• Food, medicine, and favorite toy for your service animal
• Plastic bags, disposable gloves, and other items for the animal's care

4.5.1.1 Summary Checklist for Personal Disaster Preparation

There are many parts to a personal disaster plan. Fortunately, they do not have to be completed all at once. As you finish each part of your preparation, note the date in the space provided below. Review and update this plan regularly.

Date Completed

_____Make an emergency information list.
Include--
    o Medical and emergency contact information.
    o Emergency out-of-town contacts.
    o Names and numbers of everyone in your network.
    o Name and number of a relative or friend who lives more than 100 miles away from you.

If you have a communication disability, make sure your emergency information list notes the best way to communicate with you.
    _____Fill out a medical information list.
    Include information about--
        o Medical providers.
        o Medications you use.
        o Adaptive equipment and/or body system support equipment you use.

  o Allergies and sensitivities.

  o Communication or cognitive difficulties.

  _____Attach copies of health insurance cards and related information to your medical information list.

  _____Keep at least a seven-day supply of essential medications with you at all times.

  _____Have extra copies of prescriptions.

  _____Talk with your doctor or pharmacist about what you should do if you do not have enough medicine after a disaster. Also, find out the shelf life of your medication and the storage temperature it needs.

  Determine how often you should replace stored medication

  _____Identify safe places to go to during an--

  o Earthquake.

  o Tornado.

  o Hurricane.

  o Flood.

  o Fire.

  _____Install at least one smoke detector on each level of your home, outside sleeping areas.

  _____Find the location of utility cutoff valves and switches. Become familiar with how to operate them.

  _____Identify as many exits as possible (but at least two) from each room and from the building you are in.

  _____Make a floor plan of your home. You may want your network to help you do this. Include your primary escape routes.

  _____Practice using different ways out of a building, especially if you are above the first floor in a building with many stories.

  _____Decide what type of equipment you will need for assistance during an evacuation.

  _____Be ready to give brief, clear, specific instructions and directions to rescue personnel.

  _____If you do not drive, talk with your network about how you will leave the area if authorities advise an evacuation.

  _____Ask your local emergency management office if transportation services are available to persons with your disability during an emergency evacuation. Find out how to arrange to get this service.

  _____Become familiar with the emergency or disaster evacuation plan for your office, school, or any other location where you spend a lot of time.

  _____Choose an alternate place to stay.

  _____Have a care plan for your pet.

  _____Have a care plan for your service animal.

Disaster Preparedness for People With Disabilities
from www.redcross.org/services/disaster/beprepared/apendixa.html
Appendix A: Disaster Supplies Kits and Other Essential Supplies

Basic Disaster Supplies Kit
There are six basics you should stock for your home: 1) water, 2) food, 3) first aid supplies, 4)clothing and bedding, 5) tools and emergency supplies, and 6) special items. Keep the items that you would most likely need during an evacuation in an easy-to-carry container.

Essentials
_____ Battery-operated radio and extra batteries
_____ Flashlight and extra batteries
Do not include candles. Candles cause more fires after a disaster than anything else.

Water
Store water in plastic containers, such as large soft drink bottles. Avoid using containers that will decompose or break, such as milk cartons or glass bottles. A person who is generally active needs to drink at least two quarts of water each day. Hot environments and intense physical activity can double that amount. Children, nursing mothers, and ill people will need to drink even more.
Store three gallons of water per person (one gallon for each day and for each person). Keep at least a three-day supply of water (two quarts for drinking, two quarts for food preparation and sanitation) for each person in the household.

Food
Store at least a three-day supply of nonperishable food. Select foods that require no refrigeration, preparation, or cooking and little or no water. If you must heat food, pack a can of Sterno and matches. Select food items that are compact and lightweight. Include a selection of the following foods in your disaster supplies kit:
_____ Ready-to-eat canned meats
_____ Canned fruits, dried fruits, and nuts
_____ Canned vegetables

First Aid Kit
Assemble a first aid kit for your home and one for each car. A first aid kit should include the following:
_____ Sterile, adhesive bandages in assorted sizes
_____Assorted sizes of safety pins
_____Cleansing agent/soap
_____Latex gloves (2 pairs)
_____Sunscreen
_____2-inch sterile gauze pads (4-6)
_____4-inch sterile gauze pads (4-6)
_____Triangular bandages (3)
_____2-inch sterile roller bandages (3 rolls)
_____3-inch sterile roller bandages (3 rolls)
_____Scissors
_____Adhesive tape
_____Tweezers

____Needle
____Moistened towelettes
____Antiseptic
____Rubbing alcohol
____Thermometer
____Tongue blades (2)
____Tube of petroleum jelly or other lubricant
____Extra eye glasses

Nonprescription Drugs
____Aspirin or nonaspirin pain reliever
____Antidiarrheal medication
____Antacid (for stomach upset)
____Syrup of Ipecac (use to induce vomiting if advised by the Poison Control Center)
____Laxative
____Activated charcoal (use if advised by the Poison Control Center)

Sanitation
____Toilet paper, towelettes
____Soap, liquid detergent
____Feminine hygiene supplies
____Personal hygiene items
____Plastic garbage bags, ties (for personal sanitation uses)
____Plastic bucket with tight lid
____Disinfectant
____Household chlorine bleach
____Facial tissues

Clothing and Bedding
____One complete change of clothing and footwear per person
____Sturdy shoes or work boots
____Rain gear
____Blankets or sleeping bags
____Hat and gloves
____Thermal underwear
____Sunglasses

Tools and Supplies
____Mess kits or paper cups; plates and plastic utensils
____Cash or traveler's checks, coins.
____Nonelectric can opener, utility knife
____Pliers, screwdriver, hammer, crowbar, assorted nails, wood screws
____Shutoff wrench, to turn off household gas and water
____Tape, such as duct tape
____Compass
____Matches in a waterproof container

_____Aluminum foil
_____Plastic storage containers
_____Signal flare
_____Paper, pencil
_____Needles, thread
_____Medicine dropper
_____Adhesive labels
_____Safety goggles
_____Heavy work gloves
_____Whistle
_____Heavy cotton of hemp rope
_____Patch kit and can of seal-in-air
_____Videocassettes
_____Disposable dust masks
_____Plastic sheeting
_____Map of the area (for locating shelters)

For Baby
_____Formula
_____Diapers/wipes
_____Bottles
_____Powdered formula, milk, or baby food
_____Medications

Important Family Documents
Keep these records in a waterproof, portable container:
_____Copy of will, insurance policies, contracts, deeds, stocks and bonds
_____Copy of passports, Social Security cards, immunization records
_____Record of credit card accounts
_____Record of bank account numbers, names, and phone numbers
_____Inventory of valuable household goods, important telephone numbers
_____Family records (birth, marriage, death certificates)
_____Copy of Supplemental Security Income award letter

Medical Needs
_____Heart and high blood pressure medication
_____Insulin
_____Prescription drugs
_____Denture supplies
_____Contact lenses and supplies

Items for Service Animals/Pets
_____Food
_____Additional water
_____Leash/harness
_____Identification tags

_____Medications and medical records
_____Litter/pan

Entertainment
_____Games and books
Other Disaster Supplies

Assemble the supplies below in addition to your basic disaster supplies kit. Combine these with your disaster supplies kit as you need them, and store them somewhere that is easy for you to get to.

Disability-Related Supplies and Special Equipment
Check items you use, and describe item type and location.
_____Glasses:
_____Eating utensils:
_____Grooming utensils:
_____Dressing devices:
_____Writing devices:
_____Hearing device:
_____Oxygen:
Flow rate:
_____Suction equipment:
_____Dialysis equipment:
_____Sanitary supplies:
_____Urinary supplies:
_____Ostomy supplies:
_____Wheelchair:
Wheelchair repair kit:
Motorized:
Manual:
_____Walker:
_____Crutches:
_____Cane(s):
_____Dentures:
_____Monitors:
_____Other:

Service Animal and Pet Supplies
_____Food
_____Extra water
_____Leash/harness
_____Collar
_____Identification tags
_____Medications
_____Vaccinations and medical records

Portable Disaster Supplies Kit
____Emergency information list/other lists
____Small flashlight
____Whistle/other noisemaker
____Water
____Extra medication
____Copies of prescriptions
____Extra pair of glasses
____Hearing aid
____Sanitary supplies
____Pad and pencil or other writing device

Car Supplies
____Several blankets
____Extra set of mittens or gloves, wool socks, and
a wool cap
____Jumper cables and instructions
____Small sack of sand or kitty litter for traction
____Small shovel
____Set of tire chains or traction mats
____Red cloth to use as a flag
____CB radio or cellular telephone

Disaster Preparedness for People With Disabilities
Appendix C

Emergency Information List
Please complete this form and distribute copies to your emergency contact people as well as to each member in your network.

Name:_____

Birth date:_____

Address:_____

_____

Telephone number:_____

Social Security number:_____

Local emergency contact person:_____

Emergency contact person's numbers:_____

Network members:

_____

_____

_____

_____

_____

Network member's home/work numbers:

_____

_____

_____

_____

_____

Out-of-town contact:_____

Out-of-town contact's numbers:

_____

_____

How best to communicate with me:
_____

Medical Information List
Please complete this form and distribute copies to your emergency contact people as well as to each member in your network.

Primary physician:_____

Telephone number:_____

Address:_____

_____

Hospital affiliation:_____

Address:_____

_____

Type of health insurance:_____

Policy number:_____

Blood type:_____

Allergies and sensitivities:

_____

_____

_____

_____

_____

Medications and dosages being taken:

_____

_____

_____

_____

_____

Specific medical conditions:

_____

_____

_____

_____

_____

Physical limitations:

_____

_____

_____

_____

_____

Adaptive equipment and vendors' phones:

_____

_____

_____

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Communication difficulties:

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Cognitive difficulties:

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Disability-Related Supplies and Special Equipment List
Check items you use, and describe item type and location. Distribute copies to your emergency contact people as well as to each member in your network.

_____Glasses:
_____Eating utensils:
_____Grooming utensils:
_____Dressing devices:
_____Writing devices:
_____Hearing device:
_____Oxygen:
Flow rate:
_____Suction equipment:
_____Dialysis equipment:
_____Sanitary supplies:
_____Urinary supplies:
_____Ostomy supplies:
_____Wheelchair:
Wheelchair repair kit:
Motorized:
Manual:
_____Walker:
_____Crutches:
_____Cane(s):
_____Dentures:
_____Monitors:
_____Other:

5   The Special Needs of Individuals with Complex Communication Needs

Communication is a basic human right and vital to survival. People with complex communication needs (CCN) may depend on alternative forms of communication that must be taken into account during an emergency. Although disaster preparedness plans are required to include people with motor, hearing and vision impairments, plans that address the needs of people with severe communication impairments are rare and difficult to find. This adds to the challenges faced by those who are already among the most vulnerable individuals.

The above reasons illustrate why it is imperative that people with CCN should have a personal disaster plan in place in case of emergency. They must have a way to communicate if they are with people who are not familiar with their form of communication. This section focuses on the needs unique to people who depend on alternative forms of communication. This plan should include a "go-bag" with an alternative communication method, and a "talking book" which includes prerecorded messages to help strangers understand the personal needs of an individual with complex communication needs.

5.1 Tips for People With Communication and Speech Related Disabilities

- Determine how you will communicate with emergency personnel: if there is no interpreter; if you do not have your communication devices (augmentative communication device, word board, artificial larynx).
- Store copies of a word or letter board, paper and writing materials, pre-printed messages and key phrases specific to an anticipated emergency, in all your emergency kits, your wallet, purse, etc.
- Consider carrying pre-printed copy of key phrase messages with you such as 'I speak American Sign Language (ASL) and need an ASL interpreter,' 'I do not write or read English." "If you make announcements, I will need to have them written or signed."
- Make sure emergency health information card explains the best method to communicate with you, i.e.: written notes, pointing to letters/words/pictures, finding a quiet place.
- If possible, obtain a battery-operated television that has a decoder chip for access to signed or captioned emergency reports.
- Determine which broadcasting systems will be accessible in terms of continuous news that will be captioned and/or signed. Advocate so that television stations have a plan to secure emergency interpreters for on camera emergency duty.

Call 911

The following tips were presented by Rebecca Ladew to the E9-1-1 Disability Access Summit to address the needs of speech disabled persons when calling 911. Some possible emergency preparedness suggestion/solutions are:

1.   Administer a national outreach program explaining all relay services.

2.   An emergency community center should be set up to identify who is deaf and/or speech disabled. (Neighbors looking out for neighbors who are disabled and/or elderly).

3.   People who are non-speaking should consider wearing a medic alert bracelet – these should carry a basic message. For example, "I cannot speak but I can hear. I use (symbol board, computer voice, etc). Please try and take my communication device with me."

4.   It should be mandatory that hospitals (at least in major centers) should have a symbol board in the ER. If the deaf community has interpreters, why not revoicers for people with speech disabilities who come to the ER? Probably required under the ADA.

5.   9-1-1 centers call takers should be familiar with Speech-To-Speech Relay calls (through educational programs). If someone with a speech disability cannot be understood by the 9-1-1 operator, the operator should know to ask him or her to call back through Speech-To-Speech Relay.

People who have a communication disability should a have some kind signal light that would help to locate them.

Rebecca Ladew is the East Coast Representative of Speech Communication Assistance by Telephone, Inc. (SCAT) and speech disabled representative to the national Interstate Telecommunications Relay Service (TRS) Advisory Council.

This fact sheet is designed to provide a checklist for activities for People with Communication and Speech Related Disabilities to improve your emergency preparedness in an earthquake. It is designed to be used in conjunction with Independent Living Resource Center San Francisco's general EARTHQUAKE TIPS FOR PEOPLE WITH DISABILITIES, TIPS FOR COLLECTING EMERGENCY DOCUMENTS, and TIPS FOR CREATING AN EMERGENCY HEALTH INFORMATION CARD. Without all four tip sheets, you do not have all the information you need to be prepared. Preparation may seem like a lot of work. It is. Preparing does take time and effort. So do a little at a time, as your energy and budget permit. The important thing is to start preparing. The more you do, the more confident you will be that you can protect your self, your family, and your belongings.

DATE COMPLETED/ ACTIVITIES

_____ How Will You Communicate?

_____ Store Communication Aids in all Emergency Kits.

_____ Complete Emergency Health Information Card with Communication Information.

_____ Batteries or Chargers for Communication Equipment.

Communication

Determine how you will communicate with emergency personnel if you do not have your communication devices (augmentative communication device, word board, artificial larynx).

Communication Aids

Store copies of a word or letter board, paper and writing materials, pre-printed messages and key phrases specific to an anticipated emergency, in all your emergency kits, your wallet, purse, etc.

Emergency Health Information Card

Make sure emergency health information card explains the best method to communicate with you, i.e.: written notes, pointing to letters/words/pictures, finding a quiet place.

Alternate Power Source

Obtain an alternative power source (i.e., power converter, batteries) if you use a computer or laptop computer as a means of frequent communication.

5.2 Disaster Checklist for People with Limited Speech[6]

Disasters happen everywhere. Sometimes there is a warning, but not always. Types of disasters include floods, tornados, tsunamis, earthquakes, extreme temperatures, chemical leaks, terrorist attacks on people, contamination of the water supply and so on.

1. **Do you have a support team? Does everyone know what to do? EVERYONE needs a support team. Most rescues are done by friends and neighbors. Your chances of getting the help you need may depend on your support team.**
   a. Train as many people as you can (at least three). Each team member needs to know how to help.
   b. Put the plan in writing and practice with your team. Update your plan quarterly.
   c. Include information about how you will be evacuated, sheltered and how you will communicate in your plan.
   d. Prepare Your Go Bags so you will have all necessary items available.
   e. ALWAYS HAVE A BACKUP PLAN. Not everyone may be able to get to you.
   f. If you cannot take advantage of TV, radio alerts because of hearing or vision problems, plan how you will be alerted.

Resources: Go to http://www.cdihp.org/products.html#evac_guide **to access the** Emergency Evacuation Preparedness Guide. Accessed on 7/15/08.

2. **Do you have an evacuation plan in case you need to leave home or work in an emergency situation? Do you know: (a) Where you will go? (b) How you will get there? (c) Who will transport you/come with you? (d) What you will take with you? (e) What your rights are in a shelter?**

   You need to make arrangements in advance. First, identify your support team (see #1 above). They need to be informed and updated quarterly.
   a. Put your plans in writing. Make sure each member of your support team has a copy.
   b. Do not assume you will have electric power. Plan accordingly.
   c. Practice the plan. Do a trial run of evacuation procedures to work out the quirks. Then practice regularly.
   d. You have the right to bring a service animal, your communication tools and accessories (switches, battery pack, mount) <u>with</u> you. You also have the right to bring someone who understands your communication/basic needs with you if you are evacuated.
   e. Plan for elevators being 'out' if you live/work in a multi story building

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[6] AAC-RERC. Disaster Preparedness for People Who Have Limited Speech. Retrieved December 13, 2008 from http://www.aac-rerc.com/index.php?option=com_content&task=view&id=149

Resources: Go to http://www.cdihp.org/products.html#evac_guide to access the Emergency Evacuation Preparedness Guide. Accessed on 7/15/08.

3. **Is your "Go Bag" packed?**

   You need to have a "Go Bag" packed and located where you can get it quickly in case you need to leave your home/workplace. Note: You may need more than one "Go Bag."
   a. You will NOT have time to "throw things together" or quickly access everything you will need in an emergency. You MUST prepare in advance.
   b. Don't forget to include specific equipment, such as feeding equipment, batteries, switches, chargers, a laminated communication display so you can access pertinent vocabulary.
   c. Make sure you label all items because things get lost easily in shelters.
   d. Consider making a small manual with photos to provide instructions about how you need to be lifted and seated, how you sleep and eat. Be sure to include information about how you communicate, how to maintain your equipment, *etc.*

4. **Do you have paper (laminated) communication display(s) with you <u>at all times</u>? Do your displays include vocabulary for emergencies? Do you have written instructions about how to communicate with you with you <u>at all times</u>? Communication is an important key to survival, safety and well-being during any emergency. Do not take chances.**
   a. ALWAYS have a laminated paper communication display with you. Include key vocabulary items (*e.g.*, ways to ask questions, express basic needs, pain, medication, emotions, etc.
   b. If possible, make sure someone who understands how you communicate stays with you. c. If you use an electronic speech generating device, take it with you if possible. However, be aware that shelters may or may not have electricity. d. Don't forget to take other accessories with you (*e.g.*, batteries, charger, switches, mounts, software, *etc.*).

Resources: Appendix A has some examples. [Please consider sharing your personal displays.]

5. **Do you always carry a copy of your health information in a water proof bag in case of an emergency? Insurance card? Prescriptions? Other critical medical information?**

   In a waterproof bag/container, you need copies of your important medical information, insurance cards, accommodation requirements, emergency contacts, doctor's names, instructions for activities of daily living, allergies, inhalers and medications
   a. Make multiple copies of your emergency health information to keep at work, in your wallet, wheelchair pack, or purse with your primary

identification card.
   b. Put a copy in your Go-Bags.
   c. Review and update this information whenever your medications or other information changes, but no less than twice a year.

Resources: See Appendix B for Emergency Health Information Form you can fill out and keep with you.

6. **Are you prepared to remain at home or work during an emergency? Do you have enough water and food stored for 7 days? A radio with extra batteries? Flashlights with extra batteries? Medical supplies? Enough of your own medicines for 7 days? A way to communicate? A way to call for help?**

   If you plan to stay at home/work, plan for the likelihood that telephones, power and transportation services may not function. Make sure you have enough food and water for at least seven days and that someone will periodically check on you.

7. **If you think, "Never mind….this won't ever happen to me?" THINK AGAIN. Emergencies can (and do) happen to anyone. Be PREPARED, <u>not</u> sorry.**

   The best preparation for most emergencies and all disasters is advance planning. For people with disabilities and activity limitations, it is absolutely essential to have a plan in place that includes, at the very least, a support team, 'go bags', and communication tools.

b. Don't forget to include specific equipment, such as feeding equipment, batteries, switches, chargers, a laminated communication display so you can access pertinent vocabulary.

c. Make sure you label all items because things get lost easily in shelters.

d. Consider making a small manual with photos to provide instructions about how you need to be lifted and seated, how you sleep and eat. Be sure to include information about how you communicate, how to maintain your equipment, *etc*.

6   The Special Needs of People on the Autism Spectrum

Autism seriously affects a person's ability to communicate, interact in social situations, and make sound judgments. In an emergency, these characteristics can add to the challenges that emergency and shelter personnel face in carrying out their duties. Because individuals with autism may bolt or wander away from a care provider or shelter, these individuals may need special considerations during disasters. The traits of autism are not always obvious and vary from person to person, but responders can learn to identify autistic individuals and minimize the risks.

Parents and caregivers should prepare themselves for an autism emergency in order to ensure the safety of their loved one. Simple actions such as making an emergency contact handout for your child, readying your home, and remaining calm can lower the risks faced in an emergency situation and help individuals with autism cope with the situation.

6.1 A Possible Scenario[7]

A vicious storm has just blown through your area and the power has gone out. You look out your door to find trees and power lines strewn across the road. Some buildings have broken windows and doors. You venture outside and hear soft moaning coming from the house across the street.

Your yells of "Anybody home? Anybody need help" are met with silence, save for the moaning sound. Following your ears you happen across a young teenage girl gently rocking back and forth, flipping pages of a book with the speed of a person shuffling cards. Certainly she's not reading the text as she continues to emit an unearthly "eeeee" sound.

Outside you hear an announcement: everyone is to evacuate their homes and head to the basement of the local public school before the next thunderstorm cell arrives with possible tornadoes. Your assurance to the girl, "Come along, everything is going to be all right", is met with no response. You repeat yourself a few times, each a little louder. Still no response. She doesn't even look at you. You wonder if she is in shock or hearing impaired.

You hear a strong gust of wind. "No more fooling around" you think to yourself. Quickly and without warning you neatly scoop the girl up to carry her with you to shelter and safety. The last rational thought you remember having before racing out the house towards safety was "I may have well just picked up a wild cougar."

To the well-meaning neighbor, friend or stranger who doesn't recognize the characteristics of autism, it may well have seemed the child acted like a frightened animal. One of the major characteristics of people on the autism spectrum is sensory distortions which are often combined with an exaggerated startle response. Add to his,

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[7] Accessed December 9, 2008 from http://www.autism.com/individuals/disasterprep.htm

difficulties people with autism have in experiencing change and their various communication challenges. Without advance preparedness — or at minimum, visual aids that alert a stranger that autism is present — a rescue attempt can escalate to a potentially dangerous situation of its own.

A comprehensive disaster preparedness program for people with autism will have two components: 1} the use of visual materials to alert on-the-spot responders that autism is present and that offer practical advice for helping these individuals and 2) advance preparedness in the form of training for the child or adult on the spectrum in the event of a natural disaster, and education and awareness of first responders.

6.2 Identifying Individuals on the Autism Spectrum[8]

Autism is a neurologically-based developmental disability that seriously affects a person's ability to communicate, socialize, and make judgments. Autism also affects the person's sensory responses to even normal levels of lights, sounds, touches, odors, and tastes. It is typically observed by age three, and is more common in males than females. It is not caused by the way parents raise their children. Despite ongoing research, there is no known cause or cure, although people with autism can make remarkable gains. Autism is referred to as a spectrum disorder. It affects each person differently and ranges from mild to severe. Other terms for autism may include: Asperger Syndrome, High Functioning Autism or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Parents and professionals have learned through experience and education how to recognize the common traits of autism. Autism may or may not be physically obvious--there may be no particular physical marker. No one expects an emergency responder to be able to diagnose autism, but there are some diagnostic behaviors and characteristics you may observe.

A person who has autism may:
- Be non-verbal or have limited speech;
- Avoid eye contact;
- Prefer to be alone;
- Lack fear of real danger;
- Demonstrate apparent insensitivity or high tolerance for pain;
- Have difficulty in expressing needs; does not use gestures;
- Unusual responses to lights, sounds, or other sensory input;
- Seek sensory stimulation, including heavy pressure;
- Have difficulty interacting with others;
- Exhibit avoidance of touch;
- Demonstrate sustained unusual repetitive actions;
- Display inappropriate laughing or giggling;
- Have inappropriate attachment to objects;

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[8] From Autism and Risk Management. Disaster Preparedness Link. Accessed December 1, 2008 from
http://www.autismriskmanagement.com/lawenforcement.html

- Spin or twirl objects and exhibit finger, arm, or wrist flicking;
- If verbal, may have trouble with correct speech volume (i.e., loud to whisper, and/or monotone, computer-like vocal intonation);
- Appear as if deaf, cover their ears and look away;
- Display clumsiness, toe-walk or have difficulty running;
- Rock back and forth;
- Talk to themselves or no one in particular;
- Echo words and phrases; and
- Display fascination with water, lights, reflections and shiny objects.

People with autism are as different from each other as we all are. They may inherently present autism spectrum-based behaviors and characteristics in different combinations and degrees. Each person will have a different level of independence as well. Some persons with autism will have a caregiver with them at all times. Others will live semi or fully independent lives. You will hear terms such as low functioning autism, high functioning autism, and Asperger syndrome to describe the condition. In most cases, the person will have difficulties following your verbal commands, reading your body language, and will have deficits in social understanding. As with Alzheimer's patients, a person who has autism may attempt to bolt and wander from care provider or shelter. They may be dangerously attracted to water sources, roadways, or disaster debris and emergency vehicles. They may also attempt to enter occupied dwellings.

A good training program can be designed to allow responders to better serve the public, and make the best use of valuable time and resources. (Contact author below to inquire about training and training tools.) Training designed to inform responders about the risks associated with autism and offer suggestions and options about how to address those risks is highly recommended.

Included in those risks are:
- Behaviors that draw attention
- A misinterpretation of those behaviors by others
- Person may lack fear of real dangers
- Person may not recognize authority figures or know what is expected of them if they do
- Inherent condition may present as misleading indicators of guilt such as a lack of eye contact, an apparent aloof and indifferent manner, will change topic of conversation
- Responders not being aware of associated medical conditions such as seizure disorder, asthma, or low muscle tone
- Sensory sensitivity issues that may produce fight or flight reaction
- Basic verbal and nonverbal communication difficulties
- Issues such as hypotonia-low muscle tone, high tolerance for pain and mechanical/positional asphyxia will require alternate restraint options and

techniques

Communication
- The person you are interacting with:
- May be non-verbal or have limited verbal skills
- May not respond to your commands or questions
- May repeat or mimic your words & phrases; your body language or emotional state
- May have difficulty expressing their needs

Behavior
- May display tantrums or extreme distress for no apparent reason
- May ignore your presence
- May be extremely sensitive to lights, words, aromas or touch
- May display a lack of eye contact
- May bolt away from emergency personnel
- May have no fear of real danger
- May not feel pain or discomfort
- May exhibit self-stimulating behavior; hand flapping, body rocking or unusual attachment to objects. If these behaviors are *not* presenting as a danger to themselves or others it is in your best interest not to interfere with it. Attempts to stop the behaviors may increase anxiety and cause the individual
- to act out aggressively.

6.3 Information for Law Enforcement, First Response and Criminal Justice Professionals[9]

Law enforcement responders may unexpectedly encounter or be asked to find a person with autism. Recognizing the behavior symptoms and knowing contact approaches can minimize situations of risk--risk or victimization of the person with autism, and risk to the first responder.

You may learn the person has autism from your dispatcher, someone at the scene, or the person himself or herself. Here are some tips for responders:

- Make sure the person is unarmed and maintain a safe distance because they may suddenly invade your personal space
- Talk calmly and softly
- Speak in direct, short phrases such as: "Stand up now." or "Get in the car."
- Avoid slang expressions, such as: "What's up your sleeve?" or "Are you pulling my leg?"
- Allow for delayed responses to your questions or commands

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[9] Accessed December 1, 2008 from http://www.autismriskmanagement.com/lawenforcement.html

- Repeat or rephrase
- Consider use of pictures, written phrases and commands, and sign language
- Use low gestures for attention; avoid rapid pointing or waving
- Examine for presence of medical alert jewelry or tags, or an autism handout card
- Model calming body language (such as slow breathing and keeping hands low)
- Model the behavior you want the person to display.
- A person with autism may not react well to changes in routine or the presence of strangers, even a uniformed stranger
- Officers should not interpret the person's failure to respond to orders or questions as a lack of cooperation or a reason for increased force
- Seek information and assistance from parent or others at the scene about how to communicate with and de-escalate the person's behavior
- Avoid stopping repetitive behaviors unless there is risk of injury to yourself or others. If the individual is holding and appears to be fascinated with an inanimate object, consider allowing subject to hold the item for the calming effect (if officer safety is not jeopardized by doing so)
- Evaluate for injury: person may not ask for help or show any indications of pain, even though injury seems apparent
- Be aware that the person may be having a seizure
- Be aware of person's self-protective responses and sensitivities to even usual lights, sounds, touches, orders, and animals
- If possible, turn off sirens and flashing lights and remove canine partners, crowds, or other sensory stimulation from the scene
- If person's behavior escalates, use geographic containment and maintain a safe distance until any inappropriate behaviors lessen
- Remain alert to the possibility of outbursts or impulsive acts
- Use your discretion. If you have determined that the person is unarmed and have established geographic containment, use all available time to allow the person to de-escalate themselves without your intervention

If in custody, alert jail authorities. Consider initial isolation facility. Person would be at risk in general prison population. REMEMBER: Each individual with autism is unique and may act or react differently. PLEASE contact a professional who is familiar with autism. (Debbaudt & Legacy, 2005)

6.4 Autism & Emergency Preparedness: Tips and Information for Emergency

Shelter Staff and Trainers
From http://www.autismriskmanagement.com/

Autism Emergency Contact Questions/Triage Model
- Name of child or adult
- Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- Sensory, medical, or dietary issues and requirements, if any
- Inclination for wandering and any atypical behaviors or characteristics that may attract attention
- Favorite attractions and locations where person may be found
- Likes and dislikes, for example, food, toys, topics of conversation, music, animals
- Approach and de-escalation techniques
- Method of communication, if non-verbal - sign language, picture boards, written word
- ID wear—jewelry, tags on clothes, printed handout card

Autism and Access to Shelters
- Minimize waiting time
- Talk with parent or caregiver to determine person's unique needs
- Allow patient to tour facility, as appropriate in order to become familiar with new surroundings
- Praise or reward for cooperative behavior
- If verbal, patient may produce false complaints or misleading statements
- Consider that a child or adult with autism may need more than one personal care provider
- Offer family the most sensory free environment possible
- Allow family to bring in items that they know will help the individual be calm

Special considerations may need to be made in order for the individual to reset the sensory bombardment and drastic changes an emergency situation can create.

Shelters should make sure that space for sensory quiet time is available for person with an autism spectrum disorder. This may be accomplished by several means. Access to less used or even staff-only, authorized areas may need to be considered. Two versions of Special Needs shelters may need to be considered when individual needs are at odds with each other. For example, when a person with sensitivity to sound is in proximity with a person who needs life-saving technology that emits sound. Creative use of space will be difficult under emergency situations but making every effort to accommodate individuals with autism will add to the effectiveness of the shelter as well as the shelter staff's ability to provide services to other refugees.

Remember: Each individual with autism is unique and may act or react differently during an emergency!

The parent or caregiver is your ***best resource*** of information on how to effectively interact with the person who has autism. Ask how to specifically address the following needs: communication, behavior, sensory issues, anxiety responses, and rewards.

6.5 Resources for Parents and Caregivers

Are you Prepared for an Autism Emergency?[10]
To ensure safety and lower risk for a child or adult with autism, parents and care providers will need to become proactive and prepare an informational handout. A leading cause for concern are children and adults who run away or wander from parents and care providers. Tragically, children and adults with autism are often attracted to water sources such as pools, ponds, and lakes. For instance, drowning is a leading cause of death for a child or adult who has autism.

Wandering can occur anywhere at anytime. The first time is often the worst time.

Another concern is preparation in the event that you become incapacitated or injured while caring for a person with autism at home or in the community.

An informational handout should be developed, copied and carried with you at all times—at home, in your car, purse or wallet. Also circulate this handout to family members, trusted neighbors, friends and co-workers.

If wandering is a concern, contact law enforcement, fire and ambulance agencies. Ask your local 911 call center to "red flag" this information in their 911 computer data base. Dispatchers can alert patrol officers about your concerns before they arrive. When we provide law enforcement with key information before an incident occurs, we can expect better responses.

Alert your neighbors
The behaviors and characteristics of autism have the potential to attract attention from the public. Law enforcement professionals suggest that you reach out and get to know your neighbors.
- Decide what information to present to neighbors
- Plan a brief visit to your neighbors
- Introduce your child or adult or a photograph
- Give your neighbor a simple handout with your name, address, and phone number
- Ask them to call you immediately if they see your son or daughter outside the home
- This approach may be a good way to avoid problems down the road and will let your neighbors:

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[10] Accessed December 1, 2008 from http://www.autismriskmanagement.com/parents.html

- Know the reason for unusual behaviors
- Know that you are approachable
- Have the opportunity to call you before they call 911

Knowing your neighbors can lead to better social interactions for your loved ones with autism.

Prevention
If wandering is an issue for your family, consider contacting a professional locksmith, security company or home improvement professional.

Autism Emergency Contact Handout Model
- Name of child or adult
- Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- Sensory, medical, or dietary issues and requirements, if any
- Inclination for elopement and any atypical behaviors or characteristics that may attract attention
- Favorite attractions and locations where person may be found
- Likes, dislikes--approach and de-escalation techniques
- Method of communication, if non-verbal sign language, picture boards, written word
- ID wear jewelry, tags on clothes, printed handout card
- Map and address guide to nearby properties with water sources and dangerous locations highlighted
- Blueprint or drawing of home, with bedrooms of individual highlighted

6.6 Disaster Preparedness Tips for Families[11]

Tip #1. Practice calm
Parents and care providers need to project a demeanor of calm during a disaster or emergency, even if we're not! Children and adults on the spectrum may sense your emotional state—and mimic it. Practice for and prepare to project a sense of calm.

Tip #2. Prepare for immediate needs before disaster
- Be ready to evacuate. Have a plan for getting you and your loved ones out of your home or building (ask family or friends for assistance, if necessary). Also, plan two evacuation routes because some roads may be closed or blocked in a disaster.
- Create a self-help network of relatives, friends or co-workers to assist in an

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[11] Retrieved December 1, 2008 from http://www.autisminfo.com/DisasterPreparednessTips.pdf?docID=2661

emergency.

- If you think you may need assistance in a disaster, discuss your disability with relatives, friends, and co-workers and ask for their help.
- Give a key to a neighbor or friend who may be able to assist you in a disaster.
- Contact your local emergency information management office now. (Many local emergency management offices maintain registers of people with disabilities so they can be located and assisted quickly in a disaster.)
- Wearing a medical alert tag or bracelet to identify your disability may help in case of an emergency.
- If you have a severe speech, language, or hearing disability:
  - When you dial 911, tap space bar to indicate tdD call.
  - Store a writing pad and pencils to communicate with others.
  - Keep a flashlight handy to signal whereabouts to other people and for illumination to aid in communication.
  - Remind friends that you cannot completely hear warnings or emergency instructions. Ask them to be your source of emergency information as it comes over their radio.
  - If you have a hearing ear dog, be aware that the dog may become confused or disoriented in an emergency. Store extra food, water and supplies for your dog.
- Consider your pets and plan to take care of them in advance, particularly if sheltering is necessary, so you can concentrate on the rest of the family as danger approaches.
- Have a disaster supplies kit on hand you can use these at home or in an evacuation setting. Kits should include:
  1. Flashlight with extra batteries
  2. Portable, battery-operated radio and extra batteries
  3. First aid kit and manual
  4. Emergency food and water for at least two days (per person)
  5. Manual can opener
  6. Essential medicines
  7. Cash and credit cards (be sure to withdraw cash in advance)
  8. Sturdy shoes
- Also, in case of evacuation, pack a safety & comfort kit, which can include:
  1. Blanket
  2. Pillow
  3. Folding chair
  4. Sleeping bag or cot
  5. Food and water for at least two days
  6. Medication for three to seven days
  7. Personal hygiene items

8. Identification and valuable documents (insurance, birth and marriage certificates, and special-needs forms)
9. Battery-operated radio
10. Flashlight
11. Batteries
12. Change of clothes
13. "Comfort" items such as CD players and CDs (with extra batteries) or DVD player and DVDs
14. Ear plugs or eye shades
15. Storage boxes to store small items, could be plastic with lids
16. A drawing of the building layout and map of the area to give an orientation of where you are in relation to your home.
17. An ID bracelet and autism information cards to explain behaviors to others.

Tip #3. Prepare for needs in your home *now* so that you'll be ready after disaster strikes

- Look for items that may have broken or been displaced that could cause a hazard, particularly electrical lines.
- Beware of carbon monoxide poisoning. Centers for Disease Control (CDC) send this warning: "Preliminary reports indicate that people in states affected by Hurricane Katrina have died or been poisoned by carbon monoxide. An urgent health recommendation that should be broadly distributed is to never use generators, grills, camp stoves, or other gasoline, propane, natural gas, or charcoal-burning devices inside the home, basement, garage, or camper—or even outside near an open window."
- Follow instructions for disaster supplies kit and the safety & comfort kit outlined in Tip #2.

6.7 Additional hurricane and emergency preparedness Web sites:

- FEMA hurricane and general disaster home page: http://www.fema.gov/hazards/hurricanes
- NOAA: http://www.aoml.noaa.gov/hrd/links.html
- American Red Cross: www.redcross.org
- Centers for Disease Control, with respect to concerns for carbon monoxide poisoning: www.bt.cdc.gov/disasters/carbon monoxide.asp

6.8 Information for People with Autism
From http://www.autismriskmanagement.com/people.html

Persons with autism who are able to navigate the community without assistance should strongly consider developing a personal handout for the police. Remember that the initial uninformed contact with police presents the highest potential for a negative outcome.

Some suggestions to consider during sudden interactions with police:
- Do not attempt to flee
- Do not make sudden movements
- Try to remain calm
- Verbally let officer know you have autism. If nonverbal, use alternative communication tools, such as a simple sign language card, that indicates the need to write
- Obtain permission or signal intentions before reaching into a coat or pants pocket, or reaching into a car glove box
- If unable to answer questions, consider use of a generic or person-specific autism information card
- If you lose the ability to speak when under stress, consider wearing an alert bracelet or necklace that is easy to see--one that lets the reader know you have an information card
- Ask officer to contact an advocate, if necessary and possible
- For the best protection of all involved, the person with autism who has been arrested should, either verbally or through an information card, invoke the right to remain silent and ask to represented by an attorney
- If you are a victim or are reporting a crime, you do not need to have an attorney present to speak to the police, but you may want the police to contact a family member, advocate or friend who can help you through the interview process
- Carry the phone number of an advocacy organization or personal advocate, relative or friend

Everyone should take precautions to avoid becoming victims of criminal activity. Unfortunately, persons with autism may need to take extra precautions. In order to avoid detection, arrest, and prosecution, criminally bent individuals become skilled at picking out easy victims. Robbers and con artists will notice unusual behavior when they select their next victim. An unarmed robber or con artist will operate in public places. Anywhere there's regular pedestrian traffic or large public gatherings will afford a criminal the chance to identify or mark victims. If you are threatened or asked to give up money or valuables, do not resist. Give them what they want. These things can be replaced. Once in a safe area, call the police.

To avoid victimization from street crimes or abusers:
- Avoid areas that are unfamiliar to you
- Travel in groups if possible or walk with the crowd
- Do not dawdle or appear rushed in a crowd

- Park in a secure area
- Keep car doors locked
- Take a look around the parking lot before unlocking doors and exiting vehicle
- Arrive with the crowd to work, school, events
- Avoid gawking
- Do not maintain eye contact
- Let someone know of your travel plans
- Do not carry large amounts of cash
- Dress to suit the area
- Stay in well lit areas
- Do not wander or explore off well traveled pedestrian walkways or vehicular avenues

Contact your local autism advocacy organization and suggest that they become involved in developing a partnership for ongoing law enforcement training sessions.

7   Emergency Preparedness Resources for the Hearing Impaired

In spite of efforts to address the needs of the hearing impaired during emergency situations, many weaknesses still exist in the emergency preparedness infrastructure. Of utmost concern is the effectiveness of emergency communication systems. Because these individuals cannot depend on auditory information for facts, other systems must be developed to alert the hearing impaired to emergencies.

People with hearing impairments can take precautions to ensure that their communication needs are adequately met during a disaster. In additional to the general emergency preparations previously outlined, deaf and hearing-impaired individuals should address specific needs such as hearing aids and communication plans. These actions will help ensure an individuals safety and ability to cope with a disaster.

7.1 Emergency Preparedness and Emergency Communication Access

Lessons Learned Since 9/11 and Recommendations[12]

Executive Summary
The events of September 11, 2001 and its aftermath exposed many glaring weaknesses in the emergency preparedness infrastructure that compromise the safety and security of 28 million Americans who are deaf, hard of hearing, late-deafened and deaf-blind. Experiences with emergencies during the past three years continue to reinforce the urgent need for these weaknesses to be addressed.

Top Priority: An Effective Emergency Communication System
America's current public warning and emergency communication systems get a failing grade from deaf, hard of hearing, late-deafened and deaf-blind individuals. There are too few effective options for communication and the options currently available have largely proved unreliable.

Hearing loss has a major impact on communication in emergencies because it is impossible to depend on auditory information. Sirens, shouted warnings, calls from rescue workers trying to locate people in rubble, knocks on doors to give urgent information, quick phone calls to give a heads-up about a developing situation, radios, public address systems – all can be useless. Captioning of television and Internet news and coverage for text messages is not a given. Without effective communication systems, deaf and hard of hearing individuals do not know that there is an emergency, cannot learn what steps must be taken to protect themselves and others, and have no access to critical resources in the aftermath of an emergency.

This report includes an extensive list of recommendations designed to increase the number and variety of communication options, ensure reliability, and build in

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[12] Retrieved December 1, 2008 from http://www.nvrc.org/content.aspx?page=5138&section=5

redundancy. The recommendations will require widespread consumer collaboration with government agencies, legislators, broadcasters, manufacturers, program and service providers, product developers, telecommunications and Internet providers, public safety officials, and many other entities.

Developing an effective emergency communication system for individuals who are deaf and hard of hearing will help everyone. In an emergency, many people with no hearing loss have difficulty hearing. The combination of stress and noise such as high winds, explosions, shouts, or the roar of a fire can make it impossible to hear well.

Involvement and Integration in Activities
Other weaknesses identified in the nation's emergency planning make it imperative for quick action to ensure that individuals who are deaf, hard of hearing, late-deafened and deaf-blind are actively involved in community, regional, state, and federal emergency planning processes, equipment testing, disaster exercises, CERT trainings, Citizen Corps activities, training of public safety and security personnel, and other activities. The involvement of individuals who are deaf, hard of hearing, late-deafened and deaf-blind will tap into their tremendous talents and quickly help to increase understanding of their needs in a wide variety of areas.

Emergency planners are setting up systems across the U.S. that do not take into account the unique needs of individuals who are deaf, hard of hearing, late-deafened and deaf-blind. History has repeatedly shown that redesigning and adapting equipment, programs and services because these needs were not taken into account from the beginning is almost always more expensive and rarely as effective.

Additional recommendations in this report are intended to build a national network that will encourage participation and collaboration and provide the tools to help ensure its success. This network will offer technical assistance, research, education, training, planning, advice and consultation, and development of model programs and services. It will create a knowledge bank of the nation's best expertise to tackle a wide range of needs.

7.2 12 CONSIDERATIONS FOR ACCESSIBLE EMERGENCY COMMUNICATIONS[13]

There are over 50 million people in America with a disability (U.S. Census Bureau, 2006) who are frequently overlooked in emergencies. This document is an introduction to select considerations to help meet the distinctive needs of people with disabilities (PWD) during an emergency.

TECHNOLOGY CONSIDERATIONS:

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[13] Retrieved December 8, 2008 from http://www.wirelessrerc.org/about-us/projects/development-projects/d3-wireless-emergency-communications.html

1. **Develop or provide accessible formats to disseminate alerts and information to PWD.**

   In order for alerts and other emergency information to effectively reach all people it is essential that they be disseminated in a variety of formats (text, audio, multi-media) utilizing multiple methods (broadcast, datacast, Internet/e-mail) to a variety of devices (cell phones, PDAs, TVs, radios).

2. **Manufacture/procure cost effective, universally designed (UD) devices to receive emergency communications (EC).**

   UD communications technologies can reduce the need for high-cost assistive devices. Accessibility solutions should be built into devices because existing technology often requires add-on accessibility software and/or hardware to make it usable by PWD.

3. **Develop software/hardware solutions and interoperable networks for receiving alert feeds from multiple sources.**

   Subscription-based alert services can send emergency alerts via wireline and wireless networks as text messages, voicemails or e-mails in accessible formats to PWD.

POLICY CONSIDERATIONS:

4. **Ensure that EC rulemakings consider the needs of PWD.**

   Before deployment of a national system like the Digital Emergency Alert System (DEAS) the FCC releases rulemaking proceedings seeking the valuable insights and comments of stakeholders. Participation in FCC comment periods will facilitate inclusion of stakeholders such as PWD.

5. **Ensure responsible federal agencies enforce laws safeguarding PWD.**

   The FCC, DHS's Interagency Coordinating Council on Emergency Preparedness and PWD, DOJ, and FEMA enforcement actions helps to ensure PWD are considered during emergencies.

6. **Develop EC related policymaking and regulatory initiatives.**

   The NCD, the Access Board, NOD and others are a model for public and private organizations that have not yet considered or are unaware of the specific needs of PWD in emergencies.

TRAINING & EDUCATION CONSIDERATIONS:

7. **Integrate PWD into emergency management planning, exercises and simulations.**

8. **Educate emergency/public safety personnel, and relevant community entities on how to provide communications to people with different disabilities in emergency situations.**

9. **Train emergency personnel in use of accessible communications technologies.**

10. **Provide emergency/public safety personnel, and relevant community entities with sensitivity training on needs and abilities of PWD.**

11. **Educate end-users on the benefits of receiving alerts/subsequent emergency information.**

12. **Convene stakeholders for regional workshops on emergency preparedness/communications.**
    The following is a selected list of web sites with topic specific information:

7.3 Additional Resources

TECHNOLOGY CONSIDERATIONS:

American Foundation for the Blind: www.afb.org

The Carl and Ruth Shapiro Family National Center for Accessible Media:
Access to Emergency Alerts for People with Disabilities: http://ncam.wgbh.org/alerts/
and www.incident.com/access
Access to Locally Televised On-Screen Information: http://ncam.wgbh.org/onscreen/
Captioning Solutions for Handheld Media and Mobile Devices:
http://ncam.wgbh.org/mm

Northern Virginia Resource Center for Deaf and Hard of Hearing Persons:
Emergency Preparedness and Emergency Communications Access, Lessons Learned Since 9/11 and Recommendations:
http://www.nvrc.org/content.aspx?page=5138&section=5

The Smith-Kettlewell Eye Research Institute: Emergency Information for People With Visual Impairments: Evaluation of Five Accessible Formats:
http://www.ski.org/Rehab/WCrandall/EgressIIIWeb/egressIIIabstract.html and
www.ski.org/rehab

Trace Research & Development Center: http://trace.wisc.edu/

Wireless Emergency Communications Project of the Wireless RERC:
www.wirelessrerc.org

POLICY CONSIDERATIONS:

Department of Homeland Security's (DHS) Interagency Coordinating Council on Emergency Preparedness and People with Disabilities:
http://www.dhs.gov/xprepresp/committees/editorial_0591.shtm

Federal Emergency Management Agency (FEMA): Accommodating People with Disabilities in Disasters: A Reference Guide to Federal Law:
http://www.fema.gov/news/newsrelease.fema?id=38990

The FCC's Commercial Mobile Service Alert Advisory Committee's technical standards and protocols for the delivery of alerts to mobile devices:
http://www.fcc.gov/pshs/cmsaac/

The FCC's Second Report & Order and Further Notice of Proposed Rulemaking Regarding the Emergency Alert System:
http://fjallfoss.fcc.gov/edocs_public/attachmatch/FCC-07-109A1.doc

Congressional Research Service's Report for Congress: The Americans with Disabilities Act and Emergency Preparedness and Response:
http://www.ncseonline.org/NLE/CRSreports/06Jul/RS22254.pdf

National Organization on Disability's (NOD) Information on Accessible Emergency Communications:
http://www.nod.org/index.cfm?fuseaction=page.viewPage&pageID=1430&nodeID=1&FeatureID=1134&redirected=1&CFID=10558214&CFTOKEN=13069388

Impact of Hurricanes Katrina and Rita on People with Disabilities: A Look Back and Remaining Challenges, NCD Report 2006:
http://www.ncd.gov/newsroom/publications/2006/pdf/hurricanes_impact.pdf

Research and Policy Recommendations reported in the proceedings of the "Accessible Emergency Notification and Communication: State of the Science Conference" held at Gallaudet University by the RERC on Telecommunications Access. 2006:
http://tap.gallaudet.edu/emergency/nov05conference/emergencycommconf.asp

TRAINING & EDUCATION CONSIDERATIONS:

American Association of People with Disabilities:
http://www.aapd.com/News/emergency/index_emergprep.php

The Center for an Accessible Society's Disaster Mitigation for People with Disabilities:
http://www.accessiblesociety.org/topics/independentliving/disasterprep.htm

Community Emergency Preparedness Information Network (CEPIN) at TDI:
http://www.cepintdi.org/

EAD & Associates, LLC, Emergency Management & Special Needs Consultants:
http://www.eadassociates.com/

Emergency Preparedness: Addressing the Needs of People with Disabilities. Columbia University Mailman School of Public Health:
www.ncdp.mailman.columbia.edu

National Center on Emergency Preparedness for People with Disabilities:
www.disabilitypreparedness.org

NOD's Emergency Preparedness Initiative:
http://www.nod.org/index.cfm?fuseaction=Page.viewPage&pageId=11

Saving Lives: Including People with Disabilities in Emergency Planning, NOD 2005: http://www.ncd.gov/newsroom/publications/2005/saving_lives.htm

Special Needs Assessment for Katrina Evacuees (SNAKE) Project Report, NOD 2005: http://www.nod.org/Resources/PDFs/katrina_snake_report.doc

7.4 Tips for the Deaf or Hearing Impaired[14]

- **Hearing aids**
  - Store hearing aid(s) in a strategic, consistent and secured location so they can be found and used after a disaster.
  - For example, consider storing them in a container by your bedside, which is attached to a nightstand or bedpost using a string or Velcro. Missing or damaged hearing aids will be difficult to replace or fix immediately after a major disaster.

- **Batteries**
  - Store extra batteries for hearing aids and implants. If available, store an extra hearing aid with your emergency supplies.
  - Maintain TTY batteries. Consult your manual for information.
  - Store extra batteries for your TTY and light phone signaler. Check the owner's manual for proper battery maintenance.

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[14] Retrieved October 29, 2008 from http://www.readysouthtexas.gov/hearing.asp

- **Communication**
  - Determine how you will communicate with emergency personnel if there is no interpreter or if you don't have your hearing aids. Store paper and pens for this purpose.
  - Consider carrying a pre-printed copy of important messages with you, such as: "I speak American Sign Language (ASL) and need an ASL interpreter," "I do not write or read English," and "If you make announcements, I will need to have them written or signed."
  - If possible, obtain a battery-operated television that has a decoder chip for access to signed or captioned emergency reports.
  - Determine which broadcasting systems will be accessible in terms of continuous news that will be captioned and/or signed. Advocate so that television stations have a plan to secure emergency interpreters for on-camera emergency duty.

- **Alarms**
  - Install both audible alarms and visual smoke alarms. At least one should be battery operated.

- **Advocacy**
  - Recruit interpreters to be Red Cross emergency volunteers.
  - Maintain advocacy for TV stations to broadcast all news and emergency information in open caption format.
  - Ensure hotels have access packets for the deaf and hearing-impaired persons, including visual alarms, when you travel. Ask for them when you check in.

7.5 Special-needs NOAA Weather Radio for deaf and hard-of-hearing persons[15]

NOAA Weather Radio receives National Weather Service warnings, watches, forecasts, and other hazard information 24 hours a day. (NOAA Weather Radio Brochure (PDF)

The special-needs NOAA Weather Radio was designed to adapt to the needs of the deaf and hard-of-hearing community. The Radio can warn deaf and hard-of-hearing persons of hazardous conditions, giving them around-the-clock, up-to-the-minute weather information. The Radio is a weather alerting system that can be a lifesaver, much as the now commonly-used smoke detector with flashing light, for deaf and hard-of-hearing persons.

How does the radio meet the weather alerting needs of deaf and hard-of-hearing persons?

- It provides visual and vibrating alarms and simple text readouts.

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[15] Retrieved December 14, 2008 from http://www.nssl.noaa.gov/edu/safety/specialneeds.html

- Three warning lights indicate the level of alert (Statement, Watch, or Warning).
- Liquid crystal display readout indicates specific warning such as "Tornado Warning" or "Thunderstorm Warning".
- Programmable state/county selections screen out warnings for other areas.
- Accessible technology, now being developed, will enable deaf and hard-of-hearing persons to obtain NOAA Weather Radio alert messages in text format.
- The battery-operated NOAA Weather Radio can be portable at home, work, school or play, or while traveling, boating or camping.
- For deaf-blind persons and hearing-impaired persons with low-vision, special-needs NOAA Weather Radio receivers may be equipped with special adaptions which convert the weather messages into large print and/or Braille version without depending on volunteering reading services.

What does the special-needs NOAA Weather Radio do in times of inclement weather?
- When an alert is broadcast on the NOAA Weather Radio, it will send a signal which then activates one of the following accessories:
- Pillow vibrator to wake individuals from sleep.
- Strobe light to alert individuals during waking hours.
- Bed shaker to shake a bed to wake individuals up.

Where can you obtain information on the special-needs NOAA Weather Radio?
- WeatherRadios.com
- HomeSafe, Inc.
- Silent Call Communications Corporation
- Harris Communications, Inc.
- Compu TTY
- WeatherShack and WeatherShack Education Center, a comprehensive guide to weather measurement equipment, including operation, applications and set-up

The above links are provided for convenience and information only and do not constitute an endorsement of the products offered. See Disclaimer

In addition to using the radio, deaf and hard-of-hearing persons should educate themselves on weather safety. Where can they learn weather safety?

Weather safety education is highly recommended for deaf and hard-of-hearing persons to understand basic weather knowledge. This education is vital in preparing them to respond properly to weather threats. Contact your local National Weather Service office, your state emergency management agency, the Federal Emergency Management

Agency, or your American Red Cross chapter for weather safety information. It is recommended that you:

- Educate yourself concerning the threat and danger of various weather hazards.
- Familiarize yourself with weather warnings.
- Attend safety talks.
- Follow basic safety rules.
- Develop a family disaster plan for weather emergencies.

What to Do in an Emergency: **Tips for the Deaf and Hearing Impaired[16]**

Your Silent Call vibrates and you answer your Braille TTY. Your SSP is on the line. "A hurricane is coming," he types. "You need to leave right now!"

How can you get ready for an emergency? For people who have both vision and hearing loss, getting information about an emergency is critical. So is getting adequate access to services so you can deal with how an emergency affects you, and recover from it. Planning ahead is particularly important, so you can be prepared.
Before an Emergency Happens
Make a Plan.

Ask yourself: Can I get information about an emergency before it happens?

   * Check your television news for emergency information. The TV news stations may provide emergency information through open or closed captions, scrolling text, crawls at the bottom of the screen, or pictures.
   * Use the TV, Internet, email alerts, or a buddy system to get information about an emergency. Do not call 911 unless you have a serious emergency.
   * Sign up for emergency e-mails or other notification services. Emergency emails can be sent to your computer, pager and/or cell phone. Many local governments and news stations offer text messaging services for your county or town. You can also subscribe to a national service: http://www.www.emergencyemailnetwork.com.
   * Do not get rid of your TTY or Braille TTY, even if you rarely use it. You may need the TTY and your home phone to make calls if your videophone or internet is down. Also, make sure your TTY is in full operating order. A fully-charged TTY can keep running for several hours without power.
   * Invest in a battery-operated charger for your pager or cell phone, if you use one. If your SSP, friend or family member has a charger in his or her car, ask if you can use the charger to charge your cell phone or pager. Be sure the charger is compatible with your pager or cell phone.
   * Select at least two or three neighbors who can let you know if an emergency is happening. You can also ask friends, family members, SSPs or interpreters you know who live near you to let you know about an emergency.

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[16] Retrieved December 2 from http://www.aadb.org/information/emergency_preparation/emerg_plan.html

Ask yourself: Can I contact people if emergency warning services don't work? Can people let me know an emergency is happening or going to happen?

   * Have at least three people you can contact in an emergency, and more buddies if possible. At least one person should be out of state. Another should be in your neighborhood. Don't worry about calling them before you evacuate. You can call them after you leave to let them know where you are. It is often better to call a person out of state because phone lines may be busy or not working in your neighborhood.
   * Have a neighbor, family member or friend check on you in case an emergency happens or is about to happen. You may want to agree to meet at a specific place in case of emergencies.
   * You also may want to check on your neighbors or friends to see if you can help them and if they are all right during an emergency.

Ask yourself: Do I have enough food, water and supplies to last through an emergency?

   * Prepare an emergency kit (see article elsewhere in this issue).

Ask yourself: Do I know what to do during an emergency?
Evacuate: Leave the area (hurricane, flood).

   * If at all possible, leave as soon as you hear about the emergency—don't wait! It is better to leave the area ahead of time even if the hurricane or flood doesn't hit your neighborhood or city.
   * Arrange with a friend, family member or neighbor to take you to a different place if you have to leave. Work out a way to contact each other.
   * Make arrangements to take public transportation ahead of time as another option for evacuation. Make sure you have enough money to use public transportation.
   * Sometimes you can call a local police or rescue station, or your local emergency management office to find out whether or not to evacuate.
   * Some news broadcasts may provide 800 numbers to call to find out whether or not to evacuate. You can use your TTY and a state relay service to call these numbers.

Shelter in Place:Stay in your home or a safe building nearby if air is not safe to breathe (chemical spill, bomb explosion), or if being outside is not safe (tornado).

   * Go to a hallway (without windows) or a room with no windows (bathroom or closet) and wait until the emergency has ended.
   * If you can, find the nearest building where you can take shelter. Sometimes the emergency news broadcasts can let people know where to go for shelter. Also, a local emergency management center or Red Cross chapter may have information about available shelters.
   * If you are already in a building (for example, at work), stay where you are, or go to a safe area.

* Close all doors, windows and ventilation systems (air conditioning and heating vents, fireplaces) so bad air can't get in.

For information about available emergency programs, contact your local Red Cross, usually listed in your phone book. You can also contact the website at www.redcross.org. There, you can find your local Red Cross by typing in your zip code. If you do not have access to a computer or the Internet, you can call the Red Cross at 1-866-438-4636 Voice or 1-800-526-1417 TTY. You can write them also to receive information about local Red Cross chapters at American Red Cross Headquarters, 2025 E Street, NW, Washington, DC 20006.

You may want to check with your local emergency management office to see if they have information and resources about emergency preparation. You should find your local office in your phone book.

Also, you can check with your local service agency and/or school for deaf, hard of hearing or deaf-blind people to see if they can help you with emergency planning. Some agencies may have people skilled in deafness or deaf-blindness who can help you get the services you need.

National organizations: You could consider asking people in your church, volunteer group, deaf-blind group or community organization to see if they can be your buddies in an emergency. zations such as Telecommunications for the Deaf, Inc (TDI), National Association of the Deaf, and Hearing Loss Association of America have information on emergency preparation for deaf, deaf-blind and hard of hearing people.

TDI has a special program on emergency preparedness: Community Emergency Preparedness Information Network (CEPIN). Contact information is below:

   * Telecommunicaitons for the Deaf, Inc. (TDI)
   * 8630 Fenton Street, Suite 604
   * Silver Spring, MD 20910
   * Phone: (301) 589-3006 TTY, Voice and VP
   * Website:www.cepintdi.org

7.6 Preparing for Emergencies for Non-native Speakers of English

The growing number of Limited English Proficiency (LEP) residents creates special communication needs in disaster situations. These needs are often inadequately addressed and could cause unnecessary hardship or even harm to people with low English language skills. These needs must taken into account in emergency preparations.

New Report Reveals A Lack Of Disaster Preparedness for Immigrant and Limited English Proficient Communities[17]
The Tomas Rivera Policy Institute (TRPI) and the Asian Pacific American Legal Center (APALC) released a joint study today which finds that immigrant and limited English proficient populations are not fully incorporated in disaster preparedness educational efforts and emergency response plans.

The report – "Disaster Preparedness in Urban Immigrant Communities: Lessons Learned from Recent Catastrophic Events and Their Relevance to Latino and Asian Communities in Southern California" – was prepared with assistance from the Asian American Justice Center. The study examines selected Latino and Asian immigrant communities in Southern California for disaster education and response preparations in order to improve disaster awareness among immigrant community members and to help emergency response personnel better serve limited English speaking populations.

Key findings in the report include:

- A lack of disaster preparedness materials in languages other than English that reflect the demographics of the service populations.
- A shortage of bilingual staff and volunteers among emergency response crews and nonprofits that typically do outreach during emergencies.
- That ethnic media outlets are underutilized as important tools for communication with immigrant and limited English speaking communities.
- Concern that members of the immigrant community will not come forward for assistance for fear that their status will come into question.

The report recommends that federal and state governments establish a baseline of minimal secondary language resources and that local agencies take a lead in creating informational materials and response plans that take into account the language needs of their constituents. Current state legislative efforts to address this issue include AB 1930 (Torrico) which would build upon our existing emergency preparedness system and incorporate the language needs of Californians in disaster preparedness planning, response, and recovery.

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[17] Retrieved December 2, 2008 from http://demographics.apalc.org/?p=51

Governments must also address a key concern among some immigrants that seeking emergency help could result in deportation or lead to problems with receiving benefits. "When you have a major disaster and people flee their homes, immigration documents may well be lost," said Harry Pachon, President of TRPI. "Our field researchers heard reports that people were turned away for assistance in New Orleans because they couldn't prove their legal residency status. Others avoided reaching out for help because of their fear of being deported."

"This study shows that we are ill-prepared to serve the limited English proficient community in the event of a major catastrophic disaster," said Stewart Kwoh, Executive Director of APALC. "By not taking into account the special needs and concerns of these communities in our disaster preparedness and response plans, we are putting many lives at risk."

The project, conducted over two years, involved two focus groups of Latino residents, one of Mandarin speaking residents and another comprised of Vietnamese speaking residents. Researchers also interviewed 34 members of disaster service providers, non-profit organizations and ethnic organizations in Southern California. Additional interviews focused on emergency service providers in the quake-affected areas of Northridge, Calif. (1994) and the Hurricane Katrina disaster areas in Louisiana (2005). The study addresses the need to prepare for similar large-scale emergencies and man-made disasters. The U.S. Geological Survey forecasts that California has a 46 percent chance of an earthquake with at least a 7.5 magnitude in the next 30 years.

7.7 Suggestions to Improve Services for Low English Proficiency Populations

Disaster-preparedness education
- Increase relationships with ethnic community organizations, ethnic community leaders, and ethnic media outlets to help develop culturally competent campaigns and plan appropriate methods of dissemination to communities.
- Increase the availability and frequency of informational materials, trainings, workshops, and outreach in multiple languages.
- Increase public service announcements and print information in the ethnic media.
- Mainstream disaster agencies should hire bilingual liaisons that also serve as volunteer recruitment agents and as bilingual volunteers in times of disaster.

Warning communication services
- Identify areas of the county that need emergency messages in multiple languages and establish systems to provide them.
- Increase community education and media campaigns about warning

communication systems, such as mailing fliers, expanding programs such as CERT, and broadcasting more testing and public service announcements.

- Incorporate in emergency planning methods how to communicate with the LEP population, including a list of professionally trained translators and an assessment of best methods of communication, and develop relationships with community leaders.
- Prepare standard emergency messages likely to be sent via EAS and prepare translations of these messages in the various languages.
- Plan how to link ethnic media to media networks during times of disaster and incorporate ethnic media in a plan to distribute emergency information in multiple languages.

Disaster response services
- Account for the language needs of the community as well as language capabilities of first responders; conduct survey of first responders and community members to determine how rapidly language assistance is available and where capacity lacks.
- Assess the impact on emergency services of family members, particularly children, who conduct translations.
- Include simulation of responding to LEP communities in first responder trainings and exercises; involve CBOs serving LEP populations in trainings and exercises to gather feedback.
- Mainstream agencies must sustain outreach to ethnic communities beyond the immediate aftermath of disaster by continuing to build partnerships and evaluating, testing, and refining plans for disaster services. This can include employing the best methods to gain the trust of ethnic communities, overcoming cultural barriers, and deepening civic involvement of newer residents.

Local homeland security departments also charged with preparedness and response functions must separate their immigration enforcement duties from the community response and outreach duties, especially in times of disaster, when assisting their communities could be compromised by a close relationship with immigration authorities.

8 Evacuation Preparedness for People with Disabilities for Hospitals and Institutions

It is the law and responsibility of emergency planners of hospitals and private and public institutions to include the needs of people with disabilities in the disaster preparedness plan. As emergency managers, first responders, and caregivers work to put into place the appropriate policies, practices and procedures that take into meaningful consideration the needs of people with disabilities, they should keep in mind that there is no such thing as a "one size fits all" approach. Depending on the disability, different needs may be triggered. By the same token, those responsible for emergency preparedness planning and implementation must also recognize the ways in which leaders in the disability community may provide critical insight and assistance as they themselves seek to do their part to prepare for the event of an emergency. People with disabilities should not merely be an afterthought in the process but should be involved in every facet of this work.

8.1 N.O.D. GUIDE ON THE SPECIAL NEEDS OF PEOPLE WITH DISABILITIES[18]

Involving and listening to people with disabilities assures the best insights for addressing their needs. Emergency planners should:
• Identify those in the community who might have special needs before, during and after a disaster or emergency. Doing so ahead of time results in an improved emergency plan, a better determination of resource needs, and more informed actions and decisions.
• Customize awareness and preparedness messages and materials for specific groups of people, and put them in alternative and accessible formats thereby increasing the ability of these individuals to plan and survive in the event of an emergency. Such preparedness allows appropriate allocation of critical personnel, equipment and assets during the response period, and reduces 911 call volume.
• Educate citizens with disabilities about realistic expectations of service during and after an emergency even while demonstrating a serious commitment to their special needs. Such education results in a more cooperative relationship with local authorities and enhances their appreciation of the concerns of people with disabilities. It also leads to improved response by the entire community.
• Learn and gain from the knowledge, experiences, and nontraditional resources the disability community can bring to a partnership effort with emergency professionals. By utilizing and embracing members of the disability community as partners in the planning process, emergency personnel often discover creative solutions before they are needed during an emergency. These solutions may benefit not only the disability community but also the general population.

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[18] Accessed on February 4, 2008 at
www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=1034

• Work with institutional and industry-specific groups that are not typically considered to be emergency service resources but that can offer valuable and timely support to emergency professionals. Identifying and marshalling these groups ahead of time leads to a better prepared service community that is able to take on responsibilities during an emergency. It also leads to a unified team able to quickly assess and communicate service gaps during an emergency, and to a host of additional equipment, materials, and skilled personnel.

The most effective way to view emergencies through the eyes of people with disabilities is to involve community members with disabilities in the planning and preparation process. It is important to realize that people with disabilities, even more than other demographic segments of the population, are not a homogeneous group. Individuals with disabilities have differing capabilities, opinions, needs, and circumstances, and no one individual or organization speaks for all people with disabilities.

That said, there are a number of organizations in most communities that make a sincere effort both to represent the interests of their constituencies and to work with government and civic officials to ensure that people with and without disabilities work harmoniously on issues of common concern. The three categories of representation are government organizations, institutional partners and advocacy groups.

Government Organizations

Usually, the best place to start in selecting and involving disability representatives is the disability agency or task force within the Governor's office, the Mayor's office, or the county government.

Typically, officials in these organizations can assist in identifying a cross-section of disability representatives within a locality.

Other government entities that may be helpful include:
• the Department of Health and/or Mental Health,
• the Department of Aging,
• the Department of Veterans Affairs, and
• the local Americans with Disabilities Act (ADA) Coordinator.

8.2 How to Involve People with Disabilities in Planning

Institutional Participants

Beyond government organizations, examples of institutional participants are:
• Representatives from the home-based care industry, such as the local Visiting Nurse Service and the Home Health Aides
Association, among others;
• Residential healthcare facilities, such as nursing homes, skilled care homes, and assisted living facilities;
• The local dialysis treatment network; and
• The ambulette industry.

Advocacy Groups

It is important to include representatives from advocacy groups in the disability community such as:
• The local Independent Living Center,
• Local groups serving specific and general disability populations

(e.g., people who are blind, deaf, or have limited mobility or cognitive disabilities), and
• Individuals with disabilities who, though not affiliated with a group, are known to emergency professionals and who are willing to participate in the planning efforts.

What is most important in this process is to select a range of people in terms of both affiliation and disability. Involving people with all major types of disabilities, including sensory, physical, mental and cognitive disabilities, helps to ensure the most complete picture possible of the effect of disasters on people with disabilities.
It is important to understand the local demographics of disability (e.g., large concentrations of citizens with disabilities and senior housing communities). Most people with disabilities live and work independently and are dispersed among the population. A community's emergency planning needs, and the types of people required in the planning process, will be partly determined by such demographics.
A broadly based working group will be able to assist emergency management planners in anticipating the true impact of disaster on people with disabilities. This leads to a more detailed, comprehensive, and thoughtful response plan for any community.

Before serving people with disabilities in a community, one must know whom to serve. Some people with disabilities will not require special assistance during an emergency, because they are able to care for themselves. Therefore, while some 20 percent of the total population have a disability, the national planning average used by emergency management offices, is notably lower at 10 to 13 percent. This figure acknowledges the self-support capabilities of many people with disabilities while still taking into account those who need help in an emergency. With so many community residents having some sort of disability, planning for emergencies and their aftermath can be a demanding job. It is helpful to:

• First, identify the concentrations of people with disabilities who live in the community. This includes large-scale senior housing developments, residential care facilities, and perhaps schools with large populations of students with disabilities.
• Second, work with local disability organizations to identify clusters of people with disabilities who either live or work in the community. For example, a certain apartment complex may house large numbers of residents with disabilities, even if it is not a disability facility per se. Some employers may hire many people with disabilities. Local disability organizations may help by providing membership rosters.
• Finally, consider developing a Special Needs Registry for the jurisdiction if one does not yet exist, whereby people meeting specified criteria voluntarily list themselves, making the local emergency authority aware of their presence. Some jurisdictions employ this registry only as a means of pre-emergency outreach. Others use it to alert citizens of impending emergencies. Still others rely upon it to assist in evacuations or provide emergency services such as transportation or health care during a disaster. If the community does not currently possess such a registry, creating one should be seriously considered since it can be an extremely useful tool.

Special Needs Registry

If it is decided that a special needs registry will be developed or an existing registry relied upon, there are several issues to take into account:
• If the registry system is developed, will it be approved or mandated by the local authorities?
• Are funding, equipment, and staff available to maintain such a registry? More importantly, are there resources to continually update it once it is created? An out-of-date registry is of less use during a crisis; it may even consume critical resources when emergency responders look for people who no longer live or work where the registry says they do.
• What will be the criteria for inclusion in the registry?
• Who will review applications for inclusion and make eligibility determinations?
• What expectations will be placed on individuals with disabilities once they are listed?
• What allowances and accommodations will be made for people who are temporarily disabled, including those in long-term rehabilitation, recovering from a serious illness or hospitalized?
• What safeguards will be put in place to protect registrants' privacy and the confidential information they provide? When, how and with whom can this information be shared?
Recognize that no matter how comprehensive a registry may be, not all people with disabilities will register. Some people may not wish to identify as having a disability. Others may not view their disability as creating a special need. Still others may not think to register until after they feel the impact of a disaster. Some, despite the most concerted outreach efforts, may not be aware of the registry.
Therefore any registry should be considered only as a guide in an emergency, and not as a definitive or exhaustive list.

Communication is the lifeline of emergency management. This is especially true for people with disabilities, many of whom are unemployed, socially isolated, or in other ways less connected to society than their non-disabled counterparts. Fortunately, most emergency communication can be undertaken at minimal cost, and most disability-targeted communication can be implemented as a simple adjunct to more general strategies.

Communication with members of the disability community must be viewed differently depending on the point at which it is initiated.
This can be done:
• Well before an event, as part of a preparedness outreach effort;
• Prior to an event, as an emergency warning or notification;
• During an event, as emergency information and instruction; or
• Following the event, as recovery information.
The medium used to reach people may change at different points in the timeline. In addition, the technology employed may vary, and the amount of labor required to complete the task may change. In general, however, there are some important considerations to keep in mind when directing communication on one's own or in partnership with the media:
•Television stations must be responsible to all viewers and not run a text message "crawl" across a television screen in any area reserved for closed captioning as this will make both sets of messages unintelligible for deaf or hard of hearing viewers.

• Camera operators and editors need to include the sign language interpreter in the picture if one is interpreting next to the official spokesperson presenting emergency information.

•Those setting up emergency hotlines during an event should include TTY/TDD (text telephone, also known as telecommunication device for the deaf) numbers when available, or the instruction "TTY callers use relay." Make sure the same information is provided by the official spokesperson and is used on television and radio.

8.3 Communication is the Key

• Frequently repeat the most essential emergency information in a simple message format those with cognitive disabilities can follow.

• When posting information on a website, make sure the website is accessible (see details on web accessibility, page 28).

• Provide information in alternate formats (e.g. Braille, cassette, large font, etc.) whenever possible ahead of time based on the needs of the population.

Another Communication Tool: A Disability Phone Tree

A phone tree patterned after existing internal notification and call-down systems is a particularly effective way to reach members of the disability community. It must of course be tested regularly. In addition, through a "reverse tree," members of the disability community can alert emergency professionals to issues of which they may not be aware. An effective and well-designed phone tree can multiply outreach and response capabilities while minimizing the number of staff needed to activate the tree at any time.

Community emergency managers should be responsible for initiating communication to the top-level contact persons on each branch of a phone tree. These "branch managers" might be the administrators of residential care facilities; officials at utility companies who maintain lists of life-sustaining equipment customers; staff members of disability organizations; senior housing complex managers; or even government officials providing oversight or regulation of such areas. These officials may already oversee a registry of their own residents, members, constituents or clients. They, along with backup designees, would be responsible for developing and maintaining the smaller branches of their registries and for providing labor, accurate lists, and their own tools (such as the activation of a page message or reverse TTY for some segments of the community) in the event of an emergency.

With a well-designed phone tree system in place, a consistent message is communicated, and members of the disability community have the opportunity to identify any emergency service gaps that may exist. However, even with the best-organized phone tree, it is very important – as well as being standard practice in emergency communication – to identify backup communication measures and not just to rely on telephone or fax capability. E-mail and secure access to web sites have emerged as viable options.

Not all disasters require residents to flee their homes or businesses. However, the need for escape or rapid exit is common enough that it should be explicitly addressed as part of emergency planning efforts. Such planning can be a lifesaver. Experience demonstrates that people who are aware of evacuation procedures and who engage in

escape drills are more successful in fleeing buildings than are those who are unfamiliar with the procedures. This brochure cannot fully cover all the aspects of this complex process (more detailed links are in the section on Tools and Resources, page 25), but it highlights several that should be considered.

8.4 Evacuation Planning for People with Disabilities

There are several types of facilities and structures where special consideration is required in connection with the evacuation of people with disabilities.

Buildings, Residential Facilities and Other Tall or Large Structures with Relatively Permanent Residents

As part of emergency planning efforts, it is important to work with the administrators of these facilities to ensure that each structure has a workable evacuation plan in place, and that the administrators undertake regular drills so residents or employees within their structures are familiar with these plans. These drills, of course, should pay adequate attention to the special needs of all people with disabilities, not just those in wheelchairs and with other mobility impairments, but also those with visual, hearing, or mental impairments. In addition, it is good to work with groups that represent smaller organizations, like home health care regulators or local business associations, to encourage each of their members to undertake these same activities.

Unfortunately it is often too late at the moment of disaster to educate people, already confused and harried by a crisis, about how to escape or to help individuals with disabilities do so. Some cities are already taking the lead in pre-disaster planning. The City of Chicago, for example, in 2002 promulgated new local standards requiring evacuation plans for people with disabilities to be put in place in any commercial or residential structure over 80 feet high.

Large Facilities, Such as Stadiums, Arenas, and Museums with No Permanent Residents

In these facilities, full-scale evacuation drills are usually not feasible (with certain exceptions such as schools). Nevertheless, it is critical to ensure that the managers of these facilities have effective evacuation procedures in place for people with disabilities. They must be able to communicate disaster instructions during a crisis and under unfavorable circumstances, such as the loss of power. Their staffs must be trained in supervising evacuations. Staff members at these transiently populated structures should be trained in dealing with disabilities of all types.

Entire Communities

Evacuations of entire communities typically take place over a longer period than facility evacuations. They can be even more traumatizing, since people are leaving their homes, businesses and possessions behind. Community evacuation plans should be designed to allow the necessary time, consideration, and assistance for people with disabilities to be adequately notified of evacuation plans. They also must be able to bring with them special equipment (e.g. wheelchairs, dialysis machines, and ventilators) and guide animals. In some communities, these concerns have led to the creation of staggered evacuation orders with notification to large care facilities ahead of

the general population because the lead time is so much longer. Communities may need to provide accessible transportation support and other resources if people are ordered to evacuate the area.

8.5 Include Disability Needs in the Recovery Phase

The recovery phase of an emergency typically is the longest and most difficult aspect of a disaster for a community's residents, and this can be especially traumatic for people with disabilities. In addition to coping with any personal losses or injuries that they may have suffered, people with disabilities who experience a disaster may be deprived of vital connections to attendants, guide animals, neighbors, and local business owners, and even family members. They may no longer be able to follow their accustomed routines. The disaster may also cause psychological distress by forcing individuals with disabilities to confront the limitations imposed by their disability on a more or less continuous basis, or to relive traumatic hospitalization experiences from their past.

Such possibilities are more than theoretical. The terrorist attacks of September 11, 2001, for instance, produced powerful psychological effects among the general population. According to The Washington Post, two to three months after the attacks, "nearly half of the residents of Lower Manhattan and as many as one in four Americans nationwide had difficulty sleeping, suffered flashbacks, and were easily startled – symptoms usually found among patients with post-traumatic stress disorder (PTSD)." Similarly, two months after the disaster, the New York Academy of Medicine found that the prevalence of PTSD and depression among adults in Manhattan was twice the national average. And six months after the attacks, more than one-fourth of New York City public school children exhibited mental health problems severe enough to impair their normal functioning. Like all people, those with disabilities are affected by these issues, but for this population they are often more severe.

Emergency planners, of course, can do little to counter some of these effects, such as psychological distress and changed city environments, which are frequent results of disaster. What can be done is to ensure that those services and special needs most critical to people with disabilities are restored or addressed as a priority during the recovery phase.

Some major considerations include:
- Making allowances at blockades, shelters, and other impacted areas for access by attendants, home health aides, visiting nurses, guide animals, and other individuals crucial to the immediate health care needs of people with disabilities,
- Identifying the impact on the disability community of an interruption in utility services,
- Planning for accessible shelter and appropriate temporary housing needs,
- Addressing how people with disabilities who are employed by businesses that are able to open soon after a disaster will get to work, and
- Involving representatives of the disability community in "after action reviews" or "hot wash reports" in order to capture the true impact of the disaster and to improve plans for the future.

8.6 Other Factors to Consider

Several potential problems can be particularly stressful or confusing during planning and response phases of a disaster. They require added attention.

•It is commonplace in post-disaster situations for many services to be dispensed by volunteers. It is therefore important, where feasible, to train volunteers ahead of time in the basics of dealing with their fellow residents with disabilities. Such training is important so that the volunteer workers treat neighbors with disabilities with dignity and respect. These volunteers must also recognize and respond to requests that might appear to be luxuries in time of crisis, but for people with disabilities, may be essential to their day-to-day living.

•Federal, state and local regulatory codes address special needs issues, and it is important to understand when such codes can help in the context of emergency planning. If no codes are in place, it is worth the effort to lobby for changes that can strengthen the ability of emergency professionals to incorporate special needs issues into plans and response capabilities. Examples of code-related questions that each locality must resolve include: Are nursing homes required to have an onsite source of redundant power? Can nursing students be used in a medically managed shelter? What level of emergency plans are home care agencies required to put in place for their clients with disabilities?

•Shelters must meet minimal accessibility levels so that all members of a community can find safety. The level of medical oversight to be provided must be determined well in advance of an emergency. Whether or not there will be different classes of shelters (e.g., medically managed or designated for special needs) must also be established in the planning phase. By making these determinations ahead of time, the needs of those with disabilities utilizing the shelter system will be properly identified and addressed.

•It is vital to make accessible transportation available during and after a disaster. Because transport fleets with wheelchair lifts or ramps may not be available or might be called into service in other areas, it is helpful to include non-emergency vehicles in disaster plans. Door-to-door pick-ups have been employed in some localities and should be incorporated into emergency plans if applicable.

•During the planning and preparedness phase, it is important to make sure that organizations and groups providing services to the disability community are informed about the importance of proper business continuity planning as a means of ensuring ongoing care to their client base of people with disabilities after a disaster.

•There are many types of emergency equipment for use by people with disabilities during a disaster. These include specialized evacuation chairs, transfer-height cots, communication boards, and reverse 911 notification systems. Unfortunately, there are no federal minimum safety or review standards for this equipment, and therefore "buyer beware" remains a necessary caution. To ensure the use of only the highest quality equipment, emergency professionals should rely on appropriate members of the disability community to help research and "test drive" equipment before such items are written into plans or purchased by municipalities.

9   Where to Get Support: Available Resources

This resource guide includes just a few of the guides, checklists, and toolkits available on the Internet. Access the following sites to ensure that the needs of people with disabilities are addressed in your local disaster preparedness plan, or to prepare your local government to design a disaster preparedness plan that addresses your unique needs.

American Red Cross
www.redcross.org/services/disaster/beprepared/mobileprogs.html
The American Red Cross Disaster Preparedness Services website offers tips specifically for people with disabilities. It provides a comprehensive guide to ensure that individuals with special needs are prepared in case of an emergency situation. Included are how to establish a personal network, and checklists to ensure preparedness.

American Foundation for the Blind
www.afb.org • (212)502-7600 (voice)
The AFB Senior Site provides emergency preparedness plans for visually impaired. It contains a document on how to prepare for your service animal or pet.

An ADA Guide for Local Governments
www.usdoj.gov/crt/ada/emergencyprep.htm
The Americans with Disabilities Act Publications has compiled a comprehensive guide for local governments on how to making community emergency preparedness and response programs accessible to people with disabilities.

ADA Best Practice Toolkit for State and Local Government
www.ada.gov/pcatoolkit/toolkitmain.htm
The Tool Kit is designed to teach state and local government officials how to identify and fix problems that prevent people with disabilities from gaining equal access to state and local government programs, services, and activities. It also teaches state and local officials how to conduct accessibility surveys of their buildings and facilities to identify and remove architectural barriers to access.

CDIHP Evacuation Preparedness Guide
www.cdihp.org/evacuation/toc.html
This on-line guide was created by June Isaacson Kailes and the Center for Disability Issues and Health Professions. It is a thorough and comprehensive guide for how people with disabilities should prepare for disasters.

Center for Disabled and Special Needs Preparedness
www.disabilitypreparedness.org/
The Center for Disability and Special Needs Preparedness works to ensure that all individuals are included in the development and implementation of plans for protection from natural and man-made emergencies. In almost all emergency planning people with

disabilities or other special needs have not been taken into consideration. Medical, transportation, and communication needs require the most attention.

Central Coast Children's Foundation, Inc. Disaster Preparedness for People with Disabilities Webessay
CCCF also offers an abbreviated version of this resource guide electronically.

Community Emergency Preparedness Information Network
www.cepintdi.org/
The website is designed to promote awareness in emergency preparedness activities and encourage networking among emergency responders and deaf and hard of hearing consumers for the purpose of creating such programs in local communities.

DRM Webwatcher: Disaster Preparedness for People with Disabilities
www.disabilityresources.org/DISASTER.html
This website provides link to other sites with disaster preparedness information for people with disabilities.

Emergency Readiness Wheel for People with Disabilities
www.eadassociates.com
EAD & Associates, LLC is a unique, woman-owned small business that p provides expertise in emergency management and special needs planning, a distinct discipline that ensures that people with physical, sensory, and/or cognitive disabilities are prepared for man-made or natural disasters and emergencies and their consequences. The website offers a number of services and products to include in your disaster preparedness plan.

Federal Emergency Management Agency
http://www.fema.gov/plan/prepare/specialplans.shtm • (800)480-2520 (voice)

Humane Society of the U.S.(Disaster Center)
www.hsus.org/hsus_field/hsus_disaster_center/ • (202)452-1100 (voice)
Get practical tips, information and helpful lists on how to prepare your companion animal in the event of a disaster.

June Isaacson Kailes
www.jik.com/disaster.html
An extensive, annotated collection of links by disability policy consultant.

National Organization on Disability
www.nod.org/emergency • (202)293-5960 (voice) • (202)293-5968 (TTY)
National Organization on Disability Emergency Preparedness Initiative
www.nod.org/index.cfm?fuseaction=Page.viewPage&pageId=1564
NOD launched the Emergency Preparedness Initiative (EPI) to ensure that emergency managers address disability concerns and that people with disabilities are included in all

levels of emergency preparedness- planning, response, and recovery. The website provides up to date news, programs and resources available throughout the U.S.

NOAA Weather Radio

www.nws.noaa.gov/nwr/special_need.htm

The material provided is intended as general information on how NOAA Weather Radio (NWR) can be used as an emergency warning tool for people who are deaf or hard of hearing.

Preparenow.org

www.preparenow.org

Supporting Special Needs and Vulnerable Populations in Disaster Preparedness and Response. This site assists anyone preparing or planning for these needs in any type of disaster.

U.S. Department of Homeland Security

www.ready.gov • (800) BE READY (voice) • (800)464-6161 (TTY)

The U.S.D.H. Ready America Site offers preparedness kits and instructional videos. It has a section devoted to people with disabilities and other special needs.

Federal Emergency Management Agency

www.fema.gov   • (301)447-1000 (voice)

FEMA offers several resources, such as news releases and library booklets to help people with disabilities create a disaster preparedness plan.

EAD & Associates, LLC

http://www.eadassociates.com/

 A small business that provides expertise in emergency management and special needs planning, a distinct discipline that ensures that people with physical, sensory, and/or cognitive disabilities are prepared for man-made or natural disasters and emergencies and their consequences. They market a valuable emergency readiness wheel which can actually be activated on their web site.

Appendix A.

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

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., CCC-SP

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, 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 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.

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. <u>Generic communication displays</u>. 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, *et*c., go to www.kwikpoint.com. See also a generic display being used in hospitals, ambulances and as part of emergency preparedness at www.eadassociates.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. <u>Personal communication displays and speech generating devices (SGDs)</u>. 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. <u>Yes/no responses</u>. 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. <u>Gestures and impaired speech</u>. 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 crammed, 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, 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 representations 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.

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 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. 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 USSAAC 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 infra- structure 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.

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. <u>Develop an emergency preparedness plan</u>. If evacuation is necessary, everyone needs to know where to go.

2. <u>Develop a solid local AAC infrastructure</u>. 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. <u>Prepare documentation</u>. 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. <u>Reach out</u>. Encourage families to prepare and provide them with guidance about Go-Bags, networking, self-identifying registries, and so on.

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

6. <u>Avoid profiteers</u>. 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.]

Table I. CHE related information for the AAC community

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.

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 *Emergency Readiness Wheel for People with Disabilities*. Go to www.eadassociates.com.

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

4. Communication, networking and coordination among agencies, entities and individuals are key to success but very challenging to accomplish.

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

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.

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.

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.

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.

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.

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*

References

1 Gunn, C. Silent Voices: Special Communication Needs in Complex Humanitarian Emergencies. Unpublished paper.

2 Bruce Cleveland. (Personal communication, November 21, 2007).

3 Nancy Christie. (Personal communication, January 4, 2008).

4 Judy Seligman-Wine. (Personal communication. September 27, 2007).

5 Cantos, O. (2008). ADA guidelines from the U.S. Department of Justice on sheltering for mass care. Disability and Special Needs Technical Assistance Conference: Emergency Preparedness, Response, and Recovery, January 8, 2008, Washington, DC

6 Lutzker, D. (2008). U.S. Department of Justice on sheltering for mass care. Disability and Special Needs Technical Assistance Conference:Emergency Preparedness, Response, and Recovery, January 8, 2008, Washington, D.C.