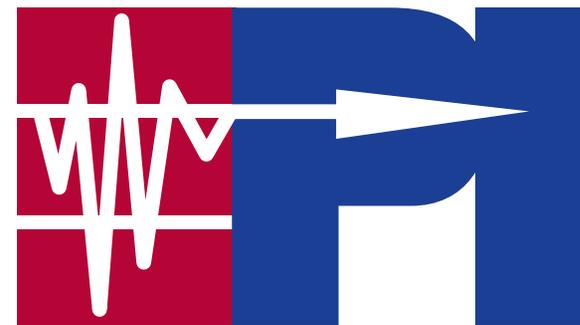


National Organization on Disability

Functional Needs of People With Disabilities

A Guide for Emergency Managers, Planners,
and Responders



**EMERGENCY
PREPAREDNESS
INITIATIVE**

National Organization on Disability/Emergency Preparedness Initiative

888 16th Street, NW, Suite 800 • Washington, DC 20006

Tel: 202-293-5960 • Fax: 202-355-1399 • TDD: 711 Relay

Website: www.nod.org/emergency

2009 Edition

Compelled by the attacks of September 11, 2001, 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.

Our national outreach, education, and awareness efforts seek to ensure that people with disabilities take measures to prepare themselves for emergencies; to ensure that preparedness officials across the country are including people with disabilities in the planning, training and exercises, and response activities undertaken at the community level; and to ensure that people with disabilities are themselves taking an active role in participating alongside preparedness officials before, during, and after an emergency.

EPI recognizes that special preparedness efforts are just as necessary for the many thousands of other natural and man-made disasters in the United States, including floods, tornadoes, hurricanes, earthquakes, fires, explosions, and transportation catastrophes. In all these emergencies, people with disabilities are especially vulnerable. The NOD/Harris Surveys found that people with disabilities are less prepared and, correspondingly, more anxious than their non-disabled counterparts. In 2005, the Special Needs Assessment for Katrina Evacuees (SNAKE) report indicated that 85.7 percent of service providers for people with disabilities did not know how to contact their local emergency manager.

People with disabilities, whose very lives depend on thorough planning for emergencies, must be involved in this planning. We urge officials at all levels to recognize the innate resourcefulness, ingenuity, and determination gained through the daily challenges of disability that can help the community at large and enhance the effectiveness of emergency operations.

We thank you, the nation's emergency professionals on the front lines of homeland security and disaster preparedness, for including us and working with us toward an America that is safe for all.

Hilary C. Styron
National Director
National Organization on Disability's Emergency Preparedness Initiative

*The National Organization on Disability
gratefully acknowledges support from the Walmart
Foundation and American International Group, Inc.
(AIG) for NOD's Emergency Preparedness Initiative
and for this publication.*

Emergency Preparedness Initiative Guide on the Functional Needs of People with Disabilities

NOD encourages the use of this publication and permits the reproduction of it in whole or in part so long as credit is properly given to the National Organization on Disability's Emergency Preparedness Initiative Guide on the Functional Needs of People with Disabilities.

NOD also welcomes comments on the Guide and on our Emergency Preparedness Initiative. Please direct them to epi@nod.org.

Author: Elizabeth Davis of EAD & Associates, LLC
Co-Author: Hilary Styron, National Director, Emergency Preparedness Initiative
Editing and Graphic Design: Rusch Communications, LLP

Contents

The National Organization on Disability's Emergency Preparedness Initiative	3
About This Guide	4
The Experience of Disaster	5
A Nation Unprepared: NOD/Harris Survey Findings.....	11
Preparing for Emergencies: Working with the Disability Community.....	16
New Legislation and Policies	18
Partnership with the Disability Community: Opportunities and Benefits	23
How to Involve People with Disabilities in Planning.....	25
Know Your Community Members	28
Communication Is the Key.....	31
Evacuation Planning for People with Disabilities	36
Service Animals and Pets.....	39
Include Functional Needs in the Recovery Phase.....	40
Other Factors to Consider	43
Include Functional Needs in the Mitigation Phase	46
Conclusion	47
Tools and Resources for Functional Needs Emergency Planning	48
Endnotes.....	62

The National Organization on Disability's **Emergency Preparedness** **Initiative**

The National Organization on Disability (NOD) launched its Emergency Preparedness Initiative in the wake of the September 11, 2001, terrorist attacks. NOD recognized that people with disabilities have a profound interest in the effectiveness of public programs to prepare for and respond to all types of disasters.

The Emergency Preparedness Initiative has two main objectives. The first is to make sure that the functional needs of people with disabilities are adequately addressed prior to an emergency in order to minimize the adverse impact on people with disabilities and their communities. This enables emergency responders to make informed decisions regarding the best use of available resources during emergencies. The second objective is to ensure that people with disabilities are included in the emergency-planning process at all levels of government and the private sector so they can offer their insights, knowledge, and resourcefulness. People with disabilities can contribute greatly to the effectiveness of local emergency-management planning.

- 54 million people in the United States have a disability.¹
- 61% of people with disabilities have not made plans to quickly and safely evacuate their homes.²
- Only 24% of people with disabilities made emergency plan preparations specific to their disability.³
- 34.7 million people (12.7% of the US population) are 65 years and older. By 2030, that number will increase to 64.9 million people.⁴

About This Guide

This Guide highlights key disability concerns to officials and experts responsible for emergency planning in their communities. It seeks to assist them in developing plans that will take into account the needs and insights of people with disabilities before, during, and after emergencies. It also is designed to help emergency managers, planners, and responders make the best use of resources in the emergency preparedness planning process. These resources include people with disabilities. This guide will be periodically updated and revised.

This publication is neither a comprehensive emergency preparedness document nor a functional needs plan in itself. Rather, it is intended to summarize issues that are critical to the functional needs of people with disabilities who live in communities all across America—issues that, if thoughtfully considered ahead of time, will make emergency management efforts easier and more effective when disaster arrives.

In this Guide are steps that every emergency manager or first responder should consider in ensuring that the needs and situations of people with disabilities are taken into account in all four phases of emergency management: mitigation, preparedness, response, and recovery. NOD encourages every jurisdiction to develop and customize a plan for its own community in light of the area's specific hazards, its unique population, and the resources available for emergencies.

This document does not propose costly and time-consuming new initiatives or an entirely separate set of emergency procedures for people with disabilities. It is a call to make sure that the interests of people with disabilities are made a full and enduring part of emergency preparedness efforts—and that community members with disabilities have just as much opportunity as people without disabilities to prepare for and survive an emergency.

A Note on Usage

The terms “special needs,” “functional needs,” and “medical-special needs” are in a state of evolution. The National Response Framework contains a definition of “special needs” to help emergency managers and planners understand the diverse population and what the functional needs may be during disasters. Please visit FEMA’s National Response Framework Website (<http://www.fema.gov/emergency/nrf>).

The Experience of Disaster

“Disasters of any magnitude can be especially difficult for people with disabilities to endure for many reasons. These include, but are not limited to, loss in terms of friends or even material possessions collected over a lifetime without the ability to replace them; a sense of disconnect from a community that scatters; a disruption in daily routine; physical impact; and even a fear of loss of independence,” notes Elizabeth Davis, founder of the emergency management consultancy EAD & Associates.

Below are a few examples of major disasters of different types that have occurred over the years and how they have affected people with disabilities.

Natural Disaster: Grand Forks, 1997

People with disabilities must be given priority during a disaster’s initial recovery phase to avoid further trauma or interruption of established services.

During the recovery phase of the 1997 flood and fire in Grand Forks, North Dakota, emergency service workers found they needed to pay special attention to people with disabilities in impacted areas to minimize further distress.

One man who used a wheelchair and lived independently was flooded out of his accessible home. After the waters receded, the home needed major repairs and cleanup. The man was offered temporary accessible housing, but it was 250 miles away and would have removed him from his support network. Local emergency planners responded and involved a Volunteer Organizations Active in Disaster (VOAD) member group, which arranged for accelerated, professional repairs and cleanup of his home.

The man was able to return to his accessible home without a prolonged disruption. Emergency planners can often reduce the duration and extent of trauma for people with disabilities. Individuals, their families, and their support networks all benefit from a rapid return to their familiar patterns.

Technological Disaster: San Francisco, 2001

Planners must look beyond individuals toward support and care networks. During the rolling blackouts in California during the summer of 2001, the San Francisco Office of Emergency Services (OES) worked with utility companies to be certain that persons relying on life-sustaining electrical equipment were notified in advance by the power authority of a regional energy reduction. This is standard planning everywhere for power concerns and for customers with critical needs.

The San Francisco OES identified potential problems and worked with the local VOAD to address them. These volunteer groups augmented emergency staff and made calls to alert home-based care provider groups and Meals-on-Wheels of upcoming energy reductions. While groups such as Meals-on-Wheels are not considered critical customers, they serve many home-restricted people, many of whom may have disabilities. The telephone calls enabled the providers to make proper arrangements in advance by either changing their cooking schedules or switching to cold meals so no client went without food.

Man-Made Disaster: New York and the Pentagon, 2001

People have survived disasters because of effective emergency planning.

While tremendous destruction and loss of life occurred as a result of the terrorist attacks in New York and Washington, D.C., on September 11, 2001, some individuals with disabilities survived these attacks because of plans that had been made in advance.

After the 1993 World Trade Center bombing, at the suggestion of the local emergency management office, The Associated Blind (a local service provider for low- and no-vision clients) worked with the New York City Fire Department to develop a building evacuation plan and drill for their staff, most of whom have limited or no vision. The Associated Blind wanted a plan for their staff members covering the range of problems that could occur during a disaster. On September 11, their efforts paid off. The entire staff calmly and safely evacuated their building's 9th floor, a success they attribute directly to the customized advance planning and drills.

Also on September 11, a wheelchair user who worked on the 68th floor of the World Trade Center was safely carried from the building, thanks to a specialized evacuation chair purchased after the 1993 bombing. And a Port Authority of New York and New Jersey employee escaped from the 70th floor because his prosthetic leg allowed him to keep pace with non-disabled workers on the emergency stairs, which he says is because of experience gained in the building's frequent fire drills since 1993.

During the attack on the Pentagon, equipment previously installed to help employees and visitors with low or no vision to evacuate the facility in the event of an emergency made it possible for dozens of sighted individuals to flee the smoke-filled corridors as well.

Natural Disaster: California, October 2003⁵

Planners must ensure that emergency notifications are accessible

to those with all types of disabilities, including those with visual, hearing, and cognitive impairments.

In the fall of 2003, a series of fires started in several counties throughout Southern California—culminating in what has been called the worst wildfire disaster in the history of the United States. The fires spread over 730,000 acres of land, destroying more than 36,000 homes. In the end, 22 people died and over 200 suffered injuries.

Many people with disabilities also suffered because they did not receive notification and could not respond properly, since accessible communications plans were not in place and alerts were not set up for those with hearing or visual impairments.

Presently, the Federal Communications Commission (FCC) carries regulatory and enforcement authority over the transmission of emergency notifications as well as access to information during broadcasts. As a result of the gaps in providing accessible emergency alerts and information to the public during the California wildfires, the FCC began to levy fines against television broadcasters. Since this incident, the FCC has issued several reminders (and fines) to broadcasters with regard to their obligation to make critical information available to all viewers.

The FCC also regularly meets with members of the disability community in order to discuss emergency warnings and how they might be improved.

Natural Disaster: Gulf Coast, August 2005

People with high-level disabilities who live in nursing homes, assisted living facilities, or similar supervised settings should be made aware of what disaster plans are in place for them and how their relatives will be notified of their whereabouts if evacuation is necessary.

Hurricane Katrina, a category 5 hurricane making landfall as a category 3, was one of the deadliest and costliest storms ever

to hit the United States. According to Lex Frieden, director of Independent Living Research Utilization, approximately 50 percent of the thousands of people who died as a result of Hurricane Katrina were either elderly or disabled.⁶

When Hurricane Katrina hit, Cheryl Pettypool was living in a nursing home in Kenner, Louisiana. “They didn’t evacuate us until four days after the hurricane,” said Pettypool. “The staff left. We had nobody to watch us except the [nursing home’s] four maintenance men.”⁷

Pettypool, who relies on a wheelchair to get around, said she was one of 60 residents left behind. For three days, the residents remained in the hallway, Pettypool noted. No one received showers and, after a couple days, their only source of nourishment came from bottled water. “There was no electricity and no water. Wednesday, we ran out of food,” she said.

The residents were finally rescued on Friday and sent by ambulance to the airport. They were then taken by Army helicopter to a makeshift trauma center located on the basketball court at Louisiana State University. Pettypool was ultimately transferred to another nursing home about three hours away. “My family and my friends couldn’t find me,” Pettypool recalls. To make matters worse, the nursing home was subsequently hit by Hurricane Rita, and residents had to evacuate for three weeks before they could return.

Mitch Granger, executive director of the Southwest Louisiana Independence Center, Inc., in Lake Charles, said that as a result of the storms, many area residents were forced to move into shelters, and many people with disabilities turned to his staff for help:

Everyone was displaced and especially the disabled. It was a nightmare because some were forced to evacuate without their equipment and their caregivers. Several lived in shelters for a period of time and they didn’t have their equipment.⁸

As a result of Hurricane Katrina, new legislation was created to ensure people with functional needs are better accounted for in planning. You will read more about this throughout the Guide.

Natural Disaster: Gulf Coast, September 2008

People with disabilities should be encouraged to have emergency plans in place that include appropriate, accessible arrangements to stay with friends or family out of town when evacuation is warranted.

A category 2 hurricane, Ike was the third most destructive storm ever to make landfall in the United States—affecting numerous areas, from Florida to the Ohio Valley, during the first two weeks of September.

On September 13, Ike hit Galveston, Texas, and forever changed the outlook of Michelle Colvard, who has spina bifida and relies on a wheelchair to get around.

According to Colvard, she and her husband decided to stay with some friends during the storm and never expected to be displaced from their home for two weeks. “I live in a condo on the third floor, and since we had no power for two weeks and the elevator was not working, returning home until the power came back on was not an option for me. We also had no running water for the first couple of days,” she said.

Over the course of two weeks, the Colvards ended up staying at three different friends’ homes due to overcrowding or their need for power. “It was sometimes difficult moving around in other people’s homes, which weren’t generally as accessible to me as my own home. I had to crawl on their bathroom floors, etc., because my wheelchair wouldn’t fit through the narrow doorways,” Colvard said.

This experience has been a life lesson for Colvard. “I learned not to be so cavalier about the potential effect of hurricanes,” she said. “It wasn’t an easy experience for me. I was lucky, but the next time that a hurricane hits, I will evacuate town early.”⁹

A Nation Unprepared: **NOD/Harris Survey Findings**

More than two years after the terrorist attacks focused national attention on the importance of planning ahead for disasters, Americans with disabilities remained insufficiently prepared and were anxious about their safety, according to a comparison of NOD/Harris Poll survey results conducted in November of 2001 and December of 2003. In 2004, a nationwide NOD/Harris Poll survey of emergency managers was conducted to determine their level of inclusive planning for people with disabilities in the jurisdictions.

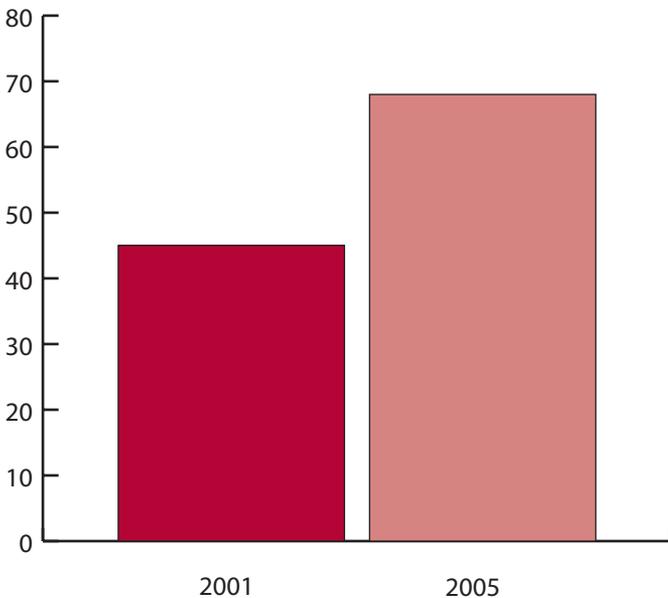
RESPONSES GIVEN BY SHELTER MANAGEMENT FOR THE SPECIAL NEEDS ASSESSMENT FOR KATRINA EVACUEES (SNAKE) SURVEY¹⁰

- Only 50% of those interviewed had policies, plans, and guidelines for accommodations in place prior to Hurricane Katrina.
- 85.7% of community-based groups surveyed answered that they did not know how to link with the emergency management system.
- Fewer than 30% of shelters had access to American Sign Language interpreters, 80% did not have TTYs, and 60% did not have TVs with open caption capability. Only 56% of shelters had areas where oral announcements were posted so people who are deaf, hard of hearing, or out of hearing range could go to a specified area to get or read the content of announcements. This meant that people who were deaf or hard of hearing had no access to the vital flow of information.

In 2001, survey results discovered that 58 percent of people with disabilities did not know whom to contact about emergency plans in their community. In 2003, the result was 53 percent. Comparison of the two surveys indicates that the number of people with disabilities who did know whom to contact increased only incrementally. Figures from the 2001 and 2003 surveys suggest that 61 percent of people with disabilities still have not made plans to quickly and safely evacuate their homes.

The new survey conducted in November 2005 found a noteworthy improvement, however, in the workplace preparedness of people with disabilities who are employed. Sixty-eight percent now say that plans have been made to quickly and safely evacuate from their jobs, a dramatic increase from 45 percent in 2001

Figure 1. Percentage of employed people with disabilities whose employers have plans to quickly and safely evacuate them from workplaces



- 58% of people with disabilities do not know whom to contact about emergency plans for their community in the event of a disaster.¹¹
- 32% of people with disabilities say plans have not been made to evacuate them from their workplace.¹²

(see figure 1). This suggests that efforts to design and implement disability-specific disaster planning are making an impact where people work.

Survey results continue to indicate that people with disabilities are anxious about their personal safety. In 2001, 18 percent of people with disabilities were “extremely or very anxious,” compared with just 8 percent of the non-disabled population. Forty-three percent of people with disabilities describe themselves as at least “somewhat anxious” about their personal safety, compared with 36 percent of people without disabilities. For people with disabilities, this figure has not changed from 2001. Thirty-six percent of people with disabilities say they are more concerned about their personal safety than they were before September 11, 2001. Twenty-seven percent of other Americans say they are more concerned about their safety than before the terrorist attacks.

A 2004 nationwide survey by Harris Interactive, commissioned by the National Organization on Disability and funded by a grant from the U.S. Department of Homeland Security, of emergency managers in states as well as large, mid-size, and small cities throughout the nation, found that 69 percent said they had incorporated the needs of people with disabilities into their emergency plans. An additional 22 percent said they have a plan under development.

The survey found that, among those who had a preparedness plan in existence or under development, only 54 percent had plans for dealing with schools for students with disabilities; 50 percent

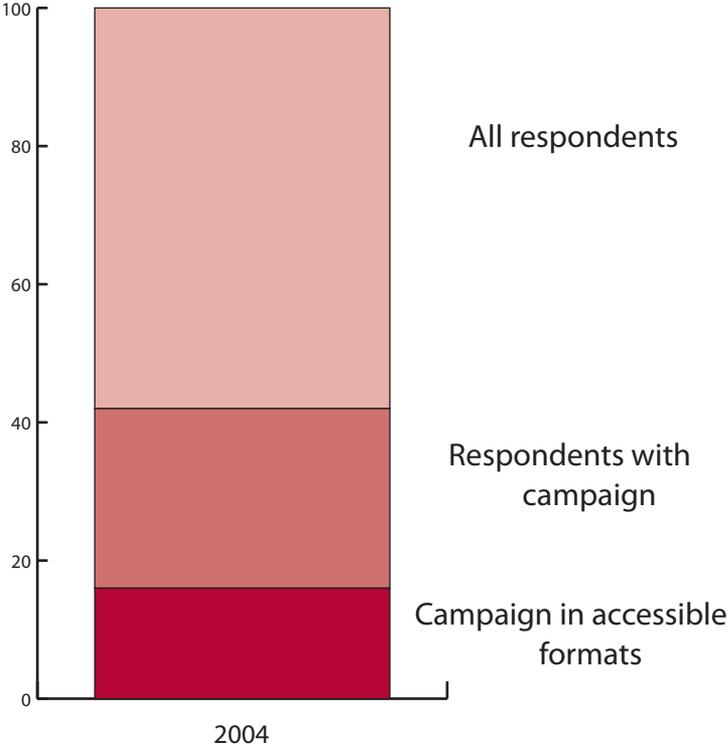
did not have a special needs registry that included people with disabilities; 59 percent did not have plans for pediatric populations; and 76 percent did not have a paid expert to deal with emergency preparedness for people with disabilities. Among all respondents, 39 percent had not purchased specialized equipment; 36 percent said no special training had been offered, and 73 percent said no funding had been received to address emergency planning for people with disabilities.

Additionally, among all respondents, only 42 percent said they had a public awareness campaign directed at providing emergency information to people with disabilities—and only 16 percent of those with a campaign make the plan available in accessible formats (i.e. Braille, cassette, large type; see figure 2). The survey also indicated that small cities (and in some cases mid-size cities) include people with disabilities in their emergency plans to a lesser extent than large cities do.

These statistics should improve over time with continued emphasis on preparedness for all people, along with a focus on the functional needs of those with disabilities.

- Approximately 1.8 million people live in nursing home facilities nationwide.¹³
- There are over 15,281 certified nursing home facilities operating in the U.S. today.¹⁴
- There are approximately 33,000 assisted living facilities operating in the U.S. today.¹⁵

Figure 2. Percentage of emergency managers who had a public awareness campaign directed at people with disabilities, and those who had campaigns in accessible formats



Preparing for Emergencies:

Working with the Disability Community

According to the U.S. Census Bureau, more than 54 million Americans—about one-fifth of the U.S. population—have a disability. Take the population of any community and divide by five. The result approximates the number of residents with disabilities in that community. Of course, some communities will have a larger or smaller proportion of citizens with disabilities, but few vary markedly from this calculation.

It is helpful to set forth a few basic statistics:

- Nearly 6.5 million people require the assistance of another person for daily life activities, such as getting dressed, eating, and bathing.¹⁶
- 21.2 million Americans are blind or have trouble seeing even with glasses or contact lenses.¹⁷
- About 36 million American adults have hearing loss and only 1 out of 5 people who need a hearing aid actually uses one.¹⁸
- 1 million Americans are completely deaf.¹⁹
- There are 1.5 million wheelchair users. An additional four million people require mobility aids, such as canes and walkers.²⁰
- There are approximately 4.76 million people with intellectual and related developmental disabilities.²¹
- Many individuals have more than one disability.²²

Figures like these reflect the range of issues that need to be taken into account in developing and carrying out emergency plans. For instance, mobility limitations may make it difficult to climb up

and down stairs or to move quickly over long distances. Vision impairments might impede the reading of signs or the traversing of unfamiliar or altered terrain. Hearing limitations could prevent one from following warnings or instructions. And a variety of cognitive/intellectual disabilities might impair an individual's ability to appreciate or respond to an emergency.

Valuable as they are, statistics give emergency planners only a superficial impression of the impact of disability during an emergency. What is more important is the experience of disability, which raises such questions as:

- What is it like to be a person with a disability during and after an emergency?
- Can one hear or understand the warnings?
- Can one quickly exit a home or workplace?
- Can one move about the community after evacuating?
- Are there necessary or even vital daily items (medicines, power supplies, medical devices) that are not likely to be available in emergency shelters?
- Are basic services, like rest rooms and showers, available and accessible to people with disabilities?
- Does the person require assistance from a caregiver?

These questions are not always easy to answer. That is why it is imperative to analyze needs and form meaningful partnerships with the disability community.

New Legislation and Policies

Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities

Established in 2004 under Executive Order 13347 by President Bush and chaired by the Department of Homeland Security (assigned to the Officer for Civil Rights and Civil Liberties), the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC) works to ensure that the federal government accounts for the safety and security of people with disabilities during disasters. The ICC is made up of the administrator of the Environmental Protection Agency, the administrator of General Services, the director of the Office of Personnel Management, the commissioner of Social Security, and the heads of the executive departments. Executive departments represented include the Department of Transportation, the Department of the Treasury, the Department of Agriculture, and the Department of Justice, among others. Other invited members include the U.S. Access Board, the National Council on Disability, and the Federal Communications Commission. The ICC is primarily a policy and coordinating body but has had active roles during major disaster activations.

National Response Framework

Formerly known as the National Response Plan, the National Response Framework (NRF) has updated information on how to conduct response efforts at the federal level, and it now takes into account those with functional needs. It is important for

- Only 16% of public awareness campaigns directed at people with disabilities are in accessible formats.²³
- There are more than 3,407 adult day care centers in the U.S.²⁴

professionals to note that during the nationwide plan review under the Bush administration, planning for special needs populations was a specifically designated review criterion, and now the NRF includes guidance on “functional needs” planning. Also worth noting is the fact that terminology (i.e. disability, special needs, functional needs) is in a state of evolution, and planners must be very clear about how they are defining their terms locally, regardless of what definitions are specified in broad guidance documents.

The definition of “Special Needs Populations” as it appears in the National Response Framework is as follows:

Populations whose members may have additional needs before, during, and after an incident in functional areas, including but not limited to:

Maintaining Independence

Individuals requiring support to be independent in daily activities may lose this support during an emergency or a disaster. Such support may include consumable medical supplies (diapers, formula, bandages, ostomy supplies, etc.), durable medical equipment (wheelchairs, walkers, scooters, etc.), service animals, and/or attendants or caregivers. Supplying needed support to these individuals will enable them to maintain their pre-disaster level of independence.

Communication

Individuals who have limitations that interfere with the receipt of and response to information will need that information provided in methods they can understand and use. They may not be able to hear verbal announcements, see directional signs, or understand how to get assistance due to hearing, vision, speech, cognitive, or intellectual limitations, and/or limited English proficiency.

Transportation

Individuals who cannot drive or who do not have a vehicle may require transportation support for successful evacuation. This support may include accessible vehicles (e.g., lift-equipped or vehicles suitable for transporting individuals who use oxygen) or information about how and where to access mass transportation during an evacuation.

Supervision

Before, during, and after an emergency individuals may lose the support of caregivers, family, or friends or may be unable to cope in a new environment (particularly if they have dementia, Alzheimer's or psychiatric conditions such as schizophrenia or intense anxiety). If separated from their caregivers, young children may be unable to identify themselves; and when in danger, they may lack the cognitive ability to assess the situation and react appropriately.

Medical care

Individuals who are not self-sufficient or who do not have adequate support from caregivers, family, or friends may need assistance with: managing unstable, terminal or contagious conditions that require observation and ongoing treatment; managing intravenous therapy, tube feeding, and vital signs; receiving dialysis, oxygen, and suction administration; managing wounds; and operating power dependent equipment to sustain life. These individuals require support of trained medical professionals.

The above examples illustrate function-based needs that may exist within the community.

Individuals in need of additional response assistance may include those who have disabilities; who live in institutionalized settings; who are elderly; who are children; who are from diverse cultures;

who have limited English proficiency or are non-English speaking; or who are transportation disadvantaged.

Post-Katrina Emergency Reform Act

As a result of the devastation caused by Hurricane Katrina, President George W. Bush signed into law the Post-Katrina Emergency Reform Act. Effective March 31, 2007, the Act aims to strengthen the Department of Homeland Security/FEMA's ability to prevent, prepare for, protect against, respond to, and recover from disaster. To ensure that a broad range of stakeholder opinions is taken into account, the National Advisory Council (NAC) was established. Within this body of appointed experts, there is an Advisor on Disability Issues in addition to an Advisor on General Special Needs. Further, the NAC established a Special Needs subcommittee, thereby elevating the issue to a high level of attention.

Additionally, the Act creates new leadership roles within DHS, including the position of National Disability Coordinator (NDC). Among the required duties of the position is the responsibility to coordinate efforts and provide guidance on matters related to emergency management and people with disabilities (<http://www.fema.gov/emergency/nrf>).

Presidential and Other Initiatives

In 2009, President Obama created and staffed the new position of Senior Advisor on Disability Issues within FEMA to report to the administrator. This senior staff position aims to address emergency management issues relating to the disability community and will enhance preparedness efforts at the agency's highest levels.

As a result of lessons learned from Hurricane Katrina, FEMA drafted *Comprehensive Preparedness Guide 302* (CPG-302) to provide planning considerations for a variety of hazards, security, and emergency functions. It also offers general guidelines for developing a state, territorial, tribal, and local government Household Pets

and Service Animals Plan (HPSAP). FEMA has also developed *Comprehensive Preparedness Guide 301: Emergency Management Planning Guide for Special Needs Populations* (CPG-301), which aims to help tribal, state, territorial, and local governments develop emergency plans for people with functional needs.

In 2009, FEMA released its National Disaster Housing Strategy, which calls for national and state efforts to plan for accessible housing that can be made available after a disaster.

The National Council on Disability (NCD) recommends that each state create task forces on disaster housing consistent with the Strategy that involves disability organizations. For more information, visit the National Disaster Housing Resource Center's Website (<http://www.fema.gov/emergency/disasterhousing>).

The Department of Justice drafted an "ADA Checklist for Emergency Shelters" (www.ada.gov/pcatoolkit/chap7shelterchk.htm), which helps emergency managers determine if a building could be utilized as a shelter and, if so, what barriers would need to be rectified in order to make it accessible/ADA compliant.

Partnership with the Disability Community: **Opportunities and Benefits**

Involving and listening to people with disabilities provides the best insights for addressing their needs. Emergency planners should:

- **Identify** those in the community who might have functional 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 it 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 functional 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 non-traditional 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, as well as in drills and exercises, 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. A number of states and localities have already created taskforces (a.k.a. Special Needs Advisory Panel, Working Groups, etc.) to address disability-related issues in emergency management and to put together inclusive plans. Stakeholders include emergency management, first responders, disability organizations and advocates, and hospital associations.

- **Work** with institutional and industry-specific groups that are not typically considered 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, as well as to a host of additional equipment, materials, and skilled personnel.

Many states have a number of Community Emergency Response Teams (CERTs) serving in the workplace and in the community at large. Teams are made up of citizens who undergo training to aid in disaster response. Some communities are now organizing Special Needs CERTs in order to engage people with all types of disabilities in the process. These individuals must also complete the CERT training program and can be activated during an emergency, just as would any other trained volunteer. In this way, people with disabilities become part of the solution. An excellent local example of such an effort can be found through the Progressive Center for Independent Living in New Jersey (<http://www.pcil.org>).

How to Involve People with Disabilities in Planning

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, including drills and exercises.

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. Remember, the “disability group” is one that people can “join” at any time.

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 state or 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:

- Department of Health and/or Mental Health
- Department of Aging

- Department of Veterans Affairs
- The local Americans with Disabilities Act (ADA) Coordinator

Institutional Participants

Examples of institutional partners are:

- Representatives from the home-based care industry, such as the local Visiting Nurse Service and the Home Health Aides Association
- Residential healthcare facilities, such as nursing homes, skilled care homes, and assisted living facilities
- Hospital associations
- The local end stage renal disease (ESRD) network (a.k.a. local dialysis network)
- The ambulette and private accessible transportation 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)
- 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

It is most important 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, as well as their caregivers, helps to establish 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.

Know Your Community Members

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 has a disability, the national planning average used by emergency management offices is notably lower. To accurately plan, one must have a solid understanding of community demographics at any given time. A lower 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. Some emergency managers are now using geographic information system (GIS) mapping to locate high concentrations of functional needs populations. Essentially, GIS relies on special software and available data to pinpoint areas where individuals with disabilities are likely to live. Should disaster strike, GIS mapping can help emergency responders know which areas may need priority attention or special consideration.

Second, work with local disability organizations to identify clusters of people with disabilities who 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. Currently, communities that do utilize registries tend to offer individuals with functional needs a few ways to register, including online, via a paper application, or by calling their local OEM or disability services office, or even 211 in some areas.

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 themselves 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 a guide in an emergency, not a definitive or exhaustive list.

Communication is the Key

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
- 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.
- Frequently repeat the most essential emergency information in a simple message format that those with cognitive disabilities can follow.
- When posting information on a Website, make sure the Website is accessible (see details on Web accessibility, page 58).
- Provide information in alternate formats (e.g. Braille, audio recording, large font, text messages, e-mails, 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 customers who use life-sustaining equipment; 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. Text messaging, blogging, Twitter, e-mail, and secure access to Websites have emerged as viable options; however, these systems could fail in times of disaster, and if they remain active, the validity of information should be monitored.

Wireless Communication Systems and New Technology

Technology is constantly changing, and new and improved systems can be put into place to help alert those with hearing impairments. Today, this population segment can receive alerts via relay services or calls placed over the Internet as well as via text messaging, e-mails, social networking Websites (i.e. Twitter, Facebook, and MySpace), videophone calls, or online video conferencing programs such as Skype.

A number of companies and organizations are also working to create new alert methods for those with hearing loss. The

Rehabilitation Engineering Research Center for Wireless Technologies (Wireless RERC), which is funded by a grant from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education, works in partnership with the Georgia Institute of Technology to promote the accessibility of wireless products and services. Founded in 2001 and located at the Shepherd Center in Atlanta, Wireless RERC also works to enhance wireless emergency communications, such as sending public emergency alert videos in American Sign Language (ASL) to cell phones.

Another new emergency alert system for those who are deaf or hard of hearing is Oklahoma's Weather Alert Remote Notification. Through this system, people can receive emergency alerts via e-mail, pager, or text messaging. This service was offered free of charge courtesy of a FEMA grant obtained by the Oklahoma Office of Emergency Management.

According to a 2009 report published by the National Council on Disability, "the National Emergency Number Association is documenting guidelines for Public Safety Answering Points and recommendations to the FCC" for video relay usage.²⁵

Accessible Media

The Carl and Ruth Shapiro Family National Center for Accessible Media (NCAM) is a research and development facility that addresses accessibility issues involving the media and information technology to promote accessibility to people with disabilities in all aspects of society. As part of this endeavor, NCAM received a multi-year federal grant for the Access to Emergency Alerts project in an effort to connect emergency alert providers, the telecommunications industry, and public broadcasting representatives with consumers in order to find ways to make emergency warnings accessible by addressing the barriers that exist (<http://ncam.wgbh.org>).

- Approximately 15 million Americans use some assistive technology.²⁶

Based in San Antonio, Texas, Deaf Link (<http://www.deafink.com>) is one of several emerging companies that utilize new technology to enhance communication for those who are deaf or hard of hearing. The company also has an interest in emergency management. Aside from listing preparedness tips on its homepage, Deaf Link was actively involved in helping FEMA and the Texas Governor's Division of Emergency Management (GDEM) send accessible alerts and updates to the deaf and hard-of-hearing community following Hurricane Ike. This was the first documented time that such an effort was undertaken during a disaster recovery process. As part of its role, Deaf Link sent updates and other alerts via the Internet in American Sign Language (ASL), in audio, and in a text format that could be converted to Braille with special equipment. GDEM also posted videos in ASL and voiceovers on a variety of hurricane-preparedness and response topics. In addition, FEMA has been using Deaf Link communications equipment to help deaf Texans apply for disaster assistance. Deaf Link has since been recognized by the International Association of Emergency Managers for their efforts and commitment.

Evacuation Planning for People with Disabilities

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 48), but it highlights several that should be considered.

There are several types of facilities and structures where special consideration is required for the evacuation of people with disabilities. These are discussed below.

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 and employees are familiar with these plans. These drills, of course, should pay adequate attention to the functional needs of all people with disabilities, not just those in wheelchairs and with other mobility impairments, but also those with visual, hearing, or cognitive impairments. In addition, it is good to work with groups that represent smaller organizations, like home healthcare regulators or local business associations, to encourage each of their members to conduct planning and drills.

Unfortunately, it is often too late at the moment of disaster to educate people, already confused and alarmed by a crisis, about

how to escape or to help individuals with disabilities to do so. Some cities, fortunately, 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 managers 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 staff members must be trained to supervise evacuations. Staff members at these non-residential populated structures should also be trained in dealing with disabilities of all types.

Entire Communities

Evacuations of entire communities typically take place over a longer period of time than facility evacuations. They can be even more traumatizing because people are leaving their homes, businesses, and possessions behind. Community evacuation plans should be designed to allow necessary time, consideration, and assistance for people with disabilities to be adequately notified of evacuation plans. People with disabilities must be able to bring with them special equipment (e.g. wheelchairs, dialysis machines, and ventilators) and service/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 need for lead time is greater. Communities may need to provide accessible transportation support and other

resources if people are ordered to evacuate the area.

In an effort to avoid many of these issues, some emergency managers are striving to find accessible facilities ahead of time that could serve as ADA-compliant shelters when needed. In the early 1990s, work began on the concept of the Senior Center Safe Center. In Florida, the first two such centers with “built-in” functional needs capacity opened in 2003 and 2005; both are in central Florida. Alabama started to retool the concept in 2005, and by 2007 the first center was opened in Guin, Alabama. In these states, new or remodeled senior centers (which are accessible) are designed for dual-purpose use and can therefore also be used as shelters, since they can withstand strong winds and are located outside the floodplain. In addition, they have extra outlets, a generator, and satellite telephones, additional square footage allocations, more rest rooms, cross-trained staff, etc. Roofs are also painted in bright colors to make identification from the air easier after an event.

- 39% of U.S. households own at least one dog and 34% of U.S. households own at least one cat.²⁷
- There are approximately 30,000 working assistance dogs, including guide, hearing, and service dogs used by people with disabilities.²⁸

Service Animals and Pets

Many people with disabilities rely on service animals to assist them with daily living activities and other functions. Service animals are highly trained and can provide assistance with retrieving items, alerting those who are deaf to certain sounds (like a ringing telephone or a knock on the door), or with navigating pathways if the person is blind. Service animals also at times serve as a source of protection.

During emergencies, service animals must be permitted into shelters so that they can remain with their owners, and efforts must be made to meet their basic needs (i.e., providing them with food, water, veterinary care, etc.). However, prior to disaster, emergency managers should encourage people with disabilities to prepare emergency kits for their service animals. Kits should include a leash, vaccination records, food, and identification.

For more information on accommodations that must be made for those with service animals, review FEMA's *Comprehensive Preparedness Guide* (CPG) 302. In draft form, this document also offers general guidelines for developing a state, territorial, tribal, and local government Household Pets and Service Animals Plan (HPSAP).

According to the guide, HPSAPs must comply with standards set in the PETS Act. This act mandates that emergency plans incorporate the needs of those with pets or service animals and it ensures that necessary assistance or services (like medical care or sheltering for the animals) are provided.

FEMA has also created the Disaster Assistance Policy (DAP) 9523.19, "Eligible Costs Related to Pet Evacuations and Sheltering," which serves as a guide on reimbursement for governments requesting public assistance for emergency-related actions involving pets.

Include Functional 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 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, service/guide animals, neighbors, 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 it may cause them 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).”²⁹ Similarly, two months after the disaster, the New York Academy of Medicine

- Even in non-emergency situations, people with disabilities are three times as likely as those without disabilities to consider transportation a problem.³⁰

found that the prevalence of PTSD and depression among adults in Manhattan was twice the national average.³¹ 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 the effect is often more severe. In the weeks following the attacks, *iCan News Service* reported that many people with disabilities living in Lower Manhattan experienced the following:

- Paratransit service in the Ground Zero area was suspended and placed under stricter limits citywide.
- Some people were not able to get necessary prescriptions filled.
- Wheelchair and other equipment repairs were delayed or unfinished because repair shops were closed.
- Many people with disabilities were not making it to critical healthcare appointments, either because they could not find transportation or were afraid to leave their homes.
- People who are blind or have low vision had to spend hundreds of hours learning how to navigate the rearranged city, on foot and by re-routed public transportation (<http://www.icanonline.net>).

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 functional needs most critical to people with disabilities are restored or prioritized during the recovery phase. Some major considerations include:

- Making allowances at blockades, shelters, and other affected areas for access by attendants, home health aides,

visiting nurses, service/guide animals, and other individuals crucial to the immediate healthcare needs of people with disabilities

- Identifying the impact on the disability community after 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
- 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

Other Factors to Consider

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

Volunteers

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 crucial 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 times of crisis, but for people with disabilities may actually be essential to day-to-day living.

Codes

Federal, state, and local regulatory codes address functional 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 functional 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 on-site 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

Shelters must meet minimal accessibility standards so that all members of a community can find safety. For more information on accessibility requirements for buildings, consult the Americans with Disabilities Act Accessibility Guidelines (ADAAG). Such regulations also apply to new construction and building renovation.

In addition, the level of medical oversight to be provided must be determined well in advance of an emergency. Whether there will be different classes of shelters (e.g., medically managed or designated for functional needs) must also be established in the planning phase. Making these determinations ahead of time will help to ensure that the needs of those with disabilities utilizing the shelter system will be properly identified and addressed.

For more information on this, review the Department of Justice's "ADA Checklist for Emergency Shelters" (<http://www.ada.gov/pcatoolkit/chap7shelterchk.htm>). The checklist will help emergency managers determine if a building could be used as a shelter and, if so, what barriers must be rectified.

Transportation

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.

As part of its Routes to Effective Evacuation Planning primer series on emergency transportation and evacuation, the Federal Highway Administration (FHWA) has released *Evacuating Populations with Special Needs*, a report that offers local transportation agencies a number of best practices and tools that can be used to address transportation issues involving those with functional needs during times when evacuation is necessary. The

report includes an evacuation checklist that can be used by officials as well as transportation providers.

FHWA's *Evacuating Populations with Special Needs* can be found online (http://www.ops.fhwa.dot.gov/eto_tim_pse/publications/index.htm).

Continuity Planning

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 after a disaster to their clients with disabilities.

Emergency Technologies

There are many types of emergency equipment designed 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.

However, this may change soon, as the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) is beginning to coordinate a review process to set such standards. Even if standards are put in place, 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.

Include Functional Needs in the Mitigation Phase

Mitigation measures offer increased levels of protection. Even so, according to findings in a 2009 report issued by the National Council on Disability (NCD), many currently recommended practices fail to address the needs of people with disabilities.³² The most effective safe rooms, for example, are underground. Plans for accessible underground safe rooms have not been developed. For additional information, review the design and guidance in FEMA 320, *Taking Shelter from the Storm, Building a Safe Room Inside Your House* and FEMA 361, *Design and Construction Guidance for Community Shelters*, both at the FEMA Website (<http://www.fema.gov>). Also see the National Storm Shelter Association shelter standard (<http://www.nssa.cc>).

This 2009 NCD report cites work from 1995 listing seven principles that involve and/or support people with disabilities in order to mitigate the effects of disasters:

1. Accessible Disaster Facilities and Services
2. Accessible Communications and Assistance
3. Accessible and Reliable Rescue Communications
4. Partnerships with the Media
5. Partnerships with the Disability Community
6. Disaster Preparation, Education, and Training
7. Universal Design and Implementation Strategies

Emergency planners need to recognize ways to overlay unique needs of people with disabilities in all four phases of emergency management.

Conclusion

This Guide should help to ensure that the needs and well-being of people with disabilities in communities across the United States are integrated fully into the emergency planning process. Numerous disasters have demonstrated that the disability community's ability to assist with its own survival during an emergency is directly related to the amount of effort put into awareness and preparedness measures before the fact. Likewise, the ability of emergency professionals to make informed and often split-second decisions for and about functional needs issues during the response and recovery phases of an emergency is also directly related to their planning and preparation prior to the disaster.

The planning and preparation efforts that are specially devised for people with disabilities are likely to benefit the general population as well—especially those who may be traumatized or disoriented by a disaster, as in the Pentagon escape example on page 7.

The message from emergency professionals to the disability community should be the same as it is for the general population: *Be prepared*. How people should be prepared and what must be taken into account will depend on many factors, whether or not they have disabilities. With adequate forethought, planning, and cooperation, all of a community's residents, with and without disabilities, will have the maximum chance to prepare for and survive a disaster, and to return to normal life as quickly as possible.

Tools and Resources for Functional Needs Emergency Planning

The following list of resources, while not exhaustive, provides some key references related to emergency planning for people with disabilities available as of July 2009.

The National Organization on Disability's Emergency Preparedness Initiative

As a service to both the emergency management and disability communities, NOD maintains an extensive section about the Emergency Preparedness Initiative on the organization's general Website (<http://www.nod.org/emergency>). We offer this as a research entry point. Here visitors will find:

- Background on the goals and activities of the Emergency Preparedness Initiative
- News from the disability community and/or emergency management community, which may impact emergency preparedness for people with disabilities
- A virtual binder from the National Capital Region Conference on Emergency Preparedness of People with Disabilities
- Suggestions for locating community residents with disabilities and links to national disability organizations with local affiliates
- Articles on the impact of disaster on people with disabilities
- Links to disability-relevant emergency preparedness information, including planning checklists, publications, survey data, emergency-related government regulations, and public testimony from hearings

- Consumer resources for coping with disaster, some of which specifically address people with disabilities
- A directory of products relevant to the disability community and emergencies/disasters
- An EPI-supported online community, where members may pose questions, offer suggestions, and find a list of good practices pertaining to unique emergency functional needs
- A collection of academic research abstracts, industry white papers, and official reports about disability and the impact of emergencies and disasters
- Short videos on emergency preparedness and the functional needs population, which can be viewed online
- A report on the Special Needs Assessment for Katrina Evacuees (SNAKE) Project can also be accessed through the site. Following Hurricane Katrina, SNAKE teams were deployed throughout the Gulf region to perform rapid assessments of the functional needs and living conditions of survivors with disabilities. The report includes findings on response and recovery efforts as well as statistics

Standards as Research Tools

- FEMA has created a series of comprehensive preparedness guides for use by emergency managers. Comprehensive Preparedness Guide 301 (CPG-301): *Emergency Management Planning Guide for Special Needs Populations*, which is in draft form, aims to help tribal, state, territorial, and local governments develop emergency plans for people with functional needs. Comprehensive Preparedness Guide 302 is based on lessons learned from Hurricane Katrina and provides planning considerations for a variety of hazards, security, and emergency functions. It also offers general guidelines for developing a state, territorial, tribal, and local government Household Pets and Service Animals

- Plan (HPSAP) (<http://www.fema.gov>).
- The Americans with Disabilities Act (ADA) requires equal access for people with disabilities to all government programs. In 2008, the President signed the ADA Amendments Act, which broadens the scope of the definition of “disability,” thereby making it easier for people with functional needs to seek protection under the ADA. This includes programmatic inclusion in all disaster plans developed for a community under Title II (<http://www.ada.gov>).
 - An ADA guide for local governments, *Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities*, was released in 2004 by the U.S. Department of Justice, Civil Rights Division, Disability Rights Section. It provides guidance for making local government emergency preparedness and response programs accessible to people with disabilities (<http://www.usdoj.gov/crt/ada/emergencyprep.htm>).
 - SARA Title III – 1986 Superfund Amendment & Reauthorization Act directs the creation and membership of Local Emergency Planning Committees (LEPC) (http://www.epa.gov/emergencies/content/epcra/epcra_plan.htm#LEPC).
 - The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) oversees standard setting for healthcare facilities as well as the accreditation of healthcare facilities, such as nursing homes and hospitals (<http://www.jointcommission.org>).
 - The National Fire Protection Association (NFPA) oversees publication of recommended safety codes and standards for the prevention of fires and other hazards. NFPA codes include fire prevention, buildings, and natural gas (<http://www.nfpa.org>).
-

- The Federal Communications Commission (FCC) oversees regulations regarding both the Emergency Alert System (EAS) and Closed Captioning (<http://www.fcc.gov>).

Local fire, safety, building, and human rights codes can also provide examples of functional needs emergency planning issues:

- Florida state law requires each county to have a Special Needs Registry that its residents can voluntarily join. An example is available online (http://monroecoff.virtualltownhall.net/Pages/MonroeCoFL_Social/SNregistry).
- Chicago local law requires building evacuation plans specifically for people with disabilities. It applies to any commercial or residential building 80 feet or higher (<http://www.ci.chi.il.us/Fire/ProposedRules/Rules9.pdf>).

Potential Areas of Funding

- Mitigation
- Preparedness
- Training
- Public/private initiatives
- Community development block grants
- Grants from state agencies or disability organizations
- Risk/loss management

Publications

Many jurisdictions and organizations have produced materials to help people with disabilities develop their own emergency plans. Below are some of the most useful ones to consider.

READY.gov, U.S. Department of Homeland Security

<http://www.ready.gov>

Access Website for family, child, and business preparedness-related materials.

The American Red Cross (ARC)

<http://www.redcross.org>

Order all publications online or contact your local Red Cross chapter.

- Disaster Preparedness for People with Disabilities, ARC- 5091; in cassette form: ARC- 5091C
- Checklist for People with Mobility Problems, ARC- A4497
- Disaster Preparedness for Seniors by Seniors, ARC- A5059
- Your Family Disaster Plan (FEMA/ARC), ARC-A4466 (English) and A4466S (Spanish)
- Your Family Disaster Supplies Kit (FEMA/ARC): ARC- 4463 (English) and A4463S (Spanish)

The Federal Emergency Management Agency (FEMA)

<http://www.fema.gov>

For all publications, contact the FEMA Distribution Center toll-free at (800) 480-2520 or order online ([http:// www.fema.gov/library](http://www.fema.gov/library)).

FEMA offers a number of manuals to aid emergency managers in working with the disability community, such as Comprehensive Preparedness Guide 301 (CPG-301): *Emergency Management Planning Guide for Special Needs Populations*. CPG-301 aims to help tribal, state, territorial, and local governments develop emergency plans for people with functional needs.

The Federal Highway Administration

<http://www.fhwa.dot.gov>

As part of its *Routes to Effective Evacuation Planning* primer

series on emergency transportation and evacuation, the Federal Highway Administration (FHWA) has released *Evacuating Populations with Special Needs*, a report on meeting the needs of those who require assistance during a local or multi-jurisdictional emergency evacuation. To view a copy of *Evacuating Populations with Special Needs*, visit the Website (http://www.ops.fhwa.dot.gov/eto_tim_pse/publications/index.htm).

U.S. Fire Administration (USFA)

<http://www.usfa.dhs.gov>

For all publications, contact the U.S. Fire Administration Publications Center at (301) 447-1189 or toll-free at (800) 561-3356, or order online (<https://www.usfa.dhs.gov/applications/publications>).

In particular, see:

- *Emergency Procedures for Employees with Disabilities in Office Occupancies* (FEMA/USFA), 1994, Item number FA-154
- *Orientation Manual for First Responders on the Evacuation of People with Disabilities* (FEMA), August 2002, Item number FA-235

U.S. Fire Administration & FEMA Fire Risks Series

- Blind or Visually Impaired (FA 205 12/99)
- Deaf or Hard of Hearing (FA 202 12/99)
- Mobility Impaired (FA 204 12/99)
- Older Adult (FA 203 12/99)

Video Training Tools: FEMA has produced several videos that illustrate the planning necessary for facilities such as hospitals and nursing homes. These titles include “Storm Alert! Hurricane Preparedness for Nursing Homes,” “Stormwatch! Hurricane

Preparedness for Hospitals,” and “Stormworthy! Medical Buildings and Hurricanes.” Also available is a video titled “Voices of Wisdom,” which is a firsthand account by seniors of their experiences during and after an earthquake.

Training Courses: FEMA/EMI G197 Emergency Planning & Special Needs Populations (delivered as a modified train-the-trainer instructional session). FEMA developed this course to provide the people who are responsible for emergency planning or for the care of people with functional needs with the skills and knowledge they will need to prepare for, respond to, recover from, and mitigate against emergency situations. There are two ways to obtain the course materials (student manual, instructor guide, and presentation slides).

1. Download from the FEMA Website (<http://training.fema.gov/emiweb/trainingann.asp>). Click on the link “New training resources for Emergency Planning and Special Needs Populations (G197) and the Emergency Management Institute School’s (K-12) Program FEMA 159 and FEMA 253.” Follow the directions to download the materials.
2. Receive course materials on CD. Send an e-mail request for the materials to Independent.Study@dhs.gov. Include your name, organization, and mailing address.

The Community Emergency Preparedness Information Network (CEPIN)

<http://www.cepintdi.org>

CEPIN offers training to promote the development and maintenance of relationships among emergency responders and people with functional needs. Its signature course, Emergency Responders and the Deaf and Hard of Hearing Community:

Taking the First Steps to Disaster Preparedness, provides emergency responders and those who are deaf or hard of hearing with the information and skills needed to prepare for, respond to, and recover from emergency situations. For more information on training or to access CEPIN's video about emergency preparedness, visit CEPIN's Website.

“Working with People with Disabilities” training DVD

The Baltimore County Fire Department and the Baltimore County Commission on Disabilities produced a training DVD for first responders who encounter people with a variety of disabilities during their usual duty calls. This DVD is approximately 30 minutes long and separated into first-person information sharing by members of the community. It also demonstrates proper emergency interaction with professionals. The training DVD carries the endorsement of over 22 government and non-governmental agencies in Baltimore County. Requests for more information about this DVD may be directed via e-mail to fireinfo@baltimorecountymd.gov.

The Humane Society of the United States (HSUS)

<http://www.hsus.org>

HSUS offers disaster preparedness information and guides, which can be accessed on its Website, so that the public and first responders can better protect pets (including service animals) and livestock. Additionally, the HSUS Disaster Services program provides training opportunities and helps communities with planning and response efforts.

Websites

A great deal of information is available on the Web. The following list of sites offers good starting points from which other information on emergency preparedness for people with

disabilities can be located.

<http://www.nod.org/emergency>

The National Organization on Disability's Emergency Preparedness Initiative provides links and other resources to help people with disabilities prepare for disaster.

<http://www.ready.gov>

The Department of Homeland Security's emergency preparedness information Website offers tips pertaining to people with disabilities.

<http://www.disabilitypreparedness.gov>

The Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities provides information for emergency planners and first responders to help them serve people with disabilities. The site also offers emergency preparedness information for people with disabilities as well as for their family members and service providers.

<http://www.aoa.gov/AoARoot/Preparedness/index.aspx>

The Administration on Aging (part of the U.S. Department of Health and Human Services) has information about the senior population and specific preparedness information.

<http://nemrc.net>

The National Emergency Management Resource Center offers cutting-edge articles and advice from peers as well as training and online conferences to help emergency managers assist those with disabilities.

<http://www.preparenow.org>

This California site is designed to help anyone prepare for

disaster. It offers general links on disasters and functional needs.

<http://www.disability911.com>

Interviews with emergency managers are posted on this site along with links to Webcasts, books, newsletters, and training materials designed to guide officials and people with disabilities.

<http://www.easter-seals.org>

Visit this site for information on their national public education campaign, S.A.F.E.T.Y First: Working Together for Safer Communities.

<http://www.jan.wvu.edu/media/emergency.html>

Access *Employer's Guide to Including Employees with Disabilities in Emergency Evacuation Plans*, the Job Accommodation Network's document on emergency evacuation for employees.

<http://www.nbdc.com>

In the search bar on left of homepage, type “emergency evacuation checklist” to get the emergency evacuation checklist for people with disabilities in the workplace.

<http://www.cdihp.org/products.html#eeguide>

This URL links to the Center for Disability Issues and the Health Professions' guide for people with disabilities and other activity limitations called *Emergency Evacuation Preparedness: Taking Responsibility for Your Safety*. To access the publication, visit the Website or call (909) 469-5380, TTY (909) 469-5520.

<http://www.thisabled.com>

Articles and podcasts on emergency preparedness for people with disabilities can be found here, as well as a forum run by

EAD & Associates, an emergency management consultancy focusing on special needs populations.

<http://www.nad.org/issues/emergency-preparedness>

The National Association of the Deaf provides extensive information on emergency preparedness on its Website, including information about available resources and accessible notification options.

<http://twitter.com> and **<http://www.facebook.com>**

These and other social networking sites can serve as helpful resources by providing up-to-date information on emergency management.

Making Your Information Accessible

Web accessibility is based on the principle that no potential Website visitors, including those with varied disabilities, should be precluded from accessing content or services the site provides. This is especially important when it comes to helping the public take self-preserving actions based on emergency management information. In fact, according to the United States Access Board's Website, "Section 508 requires Federal departments and agencies that develop, procure, maintain, or use electronic and information

Recommendations for Website 508 compliance

- Avoid hidden texts/sections
- Avoid pop-ups
- Alt tags on images must be used
- Use large print since small print is not in compliance
- Avoid Flash media

technology to ensure that Federal employees and members of the public with disabilities have access to and use of information and data, comparable to that of the employees and members of the public without disabilities—unless it is an undue burden to do so.”

A Website can be considered accessible if it meets certain widely accepted design standards, such as those outlined in section 508 of the Rehabilitation Act.

When designing your Website, be certain it meets accessibility standards so that the information will be available to all visitors, including people with disabilities.

It is also useful to solicit feedback from computer users with disabilities. For more information on standards, consult:

- United States Access Board
<http://www.access-board.gov/sec508/standards.htm>
- W3C Web Accessibility Initiative Resources
<http://www.w3.org/WAI/Resources/#gl>
- U.S. Government Accessibility & Workforce Division
<http://www.section508.gov>
- Web Accessibility in Mind
<http://www.webaim.org>
- Information Technology Technical Assistance and Training Center
<http://www.ittatc.org>
- Resources and tools to help meet Section 508 requirements
<http://buyaccessible.gov>

Currently, there are no universal indicators or clues that a Website is accessible. In the past, the “Bobby” standard was used to test accessibility levels, rank them, and permit posting of a symbol of access as a visual cue on Websites. This system is no longer available, but some Websites that once passed access tests may still bear the logo, and it is still a good indicator of usability.

When making information or materials for the public available, it is important to prepare it in alternate formats, such as Braille, larger font text, color contrasts, and audio cassette or CD versions. Disability organizations can provide guidance or referrals.

It may be useful to consult the guides published by organizations such as Lighthouse International (<http://www.lighthouse.org>) for publishing printed materials for people with low vision.

Organizations & Agencies of Interest

American Association of People with Disabilities (AAPD)

<http://www.aapd-dc.org>

Established in 1995, AAPD works to eliminate barriers and improve society for those who have disabilities. AAPD also strives to bring together the disability community and their supporters to promote the Americans with Disabilities Act.

AARP

<http://www.aarp.org>

Since 1958, AARP has worked to improve the quality of life for those over the age of 50. A nonpartisan organization, AARP advocates on behalf of senior citizens nationwide and also educates its members on various issues, including emergency preparedness, and has planning steps posted on its Website for members and non-members to use.

National Council on Disability (NCD)

<http://www.ncd.gov>

Members of this independent federal agency are appointed by the President and work to develop policies and programs that help empower people with disabilities by ensuring that they have equal opportunities for participation in society and can live independently. NCD has created a number of committees to address issues affecting those with disabilities, including

the Homeland Security Committee, which handles issues in emergency management and identifies best practices. On its Website, NCD also has a number of primary research reports on emergency management issues involving people with disabilities and their recommendations.

National Institute on Disability and Rehabilitation Research (NIDRR)

<http://www.ed.gov/about/offices/list/osers/nidrr/about.html>

NIDRR is a federal agency that oversees extensive research projects and related activities, a number of which pertain to emergency management, in an effort to promote the inclusion of people with disabilities in society and to foster independent living.

United States Access Board

<http://www.access-board.gov>

This independent federal agency includes representatives of federal departments as well as people with disabilities who have been appointed by the President. Established in 1973, the mission of the Access Board is to set standards to ensure that all federally funded facilities are accessible to those with disabilities. These standards are not limited to building codes but also include criteria for telecommunications equipment, technology, and transit vehicles. The Access Board has also become more engaged in issues surrounding post-disaster temporary and new construction and pre-disaster accessible notification systems, for example.

Endnotes

1. U.S. Census Bureau, year 2000, <http://www.census.gov>
2. U.S. Census Bureau, year 2000, <http://www.census.gov>
3. FEMA Citizen Corps, Personal Preparedness in America: Findings from the Citizen Corps National Survey, June 2009, p. 58. http://www.citizencorps.gov/pdf/Personal_Preparedness_In_America-Citizen_Corps_National_Survey.pdf
4. U.S. Census Bureau, year 2000, <http://www.census.gov>
5. A portion of the information is based on a report from the California State Independent Living Council, *The Impact of Southern California Wildfires on People with Disabilities*, Sacramento, California, April 2004. <http://www.eadassociates.com/wildfires.doc>
6. Independent Living Research Utilization, <http://www.ilru.org>
7. Excerpts of this account are courtesy of <http://www.thisabled.com>
8. Southwest Louisiana Independence Center, <http://www.silc-la.org>
9. Interview with Kelly Rouba, EAD and Associates, LLC
10. National Organization on Disability's Emergency Preparedness Initiative: *Special Needs Assessment for Katrina Evacuees Report*, October 2005. <http://www.nod.org/emergency>
11. 2003–2005 NOD/Harris Poll Surveys
12. 2003–2005 NOD/Harris Poll Surveys
13. http://www.usatoday.com/news/nation/census/2007-09-27-nursing-homes_N.htm
14. <http://www.statehealthfacts.org/comparemaptable.jsp?cat=8&ind=411>
15. http://helpguide.org/elder/assisted_living_facilities.htm
16. U.S. Census Bureau, year 2000, <http://www.census.gov>
17. 2006 National Health Interview Survey/American Foundation for the Blind, <http://www.afb.org/>
18. National Institute on Deafness and Other Communication Disorders, <http://www.nidcd.nih.gov>
19. Gallaudet Research Institute, <http://gri.gallaudet.edu/demographics>
20. U.S. Census Bureau, year 2000, <http://www.census.gov>
21. Laura Hart, Director of Communications for The Arc of the United

- States, <http://www.thearc.org>
22. U.S. Census Bureau year 2000, <http://www.census.gov>
 23. 2003–2005 NOD/Harris Poll Surveys
 24. <http://www.rwjf.org/pr/product.jsp?id=20735>
 25. <http://www.ncd.gov>
 26. [http://itemcoalition.org/press/comments%20_white_house_conference_\(9-10-04\).htm](http://itemcoalition.org/press/comments%20_white_house_conference_(9-10-04).htm)
 27. American Pet Products Manufacturers Association (APPMA), 2007–2008 National Pet Owners Survey, <http://www.americanpetproducts.org>
 28. National Association of Guide Dog Users, http://www.nfbnet.org/pipermail/nagdu_nfbnet.org/2009-January/028634.html
 29. Shankar Vedantam, “After September 11, Psychic Wounds Slow to Heal,” *Washington Post*, March 17, 2002, p. A3
 30. 2003–2005 NOD/Harris Poll Surveys
 31. <http://www.nyam.org/news/1127/hm>; <http://www.nyc.gov/html/doh/wtc/ntml/children/resources/shtml>
 32. *Effective Emergency Management: Making Improvements for Communities and People with Disabilities*, http://www.ncd.gov/newsroom/publications/2009/NCD_EmergencyManagement_HTML/EffectiveEmergencyManagement.html