

# **Saving Lives:**

## **Including People with Disabilities in Emergency Planning**



**National Council on Disability  
April 15, 2005**

National Council on Disability  
1331 F Street, NW, Suite 850  
Washington, DC 20004

**Saving Lives: Including People with Disabilities in Emergency Planning**

This report is also available in alternative formats and on the award-winning National Council on Disability (NCD) Web site ([www.ncd.gov](http://www.ncd.gov)).

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## **NATIONAL COUNCIL ON DISABILITY**

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*An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.*

Letter of Transmittal

April 15, 2005

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit to you this report, titled *Saving Lives: Including People with Disabilities in Emergency Planning*. Under its congressional mandate, NCD is charged with the responsibility to gather information on the development and implementation of federal laws, policies, programs, and initiatives that affect people with disabilities. In 2003, as a result of your Administration's initiatives in homeland security, NCD committed to evaluate the development of the Federal Government's work in that area as well as in the areas of emergency preparation and disaster relief as they relate to and affect Americans with disabilities.

All too often in emergency situations the legitimate concerns of people with disabilities are overlooked or swept aside. In areas ranging from the accessibility of emergency information to the evacuation plans for high-rise buildings, great urgency surrounds the need for responding to these people's concerns in all planning, preparedness, response, recovery, and mitigation activities. The man-made homeland security terrorist event of September 11, 2001, as well as the recent energy blackouts in the U.S. Northeast and Midwest and, more recently, the natural disaster hurricane events in Florida and the tsunami event of December 26, 2004, underscore the need to pay attention to the concerns raised in this report.

The decisions the Federal Government makes, the priority it accords to civil rights, and the methods it adopts to ensure uniformity in the ways agencies handle their disability-related responsibilities are likely to be established in the early days of an emergency situation and be difficult to change if not set on the right course at the outset. By way of this report, NCD offers advice to help the Federal Government establish policies and practices in these areas. This report provides examples of community efforts with respect to people with disabilities, but by no means does it provide a comprehensive treatment of the emergency preparedness, disaster relief, or homeland security program efforts by state and local governments.

This report provides an overview of steps the Federal Government should take to build a solid and resilient infrastructure that will enable the government to include the diverse populations of people with disabilities in emergency preparedness, disaster relief, and homeland security

programs. This infrastructure would incorporate access to technology, physical plants, programs, and communications. It also would include procurement and emergency programs and services.

NCD commends the Administration and those in leadership positions for the issuance of the July 22, 2004, Executive Order on individuals with disabilities and emergency preparedness. In addition, NCD acknowledges the work of the Department of Homeland Security (DHS) and the Federal Communications Commission in their efforts to ensure that Americans with disabilities are included in the developing infrastructure.

It is our expectation that, through this report, NCD can promote a focused dialogue and communicate critical information to you and your staff at the earliest practicable time to address issues of importance to people with disabilities in the ongoing development of DHS infrastructure.

We stand ready to work with you and the members of your Administration to improve the nation's homeland security, emergency preparedness, and disaster relief infrastructure for all Americans.

Sincerely,

A handwritten signature in cursive script that reads "Lex Frieden".

Lex Frieden  
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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## **Acknowledgments**

A variety of disability community leaders, disaster preparedness professionals, emergency managers, government employees, university professors, executive directors, and staff and board members of nonprofit organizations made valuable contributions of time and expertise to this report. We are unable to acknowledge them all individually but wish to thank them deeply for sharing their time and expertise.

The National Council on Disability thanks June Isaacson Kailes and Brandi Buchanan for conducting the research for this report.



# **Executive Summary**

## **Purpose of the Report**

All too often in emergency situations the legitimate concerns of people with disabilities are overlooked or swept aside. In areas ranging from the accessibility of emergency information to the evacuation plans for high-rise buildings, great urgency surrounds the need for responding to these people's concerns in all planning, preparedness, response, recovery, and mitigation activities. The man-made homeland security terrorist event of September 11, 2001, as well as the recent energy blackouts in the U.S. Northeast and Midwest and, more recently, the natural disaster hurricane events in Florida and the Asian tsunami of December 26, 2004, underscore the need to pay attention to the concerns raised in this report.

The decisions the Federal Government makes, the priority it accords to civil rights, and the methods it adopts to ensure uniformity in the ways agencies handle their disability-related responsibilities are likely to be established in the early days of an emergency situation and be difficult to change if not set on the right course at the outset. By way of this report, the National Council on Disability (NCD) offers advice to help the Federal Government establish policies and practices in these areas. The report also gives examples of community efforts to take account of the needs of people with disabilities, but by no means does it provide a comprehensive treatment of the emergency preparedness, disaster relief, or homeland security program efforts by state and local governments.

This report provides an overview of steps the Federal Government should take to build a solid and resilient infrastructure that will enable the government to include the diverse populations of people with disabilities in emergency preparedness, disaster relief, and homeland security programs. This infrastructure incorporates access to technology, physical plants, programs, and communications. It also includes procurement and emergency programs and services.

## **Scope of the Report**

This report describes the disaster experiences of people with disabilities. It also details the contributions and efforts of community-based organizations (CBOs). And it examines the nascent work of the Directorate of Emergency Preparedness and Response (EP&R), which includes the Federal Emergency Management Agency (FEMA), Department of Homeland Security's (DHS's) Office for Civil Rights and Civil Liberties (CRCL), and FEMA's federal, state, local, and private sector partners. It also touches on the ongoing work of the Federal Communications Commission (FCC) in specific areas that relate to issues of homeland security and emergency preparation. While other federal agencies play important roles in this effort, DHS and FCC efforts represent some of the most critical operations on behalf of Americans with disabilities. Given the nature of most disasters, general and disability-specific programs and services span many different governmental and nongovernmental organizations.

The report examines the following broad areas:

- Disaster experiences of people with disabilities and activity limitations and how their access to disaster services could be improved.
- The experience of CBOs in disasters and how partnerships with those organizations can help.
- How an effective disability-related homeland security and emergency preparedness infrastructure could be developed.

The report's recommendations urge the Federal Government to influence its state and local government partners, as well as community-based partners, to assume major roles in implementing key recommendations.

## **Who Are People with Disabilities?**

Individuals with disabilities make up a sizable portion of the general population of the United States. According to the U.S. Census of 2000, they represent 19.3 percent of the 257.2 million people ages 5 and older in the civilian noninstitutionalized population, or nearly one person in five.

In disaster management activities it is important to think about disability broadly. Traditional narrow definitions of disability are not appropriate. The term disability does not apply just to people whose disabilities are noticeable, such as wheelchair users and people who are blind or deaf. The term also applies to people with heart disease, emotional or psychiatric conditions, arthritis, significant allergies, asthma, multiple chemical sensitivities, respiratory conditions, and some visual, hearing, and cognitive disabilities.

Adopting a broad definition leaves no one behind, and the imperative is clear that emergency managers address the broad spectrum of disability and activity limitation issues. People with disabilities should be able to use the same services as the other residents of the community in which they live. Although they may need additional services, the emergency management system must work to build provisions for these services into its plans so that people with disabilities are not excluded from services available to the rest of the community. If planning does not embrace the value that everyone should survive, they will not.

## **Major Findings**

- Disaster management activities appear to have many access mistakes in common. People with disabilities frequently encounter barriers to physical plants, communications, and programs in shelters and recovery centers and in other facilities or devices used in connection with disaster operations such as first aid stations, mass feeding areas, portable payphone stations, portable toilets, and temporary housing.
- Many of these barriers are not new. Information and lessons learned are not shared across agency lines, and thus experience does not enlighten the development of new practices. Many accessibility lessons learned during previous disasters are not incorporated in subsequent planning, preparedness, response, and recovery activities. This should not be perceived as a post-9/11 problem. Segments of the disability community have reported problems in helping to develop and benefiting from emergency services over many decades.
- People with disabilities and activity limitations are left out of preparedness and planning activities. These activities include analyzing and documenting the possibility of an emergency or disaster and the potential consequences or impacts on life, property, and the environment.

- Disaster preparedness and emergency response systems are typically designed for people without disabilities, for whom escape or rescue involves walking, running, driving, seeing, hearing, and quickly responding to instructions, alerts, and evacuation announcements.
- Access to emergency public warnings, as well as preparedness and mitigation information and materials, does not adequately include people who cannot depend on sight and hearing to receive their information.
- FEMA recently developed one new course with disability-specific content. Information related to the emergency needs of people with disabilities, however, is not widely integrated into a number of general emergency management courses.
- The strengths and skills of CBOs serving people with disabilities are not well integrated into the emergency service plans and strategies of local government. Emergency managers need to strengthen their relationships with these organizations by recruiting, encouraging, and providing funding and incentives to CBOs so that they can participate and assist in disaster preparedness and relief.
- The CRCL and EP&R/FEMA do not get many formal complaints about discrimination related to people with disabilities and activity limitations. This fact is in dramatic contrast to the barriers reported by people with disabilities.
- DHS has not initiated funding terminations to enforce Section 504 of the 1973 Rehabilitation Act against grantees that violate the law.
- Stronger outreach, targeted technical assistance, and training initiatives focused on Americans with Disabilities Act (ADA) and Section 504 compliance issues are needed.
- Data on complaint filings and compliance reviews initiated, specific Section 504 issues, trends in complaint and compliance reviews, and outcomes and enforcement actions is not available on DHS's Web site.
- There is little evidence of DHS's grants program encouraging potential grantees to integrate and address disability and access issues.
- Current DHS criteria for proposal selection lack disability-specific indicators for evaluating proposals.

## **Key Recommendations**

- DHS should establish a Disability Access Advisory Group, in addition to the Interagency Coordinating Council on Emergency Preparedness, made up of qualified people with disabilities and others with disability-specific disaster experience who meet regularly with senior officials to discuss issues and challenges.
- The EP&R should integrate information on people with disabilities and activity limitations into general preparedness materials. It also should inform readers and information users on how to get access to more customized materials.
- The CRCL should regularly issue guidance for state and local emergency planning departments to reinforce their legal obligation to comply with ADA and Section 504 and 508 of the Rehabilitation Act in planning for, operating, and managing programs and services such as Citizen Corps, shelters, and other disaster services.
- The CRCL should proactively conduct compliance reviews to identify weaknesses and problems in complying with ADA and Sections 504 and 508 of the Rehabilitation Act.
- The FCC should develop stronger enforcement mechanisms to ensure that video programming distributors, including broadcasters, cable operators, and satellite television services, comply with their obligation to make emergency information accessible to people with hearing and vision disabilities, that it acts immediately on violations, and that it is proactive on Section 255 hearing aid compatibility.
- DHS should develop and offer technical assistance and guidance materials for grantees about their ADA and Section 504 legal obligations and compliance strategies.
- DHS should conduct proactive reviews of recipients' compliance or noncompliance with Section 504 and ADA.
- The CRCL and EP&R/FEMA should develop information systems that comprehensively collect, aggregate, and summarize detailed information about complaints or compliance reviews and their outcomes. This information should be made available to the public.

- DHS should collect and analyze Section 504 and ADA program data (complaints or compliance reviews and their outcomes) for progress made, deficiencies, best practices, and areas in which DHS could provide coordination or technical assistance.
- To ensure the widest possible usage, Portable Document Format (PDF) documents posted on all DHS Web sites should also be posted in an alternative accessible format.
- DHS should fund disability-specific initiatives.
- DHS should integrate disability-specific indicators into its proposal selection criteria.

NCD believes this report will contribute to America's commitment to building a solid and resilient infrastructure that incorporates access to emergency programs and services and includes physical, program, communication, and technological access for people with disabilities. NCD acknowledges the good work that federal agencies have undertaken and stands ready to assist in continuing this work.

## **Part I. Introduction**

*“On July 22, 2004, I signed an Executive Order that makes government agencies responsible for properly taking into account agency employees and customers with disabilities in emergency preparedness planning and coordination with other government entities. To help coordinate this effort, the Executive Order establishes the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities.”*

President George W. Bush

### **Purpose of the Report**

All too often in emergency situations the legitimate concerns of people with disabilities are overlooked or swept aside. In areas ranging from the accessibility of emergency information to the evacuation plans for high-rise buildings, great urgency surrounds the need for responding to these people’s concerns in all planning, preparedness, response, recovery, and mitigation activities.

This report describes the need for the Federal Government, in partnership with state and local governments and communities, to build an infrastructure that will enable federal agencies to include the diverse populations of people with disabilities in programs and services involving homeland security, emergency preparedness, and disaster relief. This infrastructure would incorporate access to technology, physical plants, programs, and communications. It also would include procurement practices and emergency programs and services. This report discusses the status of selected federal agency efforts in the development of such an infrastructure.

Through this report, National Council on Disability (NCD) offers information that should help the Federal Government establish policies and practices in these areas. The report also gives examples of community efforts to take account of the needs of people with disabilities, but by no means is the report intended to serve as a comprehensive treatment of the emergency preparedness, disaster relief, or homeland security program efforts by state and local governments.

## **Scope of the Report**

This report primarily focuses on the seminal work of the Directorate of Emergency Preparedness and Response (EP&R), which includes the Federal Emergency Management Agency (FEMA), the Office for Civil Rights and Civil Liberties (CRCL) in the Department of Homeland Security (DHS), and FEMA's federal, state, local, and private sector partners. It also touches on the work of the Federal Communications Commission (FCC). It examines the disaster experiences of people with disabilities. Finally, it looks at the role that community-based organizations (CBOs) exercise in the areas of homeland security and emergency preparedness on behalf of people with disabilities.

Now is the best time to integrate disability issues effectively and reinforce and strengthen the nation's commitment to homeland security and emergency preparedness, while the implementing agencies are still in their formative stages. The newly created DHS is a massive organization of government agencies that is still in its early stages of development. DHS is focusing on developing an efficient and integrated operation (Walker 2004). The department's unparalleled size, scope, and complexity sometimes make it difficult to decipher specific budgets, action plans, priorities, and partnerships or, more important, to determine the most appropriate and objective entry points.

## **Research Methods**

Research for this report spanned the 16-month period from September 2003 to December 2004. The research methods included identifying and obtaining source materials through extensive document and Internet searches, literature reviews, and analysis of items recommended by interviewees. Documents and materials reviewed came from federal and state publications, journals, news reports, and public and private Web sites, Webcasts and Webcast transcripts, reports, meeting minutes and correspondence, public and private disaster and evacuation plans, and disaster-specific conference content and materials.

In addition, in-depth structured interviews were conducted with individuals, inside and outside of government, who had relevant knowledge and background as well as extensive and diverse experience in disability and emergency management. Key interviewees included people in the

disability communities, in emergency services, and in local, state, and federal agencies. Interviews covered these people's occupational background and experience; involvement with public or private agencies; knowledge of resources used, training procedures, guides, and courses, and organizations that have incorporated good disability-specific practices; and referrals to additional people and materials with relevant information.

Most interviews were conducted by phone. Notes were taken and interviews were often taped for reference purposes. When all of the interviews were completed, responses were grouped by topic and analyzed for qualitative and quantitative information.

## **Who Are People with Disabilities?**

Individuals with disabilities make up a sizable portion of the general population of the United States. According to the U.S. Census of 2000, they represent 19.3 percent of the 257.2 million people ages 5 and older in the civilian noninstitutionalized population, or nearly one person in five.

In this report, the term people with disabilities includes people who are “vulnerable” or “at risk” and cannot always comfortably or safely use some of the standard resources offered in disaster preparedness, relief, recovery and mitigation. They may include people who have a variety of visual, hearing, mobility, cognitive, emotional, and mental limitations, as well as older people, people who use life-support systems, people who use service animals, and people who are medically or chemically dependent.

Adopting a broad definition helps to ensure that no one is left behind, and the imperative is clear that everyone address the broad spectrum of disability and activity limitation issues (Reis, Breslin, Iezzoni, and Kirschner 2003). If planning does not embrace the value that everyone should survive, they will not.

## **Disaster Experiences of People with Disabilities**

There is a wealth of disaster related anecdotal accounts from the disability community in the popular press, the disability press and in meeting minutes, unpublished reports and

correspondence. There is, however, scarce research on experiences of people with disabilities and activity limitations in disaster activities that include planning, mitigation, preparedness, response, and recovery (Pollander and Rund 1989, White 2003, White et al. 2004). One study, “Nobody Left Behind: Investigating Disaster Preparedness and Response for People with Disabilities,” was conducted at the Research and Training Center on Independent Living, Kansas University (White et al. 2004).

The same access mistakes appear to be made repeatedly in disaster management activities. Lessons learned after a disaster about reducing access barriers following disasters are not integrated into subsequent practice. Such barriers include access to physical plants, communications, and programs in recovery centers; other structures and buildings used in connection with disaster operations such as first aid stations, mass feeding areas, portable payphone stations, portable toilets, temporary housing; and shelters, which may present barriers to identification, access, management, training, and services (California Department of Rehabilitation 1997, California State Independent Living Council 2004, Center for Independence of the Disabled 2004, Kailes 2000a, U.S. Department of Justice 2004, White et al. 2004).

The following is a sample of the types of barriers experienced by people with disabilities that are documented by empirical research:

- People with disabilities have little input into counties’ disaster planning (White et al. 2004).
- Only 39 percent of people surveyed had an emergency plan in place for evacuating their home in the event of an emergency (National Organization on Disability [NOD] 2002b).
- Only 39.9 percent of Texas residents with disabilities in cities surveyed were involved in disaster planning and preparedness activities. However, cities surveyed reported that 77 percent of their emergency shelters were physically accessible. After security perimeters were expanded at government buildings and airports following 9/11, only 45.9 percent reevaluated accessible parking and paths of travel to ensure compliance with ADA (Pound 2002).

- Disaster preparedness and emergency response systems are typically designed for people without disabilities, for whom escape or rescue involves walking, running, driving, seeing, hearing, and quickly responding to directions (White et al. 2004).
- People with disabilities often do not have as much access to earthquake preparedness materials as people without disabilities. Sometimes disaster advice for the general population is not equally applicable to people with disabilities (Rahimi 1991).
- The lack of captioning on major broadcast systems, as well as on Internet news sites, created anxiety as many people could see pictures of the Twin Towers collapsing and the fire at the Pentagon without knowing what was happening (Heppner, Stout, and Brick 2004).
- The lack of captioning kept many people in California from understanding the danger they were in during the California wildfires of 2003, as the visual images often did not include printed names of specific areas and neighborhoods. This affected their ability to evacuate the area safely or in a timely manner. People with hearing disabilities did not hear the evacuation announcements being broadcast from patrol cars (California State Independent Living Council 2004).
- Many people with disabilities were inappropriately referred to medical facilities during the Northridge, California, earthquake in 1994 when Red Cross personnel misidentified their disabilities as acute medical conditions. Some shelters refused people on the basis of these mislabeled conditions (Bowencamp 1994, Lathrop 1994).
- Emergency disaster organizations are not trained in what constitutes accessible facilities when selecting sites for and operating shelters and disaster recovery centers and disaster field offices (Kailes 1994, 2000a, Kailes and Jones 1993).
- During the 1997 Minnesota Red River flood, people with disabilities experienced many barriers, including inaccessible disaster relief centers and temporary housing such as travel trailers and mobile homes (Options Resource Center for Independent Living 1997).
- Although local, state, regional, and Federal Government agencies play a major role in disaster planning and response, traditional government response agencies are often ill-equipped to respond to the needs of vulnerable populations. The traditional response and

recovery systems are often not able to satisfy many human needs successfully. The usual approach to delivering emergency services does not always provide the essential services for segments of the population (City of San Leandro 2004).

- At higher levels of (homeland) security, as perimeters expand, unique problems for people with disabilities arise. These include loss of the use of accessible parking unless it is redesignated, unavailability of close dropoff points, and longer walks from available parking (Pound 2005).

These experiences and others are described in greater detail in Part III of this report.

## **Part II. Improving Access to Disaster Services for People with Disabilities**

### **Improving Access**

#### **Research gaps**

There is a wealth of disaster related anecdotal accounts from the disability community in the popular press, the disability press and in meeting minutes, unpublished reports and correspondence. There is, however, scarce research on experiences of people with disabilities and activity limitations in disaster activities that include planning, mitigation, preparedness, response, and recovery (Pollander and Rund 1989, White 2003, White et al. 2004). One study, “Nobody Left Behind: Investigating Disaster Preparedness and Response for People with Disabilities,” was conducted at the Research and Training Center on Independent Living, Kansas University (White et al. 2004).

#### **Planning**

People with disabilities are often left out of emergency management activities. Many of the barriers encountered are not new. Accessibility lessons learned during previous disasters often do not appear to be incorporated into subsequent planning, preparedness, response, and recovery activities.

This should not be perceived as a post-9/11 problem. Segments of the disability community have reported problems in participating in and benefiting from emergency services over many decades. This section reviews a representative sample of barriers and details recommendations to help to begin to eliminate these barriers.

#### **Disability-specific plan content**

People with disabilities are often left out of planning activities such as analyzing and documenting the possibility of an emergency or disaster and the potential consequences or impacts on life, property, and the environment. These activities include assessing the hazards,

risks, mitigation, preparedness, response, and recovery needs. Planning includes development and preparation of emergency plans and procedures and the identification of necessary personnel and resources to provide an effective response.

People with disabilities should be able to use the same systems as other residents of the community in which they live. Although they may need additional services, the emergency management system must work to build provisions for these services into its plans so that people with disabilities are not excluded from services available to the rest of the community (National Emergency Training Center Emergency Management Institute 1993).

The California Specialized Training Institute conducted a survey of more than 1,200 California agencies to determine what plans community organizations have to address the disaster needs of people with disabilities. The study found that few of the 168 respondents believed that plans had been made in their communities. Other findings included the following:

- Fewer than half had plans in place to assist people with disabilities.
- One-third believed that their communities had plans in place to transport institutionalized people with disabilities.
- Seventy percent of those in public safety agencies reported that their organizations did not have plans for people with disabilities, or they believed that the existing plans would not work in an actual disaster (California Specialized Training Institute 1983, *Challenge Magazine* 1983).

Members of the emergency management community must learn to discuss and think about a broad range of issues related to people with disabilities, including not only the range of disabilities but also how to integrate people with disabilities into the existing emergency services (National Emergency Training Center Emergency Management Institute 1993).

Many state, regional, and local plans do not specifically address the transition needs to reestablish predisaster conditions that are required for people with mobility disabilities (White et al. 2004).

### **Participation in stakeholder and planning groups**

People with disabilities are often not included in stakeholder and planning groups. Stories include roadblocks encountered by some who proactively attempted to participate. People with disabilities have received flip responses like “Don’t worry, you’ll be taken care of; after plans are formulated we will include you” or “Meetings take too long as it is without adding someone else” or “I’m not the person you want to speak with” (Cohen 2004).

The “Nobody Left Behind” study’s preliminary findings show that people with disabilities have little input into counties’ disaster planning (White et al. 2004).

### **National Response Plan**

The Homeland Security Act mandates the creation of a National Response Plan (NRP) predicated on a new National Incident Management System (NIMS). The NRP and the NIMS provide the structure that weaves the capabilities and resources of all of the jurisdictions, disciplines, and levels of government and the private sector into a cohesive, unified, coordinated, and seamless national approach. The NRP is intended to help develop a unified approach to domestic incident management across the nation (Department of Homeland Security [DHS] 2004b). The overall goal is to harmonize and integrate existing federal domestic prevention, preparedness, response, and recovery plans into a single all-hazards plan.

The NRP’s Emergency Support Function (ESF) Annexes (listed in Part I—Emergency Support Functions) provide detailed descriptions of the mission, policies, structure, and responsibilities of federal agencies for coordinating resource and programmatic support to a state or other federal agencies during incidents of national significance. The Support Annexes provide functional descriptions and specific administrative requirements for operational elements common to most incidents that are not addressed in the body of the NRP. Support Annexes cover the following topics:

- Donations Management
- Financial Management

- Insular Affairs
- International Coordination
- Logistics Management

These NRP annexes should incorporate disability-specific access information in at least two ways. One is to integrate disability-specific access issues into all appropriate annexes. The other is to establish a disability-specific annex as a means of supporting disability content in more depth.

## **Preparedness**

People with disabilities are left out of preparedness activities. Preparedness activities are needed when mitigation measures have not prevented disasters or cannot prevent them. In the preparedness phase, governments, organizations, and individuals develop plans to save lives and minimize disaster damage (e.g., compiling state resource inventories, conducting training exercises, installing early warning systems, and preparing predetermined emergency response forces). Preparedness measures also seek to enhance disaster response operations (e.g., by stockpiling vital food and medical supplies, through training exercises, and by mobilizing emergency response personnel on standby) (Johnson 2000).

For example, at the time of Florida's Hurricane Andrew in 1991, people with disabilities did not have emergency plans in place to cope for several days without power or telephone service. Nobody checked on them and nobody knew they needed help. Adequate records were not being kept, and individuals spent days trying to locate loved ones (Queen 1993).

## **Survey results**

Although it would seem that the events of September 11, 2001, would have created widespread change and innovation related to disaster preparedness for all individuals, including people with disabilities, this has not been the case. A December 2003 Harris poll found only 44 percent of people with disabilities knew whom to contact to get information in times of disaster or

emergency, compared with 40 percent in a 2001 poll conducted soon after the events of September 11 (NOD 2001b, 2004).

The National Organization on Disability (NOD), which conducted both surveys, was disappointed to learn that in 2002, only 39 percent of people surveyed had a plan for evacuating their home in the event of an emergency, compared with the 38 percent who had a plan in the 2001 survey. People with disabilities also noted higher rates of anxiety than were found in the general population about future disasters and emergencies (NOD 2002b, 2004). Alan Reich, NOD president, says “The disability community has good reason to be anxious. The 54 million American children, women, and men who have disabilities are among the most vulnerable in disasters” (NOD 2004).

A 2002 poll by the Texas Governor’s Committee on People with Disabilities found similar results. Only 30 percent of cities surveyed have training and procedures to accommodate service animals, and fewer than half said they had training and procedures for providing and allowing use of medical equipment such as wheelchairs, walkers, and canes. Only 21 percent said they were prepared to provide specific diets, and 25 percent said they could provide insulin or asthma medications. While 76 percent of cities surveyed said they had telecommunication devices for the deaf (TDDs), 15 percent said they provide no training for shelter staff to use them (Pound 2002).

Employers and people with disabilities have made some improvement in workplace planning and emergency preparedness. The 2004 Harris poll indicates that 68 percent of people surveyed have established evacuation plans in the event of an emergency, up from 45 percent in the 2001 poll (NOD 2001b, 2004).

### **Evacuation experiences**

Disaster preparedness and emergency response systems are typically designed for people without disabilities, for whom escape or rescue involves walking, running, driving, seeing, hearing, and quickly responding to directions (White et al. 2004). “A common theme emerging after 9/11 is there are virtually no empirical data on the safe and efficient evacuation of persons with disabilities in disaster planning,” White (2003) found. The media heightened the public’s

awareness of this problem from the reports of many individuals with disabilities trapped in the World Trade Center towers on 9/11. While one can hope that such acts of terrorism are rare, other catastrophic events such as floods, tornadoes, hurricanes, and fires are frequent occurrences across this nation and can lead to tragic results (White 2003).

One man's final image as he left the 80th floor (of the World Trade Center on September 11, 2001) and made it to safety was that of a room full of people using wheelchairs and walkers waiting to be rescued by the firefighters who were coming up the stairs. They all perished as the building collapsed shortly after....After the [earlier] 1993 bombing, many tenants of the World Trade Center and the building management for the complex were aware that evacuation plans for people with disabilities were needed. Unfortunately, the evacuation plan for people with disabilities was lethal to them: it consisted simply of requiring them to go to predetermined meeting sites within the building and wait for evacuation assistance (Center for Independence of the Disabled 2004).

The media repeatedly reported stories about the two wheelchair users who successfully escaped from the World Trade Center using evacuation chairs on 9/11 and a story about one wheelchair user who died (Byzek and Gilmer 2001). The public did not hear about others whose activity limitations prevented them from successfully evacuating. The public did hear reports from those who successfully evacuated the towers and who told of passing people who could not keep up (e.g., older people, people with respiratory conditions and limited endurance, and other people with no apparent disability). Their chances of surviving could have significantly improved if evacuation plans had been in place that included them, and that were regularly practiced by using both announced and unannounced drills for reviewing procedures. It is essential that regular drills be conducted, and that people with disabilities and activity limitations not be excused from participating.

One wheelchair user who did escape from the World Trade Center on 9/11 using an evacuation chair told the press that she forgot that the evacuation chair was under her desk. Two secretaries remembered and reminded her where it was (Byzek and Gilmer 2000). The fact that this woman forgot about the device, and that another wheelchair user who worked at the

World Trade Center recalled only a single demonstration of the device shortly after the 1993 bombing, are clear indications that the need for preparedness had worn off soon after the first attack. Whatever evacuation plan existed had not been practiced regularly. When disaster struck, the plan fell apart. Most of those who had been assigned to help with rescue devices were frightened and fled downstairs.

Michael Hingson, a 9/11 survivor who is blind, used his guide dog, his associates, and his previous experience during drills to evacuate the building safely. He says, “I feel like I was as prepared as possible. I knew the evacuation procedures, I attended all the building fire drills, I knew the exit routes. So when the attacks hit, I had a sense of preparedness, self-sufficiency, and the confidence to take a leading position in evacuating myself and others to safety” (Kailes 2002a).

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 the staff, most of whom have limited or no vision. The Associated Blind wanted a plan for its 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 (Center for Independence of the Disabled 2004).

On 9/11, Ed Beyea, a wheelchair user, was working on the 27th floor of One World Trade Center. He declined an offer of assistance from a coworker because he knew his weight of 300 pounds required several people to move him properly. Abe Zelmanowitz, a friend of Beyea’s, stayed by his side, waiting for help from fire personnel, while Beyea’s personal assistant, Irma, traveled down to the street to find help. She told a fireman where Beyea and Zelmanowitz were and that Beyea would need oxygen. Zelmanowitz talked to his mother by cell phone to notify her that he was all right. She encouraged him to get out. Zelmanowitz and Beyea have not been heard from since (Byzek and Gilmer 2001).

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 (Center for Independence of the Disabled 2004).

Experiences with other disasters yielded similar reports.

- At the time of the earthquake in Northridge, California, in 1994, a woman who used a wheelchair was living on the second floor of a building whose elevator was shut down due to the power outage. She was told by another resident, “We all have our problems,” when she questioned how to evacuate their unsafe apartment building (Hammitt 1994).
- In 2001, Paul Ray, a programmer, was a contractor for Ford Motor Company in Dearborn Heights, Michigan. His office had a fire drill. Ray, who had quadriplegia and worked on the second floor, said it was the first fire drill in the 18 months he had worked there. When the alarm went off, he went to the elevator bank, where he said designated fire wardens seemed surprised to see him. He said he had never been told about the building’s evacuation plan. “I was a little surprised. I thought Ford would have a little better control over the situation,” he said. “I’m hoping that [now] they’re at least a little more aware of the fact that I am there, working on their second floor...I don’t know if it’s something they just don’t think about it or everybody’s just so stressed out with their other nonsense that they don’t have time to deal with it. As a quadriplegic I do not go down stairs, period. I don’t have the balance for it. It’s a little disturbing” (Bondi 2001).
- In New York City, one individual responded to a survey: “I ambulate with forearm crutches and my leg stamina is limited. As a social service provider in New York City, I am in tall buildings often and one in particular they had an evacuation drill. There were no plans or equipment to assist me. They told me to ignore the drill. *I felt very vulnerable because I attend regular work meetings in this building*” (Research and Training Center on Independent Living 2004).
- In response to another survey in Los Angeles, an individual said: “I have juvenile rheumatoid arthritis and use a wheelchair. We had a bomb threat at work, which was very scary.

Everyone evacuated, but I was still left on the third floor by the stairwell for the firefighters to come get me. But no one came. Finally, I just struggled, and I used pure fear to get myself down the stairs and outside. *It was scary just to realize that there are not really any procedures in place to help someone like me in an emergency*” (Research and Training Center on Independent Living 2004).

- In Oklahoma, a person reported, “We had a fire at work and the evacuation plan didn’t work to get me out. Even so, management refused to change the plan” (Research and Training Center on Independent Living 2004).

### **Disability-specific materials**

One study conducted following the 1989 Loma Prieta Earthquake found that people with disabilities often did not receive as much earthquake preparedness materials as people without disabilities. Rahimi (1991) commented that sometimes disaster advice for the general population is not equally applicable to people with disabilities. “For example, many wheelchair users cannot take cover under tables and desks, advice commonly given regarding how to respond to an earthquake.”

Examples abound of information that is vague, incomplete, impractical, and naïve, and of language that is outdated and that perpetuates negative attitudes and false stereotypes.

- According to FEMA’s *Disaster Preparedness for People with Disabilities* (Federal Emergency Management Agency [FEMA] 2003a), people who use wheelchairs as their primary modes of transportation are instructed: “Show friends how to operate your wheelchair so they can move you if necessary. Make sure your friends know the size of your wheelchair in case it has to be transported.” FEMA comments, “This information is vague. What about the option of having a light weight manual chair available for emergencies? What if the chair is a heavy motorized chair; and the individual is unable to transfer without the assistance of several strong people? What if your trained friends are not with you during a disaster?”
- One volume of the Fire Risk Series published by FEMA and the U.S. Fire Administration (1999) instructs: “*Have a Fire Extinguisher and Learn How To Use It*. If you are confined to a

wheelchair, consider mounting (or having someone mount) a small ‘personal use’ fire extinguisher in an accessible place on your wheelchair and become familiar with its use. Then, if you cannot ‘stop, drop, and roll’ during a fire, you should ‘pull, aim, squeeze, and sweep.’”

- The National Emergency Training Center Emergency Management Institute (1993) reported that “Many people with disabilities and activity limitations do not receive information through social services agencies because they have no need to seek support from these organizations. Information must be easily available, through the same means as other material is distributed to them with specific and useful advice in accessible formats.”
- Emergency preparedness information often is not available in accessible formats (e.g., Braille, large print, disks, audio cassettes, and accessible media, including Web sites or captioned and audio-described films and videos).

### **Access to emergency public warnings**

Many community emergency public warning systems remain inaccessible to a segment of the disability community with hearing or vision disabilities. The following are some examples.

- The September 11 television scenes were disturbing, and without efficient and correct captioning, people who are deaf experienced heightened anxiety and confusion as they struggled to learn about the events (Heppner et al. 2004, Independent Living Research Utilization [ILRU] 2002b). The lack of captioning on major broadcast systems, as well as on Internet news sites, created anxiety as many people could see pictures of the towers collapsing and the fire at the Pentagon without knowing what was happening. Scrolling messages often blocked captions, making it difficult to read captioned information. The increased rate of captioning errors because of increased anxiety and long working hours for the captioners made it necessary for many people who are deaf or hard of hearing to decode and unscramble emergency information. The inability to use TTYs (teletypewriters), amplified phones, and other equipment dependent on electricity was a problem for many deaf individuals. They could not hear auditory announcements on airplanes and did not know why their planes landed early and in the wrong destinations. A deaf individual working in the

Pentagon smelled the smoke from the fire before learning that a plane had crashed into the building, whereas other individuals knew long before they smelled smoke.

- A deaf individual had no knowledge of what had happened at the Twin Towers or the Pentagon. A coworker hand-signed the word “war” and told him to get out. When he was outside the building, he didn’t see any of his coworkers, so he went back into the office. One coworker who was still there spelled out in sign alphabet the word “war” and told him to go home. He had no detailed information on what was going on (U.S. Department of Labor’s Office of Disability Employment Policy 2004).
- Emergency e-mail and wireless network alerts are viewed as helpful by the deaf and hard-of-hearing communities, but information can be spotty. For example, before a hurricane in the Washington, D.C., area in 2003, information about the storm’s approach was sent frequently to keep people updated. Once the hurricane hit, there was no information about such things as where emergency shelters were and no warnings about water not being safe to drink, and so on. In addition, Heppner (2004) wrote, some information is truncated when sent to various devices.
- During the California wildfires of 2003, the lack of captioning kept many people with hearing impairments from understanding the danger they were in, as the visual images often did not include printed names of specific areas and neighborhoods. Also, people did not hear the evacuation announcements from patrol cars. As a result, the California State Independent Living Council (2004) reported, these people were not able to evacuate the area safely and quickly.
- Queen (1993) wrote that during Hurricane Andrew in Florida in 1991, people with hearing loss were unable to access the emergency broadcast system.
- On September 11, 2001, flashing news updates on TV broadcasts often were not accompanied by verbal reports critical for people with visual disabilities (Heppner et al. 2004).
- A national reverse 911 phone-based public warning system that can quickly target a precise geographic area and saturate it with **thousands of calls per hour** and that also has capability for TTY calls was not used (Sigma Communications 2004).

## **Mitigation**

Mitigation includes ongoing efforts that can prevent a hazard or lessen the impact of disasters on people and property (National Council on Disability [NCD] 2004, 2005). Mitigation also includes long-term activities designed to reduce the effects of unavoidable disaster (e.g., land use management, establishing comprehensive emergency management programs such as vegetation clearance in high fire danger areas, or building restrictions in potential flood zones).

People with disabilities and activity limitations sometimes lack the resources or the support systems to undertake some of these mitigation activities, such as the following:

- Installing hurricane shutters
- Strengthening roofs
- Installing fire-resistant shingles
- Installing shatter-resistant window film
- Anchoring outdoor items that can become projectiles in hurricanes and high winds
- Implementing vegetation management—for example, removing fire-prone dry plant material from gutters and around residences and other buildings, or trimming tree limbs that overhang roofs to avoid roof damage during hurricanes, tornadoes, or high straight-line winds
- Clearing streams
- Bolting bookshelves to walls
- Installing backflow valves—special valves that prevent toilet overflows when the household sewer is infiltrated with floodwater
- Building safe rooms—specially designed rooms built to withstand high winds generally associated with tornadoes
- Placing a fuse box higher on a wall in a flood-prone area (FEMA undated-a)

During the 2003 California wildfires, people with activity limitations had difficulty with fire prevention and maintenance activities, such as cutting back trees and underbrush to create a defensible fire-safe perimeter (California State Independent Living Council 2004).

## **Response and Recovery**

Response activities following an emergency or disaster are designed to provide emergency assistance for victims (e.g., search and rescue, emergency shelter, medical care, and mass feeding). They also seek to stabilize the situation and reduce the probability of secondary damage (e.g., shutting off contaminated water supply sources, and securing and patrolling areas prone to looting) and to speed recovery operations (e.g., damage assessment).

Recovery activities are needed to return all systems to normal or better. Short-term recovery activities return vital life support systems to minimum operating standards (e.g., cleanup, temporary housing, and access to food and water). Long-term recovery activities may continue for a number of years after a disaster. Their purpose is to return life to normal or improved levels (e.g., redevelopment loans, legal assistance, and community planning).

After an earthquake at Glendora, California, a resident told the Research and Training Center on Independent Living (2004): “Disabled persons have the same freedom of choice as any other American. The paternalistic attitude was frightening beyond belief that I experienced [while trying to access after-disaster services and information].”

In the aftermath of the 2003 hurricanes in Florida, individuals who are deaf and hard of hearing reported that they did not receive information about the availability of dry ice during the power outages and that in some locations water was unsafe to drink (Heppner 2005).

## **Physical, Communication, and Program Access**

Common access mistakes appear to be made repeatedly in disaster management activities regarding access to physical plants or buildings, communications, and programs. Lessons learned after each disaster about access do not get integrated into subsequent practice (California

Department of Rehabilitation 1997, California State Independent Living Council 2004, Center for Independence of the Disabled 2004, Kailes 2000a, U.S. Department of Justice 2004, White et al. 2004).

The Center for Independence of the Disabled (2004) reported a number of lessons learned during and immediately after 9/11 about preparation and accommodations for people with disabilities. The most prominent and disturbing conclusion was that—even though many of these lessons had been learned before 9/11—systemic preparation conceived of or conducted by mainstream emergency responders and relief agencies did not consistently take into account the specific needs of people with disabilities. Or when these issues were taken into account, the results often were not shared across agency and jurisdictional lines.

### **Physical access**

Physical access involves the removal of architectural barriers such as curbs and steps; narrow exterior and interior doorways and aisles; narrow rest room doorways and stalls; and inaccessible parking spaces, food service, drinking fountains, and telephones. Physical access allows individuals to get to, into, and around facilities.

These are a few of many examples of continuing physical access problems needing attention:

- During the 1994 earthquake at Northridge, California, many people with disabilities were inappropriately referred to medical facilities when Red Cross personnel misidentified their disabilities as acute medical conditions. Some shelters refused people because of these mislabeled conditions (Bowencamp 1994, Lathrop 1994).
- Emergency disaster organizations are not trained to understand what constitutes accessible facilities when they are selecting sites for and operating shelters, disaster recovery centers, and disaster field offices (Kailes 1994, 2000a, Kailes and Jones 1993). These facilities are not surveyed using a comprehensive accessibility checklist. Shelter managers and volunteers are not trained in how to clearly designate a facility as fully or partially accessible or how to

maintain, and how important it is to maintain, accessible routes and walkways for safe mobility, prevention of falls, and so on.

- During the 9/11 crisis and the 2003 California wildfires, emergency housing and shelters were not adequately equipped for people who needed accessible lodging (California State Independent Living Council 2004). Temporary housing (tents, travel trailers, mobile homes, and accessible hotel rooms within the community or in nearby communities) did not include identification of accessible units.
- One of the many recorded complaints was that during a hurricane in Alexandria, Virginia, “The disaster volunteer was not trained on accessibility issues. He said that the shelters should be accessible since the law requires it. He didn’t understand the impact of me getting there only to discover that they were in violation of the law” (Research and Training Center on Independent Living 2004). Another complaint, following the earthquake in Los Angeles, was that “We had to move out of our house for several weeks to have it repaired. All the places that people referred us to were not accessible to me in my scooter” (Research and Training Center on Independent Living 2004). A third complaint, after the earthquake at Northridge, California, was that “At the temporary shelter I couldn’t get to the bathrooms, as you had to walk up stairs” (Research and Training Center on Independent Living 2004).

### **Communication access**

Communication access enables effective communication with people who are deaf or blind or who have speech, vision, or hearing limitations. It includes the use of written materials available in alternative formats (e.g., Braille, large print, disks, audio cassettes), and hearing-assistive technologies such as amplified phones, TTYs, and listening systems. Communication access also involves the use of auxiliary aids and services, when needed, such as sign language interpreters, CART (communication access real-time translation) readers, people to assist with completing paperwork, and people to take notes. In addition, it includes accessible media such as Web sites, captioned and audio-described films and videos, videoconferences, and public service announcements.

Shelter managers and volunteers are not trained in communication access issues. Hammit (1994) reported after the 1994 earthquake in Northridge, California, that a deaf person had been turned away from a shelter because no one understood sign language. After the same earthquake, the text of oral announcements was not posted in a public area so that 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 (California State Independent Living Council 2004, Kailes 2000a). The Independent Living Center of Southern California (1994) reported that a “deaf man applying for admittance to a shelter was given a form to complete which asked about ‘Medical Problems.’” When asked to list all past and present conditions, he included having tested positive for TB more than five years ago. As a result, shelter volunteers told him he could not be admitted. A woman who was able to sign saw the man frantically signing to the Red Cross worker. She went over, signed to the man, and found he was concerned he might pick up a disease in the shelter. She tried to communicate this verbally to the Red Cross worker. The worker did not understand what she was telling him. As a result, neither of them was allowed into the shelter. The worker assumed they were together because they were both deaf.

During the 2003 California wildfires, telephones on temporary telephone access trailers placed at shelters were not within reach of some people with disabilities and they were not equipped with TTYs (California State Independent Living Council 2004).

### **Program access**

Program access refers to overall accessibility of programs to people with disabilities. It involves individuals being able to participate fully in programs and services provided by organizations. Publicly funded organizations are prohibited from denying people with disabilities equal access to participate in programs and activities because facilities are not accessible. Program access means that publicly funded organizations operate each program so that when viewed in its entirety, the program is readily accessible to and usable by people with disabilities. Program access can be achieved by creating physical access through both structural methods and nonstructural methods.

The following lists give a few examples of continuing program access problems that need attention.

*Shelters.* It is common that alternatives to inaccessible shelters are not thought through and are not clearly communicated to people. If a shelter cannot accommodate people with a specific set of needs, prompt transfer to a better equipped facility should be offered.

- For example, if one shelter is well equipped to assist people who are deaf and another shelter is equipped to assist people with mobility disabilities, an agreement for cross-referring should be established quickly.
- Recognition of a family's need to stay together has not been given proper attention. The person with a disability is not the only one who will need to be transported to a more accessible shelter. Accessible transportation (equipped with a lift or ramp) to another shelter should be provided for the individual with a disability and his or her family (Kailes 2000b).
- When there is only one shelter, it is especially important to have a plan in advance for acquiring additional shelter services when they are needed. In 1993, for example, Red Cross volunteers were allowed to drive people to get a shower and their mail. But they were not allowed to transport people with disabilities (Independent Living Center of Southern California 1994).

*Food and Supplies.* FEMA and the County Department of Public Social Services arranged for food stamps to be provided on an emergency basis after the 1994 Northridge, California, earthquake. But people with disabilities and activity limitations were unable to wait in long lines, from three to eight hours, to complete applications, and distribution centers were not accessible to many people with disabilities. Many did not have friends or family they could send as their designees (Westside Center for Independent Living 1994). The state agreed to allow SSI (Supplemental Security Income) recipients to get the emergency food stamps by mail. They were mailed an application for the stamps, and once the form was returned, the state mailed an approval letter with the location where the food stamps could be picked up. This had been the problem in the first place—people were unable to get to the distribution site (Independent Living Center of Southern California 1994).

After San Francisco's Loma Prieta earthquake in 1989, a critical need was water. But for people with disabilities it was difficult to impossible to wait up to seven hours in lines (Wangeman and Nandi 1996). First aid stations lacked the capacity to keep certain life-sustaining medications. Stocked supplies for shelters, temporary housing, and assistance did not include access signs (wheelchair logo) to indicate the location of accessible routes and accessible lines for food, water, and disaster relief applications; auxiliary air and heating units; or portable emergency call units for people at risk of falling or other isolation-related risks.

During the 1997 Minnesota Red River flood, people with disabilities experienced many barriers, including inaccessible disaster relief centers and temporary housing (i.e., travel trailers and mobile homes) (Options Resource Center for Independent Living 1997).

A problem for many people with disabilities after the 1994 Northridge earthquake was finding permanent housing. FEMA provided vouchers that were valid for 18 months. At the end of this time people were in jeopardy of losing their ability to remain in their community. Most were long-term residents who had lost affordable housing and faced pressure to relocate to more affordable, but higher crime neighborhoods (Westside Center for Independent Living 1994).

*Mental Health.* In New York City after 9/11, trauma counselors did not always fully appreciate the experience of trying to remain independent when routine services and supports are no longer available. Relief volunteers, many of them from other states, were unfamiliar with Manhattan and unable to offer reliable assistance (ILRU 2002a).

Following 9/11, a deaf person in New York City who was unable to get accessible trauma counseling was asked to assist in counseling another deaf person seeking the same services because of that person's ability to both speak intelligibly and sign (Heppner 2005).

*Transportation.* Following the California wildfires in 2003, public transportation was limited because many of the areas affected by the fires are rural and people did not have emergency transportation plans in place (California State Independent Living Council 2004).

After 9/11, relief workers often had difficulty understanding why the public transportation shutdown prevented people from getting access to emergency assistance (ILRU 2002a).

Even if transportation systems are not damaged, emergency response personnel may restrict travel for security or other reasons. Personal vehicles were not allowed into Manhattan for a period of time after the 9/11 attacks. Without public or accessible transit, people who had medical appointments or needed to travel to apply for relief benefits or on other important business had no way to get into town (ILRU 2002a).

After Florida's Hurricane Andrew in 1991, transportation plans for accessible emergency evacuation did not exist (Queen 1993).

## **Training**

FEMA's National Emergency Training Center in Emmitsburg, Maryland, is home of the Emergency Management Institute and the National Fire Academy. There, emergency managers, firefighters, and elected officials take classes in many areas of emergency management, including emergency planning, exercise design and evaluation disaster management, hazardous materials response, and fire service management. FEMA courses are also given by many states. An independent study program is also available to private citizens. Special seminars and workshops are offered via satellite as part of FEMA's Emergency Education Network, called EENET. From "tabletop" discussions of a specific problem to full-scale exercises (e.g., dress rehearsals for the real thing) that involve a detailed disaster scenario that unfolds over several days, FEMA coordinates events that bring together every agency and volunteer organization that would respond in a real disaster.

### **Disaster workers training**

From the outset, lack of appropriate access and accommodations for people with disabilities seeking response and recovery services in the aftermath of the World Trade Center attack was evident, reflecting, among other factors, methods of program administration that disregarded needs specific to those with physical, medical, cognitive, or psychiatric conditions. Through its

work with World Trade Center consumers, CIDNY (the Center for Independence of the Disabled, New York) identified a series of administrative procedures that resulted in inappropriate service denials with a wide range of public and private agencies (Center for Independence of the Disabled 2004).

After the 9/11 attacks displaced a woman with a mobility disability, she called FEMA to register and assess damage to her apartment. FEMA regulations required that she meet the FEMA representative at her apartment to assess damage. This was physically impossible for her, given the debris and other barriers situated around Ground Zero. When she was unable to comply, FEMA discontinued her application. The independent living center successfully advocated with FEMA to establish a waiver of this requirement for people with mobility disabilities (Center for Independence of the Disabled 2004).

Shelter managers and volunteers are not trained to work with people with disabilities. After 9/11, the Center for Independence of the Disabled (2004) reported, people at the Red Cross were polite and interested, but everything had to be brought to their attention. Their volunteers were from all over the country. They did not understand transportation issues for people with disabilities in New York City. Volunteers would ask, “can’t they get a neighbor to drive them?” and would have been told that “the neighbors don’t have cars.”

After the earthquake at Northridge, California, in 1994, individuals with cerebral palsy and multiple sclerosis were denied help at a shelter because they were perceived as being under the influence of drugs or alcohol (Hammit 1994, Independent Living Center of Southern California 1994).

After the Northridge earthquake, the Los Angeles independent living center servicing the San Fernando Valley reported the Red Cross to be ignorant of disability issues and unwilling to work at the national level with disability organizations. Complaints received by the center included inaccessible shelters, unreachable supply distribution points, and poorly trained volunteers—in a number of cases, people with disabilities were turned away from shelters and told to go to hospitals by staff members who assumed that they were sick or injured (Lathrop 1994).

A blind individual using a service animal after that 1994 earthquake was denied access to a shelter because he would not agree to place his guide dog in a kennel for the length of his stay at the shelter (Westside Center for Independent Living 1994).

Shelter managers and volunteers were not trained in how to identify at-risk individuals to help prevent unnecessary deterioration of their emotional and physical health, or in the importance of designating an area for people who use service animals (e.g., guide dogs) and for pets of other people, especially older single people, for whom their relationships with their pets may be life sustaining.

### **First responders**

In April 2004, the New York City Transit Authority conducted training drills to educate and instruct transit workers about what to do in the event of an emergency. During one such drill in the New York City subway system, participants were told that “Our main concern is to evacuate as many people as possible, as quickly and safely as possible.” The instructor then proceeded to tell the students to move the handicapped person off to the side and provide assurances that “help is on the way.” The rider would probably have to wait for firefighters to arrive (Luo 2004). Such assistance may never arrive. Some people in the disability community feel this is equivalent to leaving the individual in the oven. Some people with disabilities were left behind in evacuated buildings because rescue agencies did not fully understand how someone could not be aware of the evacuation effort (ILRU 2002a).

There are few training opportunities for first responders related to the specific needs of people with disabilities and activity limitations. First responders, including police officers and law enforcement officials, rely on street experience and react to situations as they arise (Homeland Defense TV 2004).

Lack of training and experience dealing with people with disabilities is a problem and a safety issue for people with disabilities and for responders. When triage methods are used, people with disabilities are often told to wait in a specific location for assistance. This practice puts people

with disabilities and activity limitations and responders at risk. These practices need to be rethought and updated.

If first responders receive proper training and have plans to assist people with disabilities, reported Homeland Defense TV (2004), they will eliminate the risk of having to go back or use triage planning for people with disabilities, and they are likely to become more competent in serving all victims of disaster.

### **Information transfer**

After the 1994 Northridge, California, earthquake, a significant number of disaster response problems affecting people with disabilities were reported. Most of these problems were the same problems reported five years earlier after the 1989 Loma Prieta earthquake (California Department of Rehabilitation 1997). These issues included accessibility of shelters, potentially discriminatory policies toward people with disabilities, lack of knowledge and coordination of existing disability-related resources that could have ameliorated some of the problems, and lack of support services needed by people with disabilities.

Common access mistakes appear to be made repeatedly in disaster management activities. Lessons learned after each disaster about physical, communication, and program access for recovery centers, and other structures and buildings used in connection with disaster operations (e.g., first aid stations, mass feeding areas, portable payphone stations, portable toilets, and temporary housing, as well as shelter identification, access, management, training, and services) do not appear to get integrated into subsequent practice (California Department of Rehabilitation 1997, California State Independent Living Council 2004, Center for Independence of the Disabled 2004, Kailes 2000b, U.S. Department of Justice 2004, White et al. 2004).

One major issue was the need for accommodations at the disaster assistance centers, where people applied for assistance from dozens of government and private relief agencies. Multiple visits were often required. Many people with disabilities were unable to apply for benefits because they could not stand in line for the long periods of time required. At the start, there were

no chairs at centers, and people were not allowed to send representatives to file applications on their behalf, even if they were homebound before the attack.

As the anecdotal evidence illustrates, there has been a significant amount of relearning and reinventing of good disability-specific practices during response to new disasters. Deploying well-versed disability-related experts would mean that more of these lessons would be learned quickly and permanently integrated into existing protocols, strengthening the nature, sensitivity, and quality of the response.

FEMA devotes significant resources to training. This report underscores the need for more focus on integrating disability issues into all aspects of this training. In an attempt to infuse disability content into a variety of disaster management training, DHS's CRCL is expecting to learn more and improve its efforts. One venue for this was the Conference on Emergency Preparedness for People with Disabilities, held in Arlington, Virginia, on September 22–24, 2004, sponsored by the NOD in partnership with DHS and the National Capitol Region. High-level authorities from the emergency management community, disability communities, government agencies, private business, and the service, advocacy, and care networks shared and learned from each other's experiences, resources, and best practice models.

FEMA has three national processing centers that centralize disaster application services for FEMA customers. These centers house an automated "teleregistration" service—a toll-free phone bank through which disaster victims apply for assistance for individuals and households and have their applications processed and questions answered. A major advantage of teleregistration is timeliness. Toll-free lines can be staffed quickly, although in catastrophic or multiple disaster situations there may be busy signals until staffing is complete. Calls can normally be taken within hours after the President declares a major disaster (FEMA 2003g).

An Internet search reveals that, typically but not always, a TTY phone number is posted for these centers. For example, FEMA can provide disaster housing assistance to those whose homes are damaged or destroyed. To apply for assistance, all you have to do is call the special toll-free

telephone number, 1-800-621-FEMA (3362), and register. Specially trained operators at one of FEMA's national processing service centers will process your application (FEMA 2003f).

A disaster recovery center is a facility established in, or in proximity to, the community affected by a disaster where people can meet face-to-face with representatives of federal, state, local, and volunteer agencies (FEMA 2003a-i) to discuss their disaster-related needs; obtain information about disaster assistance programs; teleregister for assistance; update registration information; learn about measures for rebuilding that can eliminate or reduce the risk of future loss; learn how to complete the Small Business Administration loan application; and request the status of their application for assistance to individuals and households.

## **Part III. Role of Community-Based Organizations**

CBOs are local organizations (usually nonprofit) serving the needs of specific populations within the community. They represent a vast array of human and social service organizations, faith-based organizations, and neighborhood associations.

### **Experience of CBOs in Disasters**

These are a few of many examples of the experiences of CBOs in disaster mitigation, preparedness, and response:

- After Hurricane Andrew in Florida in 1991, no plans existed for people with disabilities who use group homes, residential programs, day programs, and other supportive communities and environments to continue to receive the assistance and services that were essential for their daily living (Consortium for Citizens with Disabilities 1992).
- Service organizations lacked emergency plans that would have enabled them to locate the people they work with and inquire about their needs (Queen 1993).
- Group homes did not have plans for emergency housing of residents, with the result that some people were reinstitutionalized (Queen 1993).
- There were few disability-specific agencies to pitch in and help the affected areas (Queen 1993).
- After the 1997 Minnesota Red River flood, many people with disabilities were displaced from their homes. Finding no housing and other resources to meet their needs, people in Grand Forks and East Grand Forks had to band together with CBOs to find ways to meet individual needs and design a recovery plan (Options Resource Center for Independent Living 1997).

On 9/11 the executive director of CIDNY watched the World Trade Towers collapse. “An act of war happened down the street from us!” CIDNY was simply not prepared to handle a disaster of

this magnitude. “I think we were on the right track with everything we’ve been doing [beginning to plan for emergencies]. I wish we had been further along” (ILRU 2002a).

## **Networking with Other CBOs and Government Emergency Response Agencies**

“I wish we’d had a stronger relationship with all the other community-based agencies so we could coordinate efforts,” CIDNY’s executive director said. “The time to build relationships is not in the middle of a crisis. I wish we’d paid more attention to efforts to include people with disabilities in disaster planning. I wish we’d had better mechanisms in place to get the word out that we exist and what we can do for people who need help” (ILRU 2002a).

Before September 11, CIDNY had no relationship with the big players—FEMA, the Red Cross, and many other local, state, and federal assistance agencies. Now the big players realize that the independent living community has a responsibility to educate and work with these agencies on an ongoing basis (ILRU 2002a).

An important lesson these agencies learned after 9/11 was not to trust that the needs of their clients would be met by emergency management personnel during an emergency. Emergency personnel do not have the knowledge or the resources to provide all the necessary services to these populations (National Emergency Training Center Emergency Management Institute 1993). People with disabilities should not assume that emergency and relief agencies understand accessibility, accommodations, communication, transportation issues, or any other aspect of disability or independent living. If people with disabilities haven’t worked to raise the awareness of emergency personnel before the emergency, people can plan to spend a lot of time educating them in the midst of the crisis (ILRU 2002c).

In the past, CIDNY had been invited to participate in various emergency preparedness meetings; but in the day-to-day reality of providing independent living services after 9/11, those meetings were not given much priority. That has changed now, and CIDNY hopes to build on the relationships and learning that have occurred since 9/11.

## **Individual Preparedness Plans for People with Disabilities**

CIDNY will also pay more attention to helping consumers develop personal emergency preparedness plans. The executive director explains, “We’ve come to know a lot of people who were doing their own things and had successfully created their own support networks. When their support systems crumbled,” as they so dramatically did, “many still thought they could work things out themselves. But as things dragged on, they found they needed assistance” (ILRU 2002a).

## **Funding**

Federal and state legislation is often a major obstacle because it is not geared toward emergency response. Social services agencies often are reluctant to take on added responsibility during a disaster because spending additional money may leave them unable to provide basic services to their clients for the rest of the fiscal year. Private nonprofit organizations and private for-profit organizations are not eligible for reimbursement from federal disaster funds unless they are mandated or identified before a disaster by a local or state agency to have specific disaster responsibilities (National Emergency Training Center Emergency Management Institute 1993).

CIDNY’s first attempts to get the attention of FEMA and the Red Cross were hampered by the general lack of understanding about the diverse, and sometimes complex, needs of people with disabilities. The funding organization was finally convinced after CIDNY submitted an explicit grant application detailing real-life examples of the problems people are facing and the center for independent living’s unique capability to understand and help resolve them (ILRU 2002a).

Shortly after 9/11, CIDNY staff and volunteers started a log to track the multitude of contacts and requests for assistance. This is a sampling of log notations from November 5, 2001. It is a chronicle of the diverse ways people with disabilities were affected when New York City’s complex system of services and supports collapsed in the aftermath of the attack on the World Trade Center (ILRU 2002a).

- ...young architect has multiple sclerosis...uses a scooter that he had to leave behind...went to parents’ home...60-year-old father carrying him up and down stairs daily...

- ...has CP...uses walker...was told he would have to walk from Brooklyn Bridge or Canal Street to his school...
- ...had to stay in the hospital because there was no way to get back and forth for dialysis...
- ...21-year-old woman with significant traumatic brain injury...witnessed WTC collapse and is traumatized...has no food/income...is scared and highly vulnerable...
- ...claims she has made 36 trips to four different Red Cross centers...
- ...consumer with lung and brain cancer was displaced from her home...currently staying in hotel...needs transportation to her medical appointment next week...

## **Recognizing the Value and Talent of CBOs in Disaster Activities**

Although local, state, regional, and federal government agencies play a major role in disaster planning and response, traditional government response agencies are often ill-equipped to respond to the needs of vulnerable populations. The traditional response and recovery systems often are unable to satisfy many human needs successfully. The usual approach to delivering emergency services does not always provide the essential services for segments of the population (City of San Leandro 2004).

It is critical for emergency preparedness and response plans to address and accommodate all individuals, including vulnerable populations. Numerous agencies and organizations exist that have extensive knowledge and expertise on the needs of these populations. CBOs are often a part of naturally occurring local networks, which are powerful support tools (Davis and Cahill 2003).

CBOs have unique and credible connections with—and expertise in delivering services to—people with disabilities and activity limitations. This unique know-how and understanding can be a valuable resource during planning, preparedness, response, recovery, and mitigation activities. CBOs should be included as partners in working with local, state, regional, and federal public and private response agencies to deal more effectively with and understand the needs, geography, demographics, and resources of their local areas.

“Social service agencies must understand that they have a significant role in emergency preparedness, response, and recovery. They provide a support network for people with disabilities that emergency management cannot replace. In planning, FEMA, other federal agencies, and state and local emergency planners must help to set the expectations for the performance of social services agencies, and the social services agencies themselves must educate their clients about agency roles in a disaster” (National Emergency Training Center Emergency Management Institute 1993).

Emergency managers generally have little knowledge about the needs of people with disabilities. “To effectively provide services to these populations and meet the requirements for accommodations under ADA, emergency managers must understand the needs of these groups, the social services mechanisms that are in place to serve them, and how to work with social service agencies to integrate these mechanisms into emergency planning” (National Emergency Training Center Emergency Management Institute 1993).

The social services network for people with disabilities is based on categorical needs and therefore is fragmented. As a result, it is not easy to make this network fit into a network to provide general services. No single specific-needs system exists, and agencies that provide services to a particular group of people often are unaware of agencies with similar missions for other groups (National Emergency Training Center Emergency Management Institute 1993).

Disability-specific CBOs often

- Are able to assist in preparedness planning and disaster assistance because they know and can protect best the specific interests and needs of groups that they assist on a daily basis.
- Know best how to reach out to the populations they assist.
- Have the most current records.
- Are accessible in terms of design and layout of facilities, environmental needs such as indoor air quality and temperature, and communication—the way information is delivered through signage, technology, interpersonal exchanges, sign language interpreters, picture books for

people with cognitive disabilities, and materials in alternative formats (e.g., Braille, large print, disks, audio cassettes).

- Are able to distribute supplies and administer emergency aid.
- Can serve as satellite distribution sites to provide alternatives, for some individuals, to traditional shelters.

Because effective disaster response always takes place locally, the challenge for emergency management professionals is to integrate the CBOs' skill and knowledge into the emergency service plans and strategy, and connect them to local government. Emergency managers need to recognize, recruit, encourage, and provide funding and incentives so that CBOs can participate in disaster preparedness and relief.

## **Promising Practices**

These are examples of CBOs' promising practices in disaster planning, response, recovery, and mitigation that could be modeled, piloted, and implemented.

### **Triad Alliance**

“There is a 70 percent probability of at least one magnitude 6.7 or greater quake, capable of causing widespread damage, striking the San Francisco Bay Region before 2030. Major quakes may occur in any part of this rapidly growing region,” said the U.S. Geological Survey in October 1999. This quote emphasizes the urgency for all communities in the Bay region to continue preparing for earthquakes. Acknowledging this significant risk, and recognizing the special needs of the community's vulnerable population, the Triad Alliance was developed to ensure that high-risk clients do not fall through the cracks during the response and recovery phases of an emergency. The “triad” consisted of the City of San Leandro, California (in the San Francisco Bay Area region); the Collaborating Agencies Responding to Disasters (CARD); and CBOs in the region. This Triad Alliance has taken the steps to address the special and unique needs associated with the community's vulnerable population during and after a disaster (City of San Leandro 2004).

The usual approach to delivering emergency services does not always provide the essential services for the portion of the population who have special needs. This population may represent those people who are physically or mentally disabled, medically or chemically dependent, elderly, children, homeless, and non-English speakers. Recent disasters demonstrate that traditional response agencies are often ill-equipped to respond to the special needs of our vulnerable populations. Following the Loma Prieta earthquake in October 1989 in the San Francisco area and the Northridge earthquake in January 1994 in the Los Angeles area, emergency services professionals became painfully aware that the traditional response and recovery systems were not able to satisfy all the human needs successfully. The usual approach to delivering emergency services does not always provide the essential services for that portion of the population requiring special needs—the vulnerable population (City of San Leandro 2004).

Given the high potential for future catastrophic disasters throughout the United States, it is imperative to establish an emergency protocol and plan for delivering services to people with language, cultural, and accessibility needs. The vulnerable population is usually served by CBOs, the local organizations that meet the needs of specific populations within the community. CBOs bring unique expertise in delivering services to people with special needs. The challenge for emergency management professionals is to integrate the CBOs' skill and knowledge into the emergency services plans and strategy, thus connecting them to local government. This connection enhances the response and recovery efforts to our vulnerable populations. The Triad Alliance provides that essential participation and linkage (City of San Leandro 2004).

The Triad Alliance is the best assurance that the special needs of the vulnerable population will be successfully addressed during long- and short-term emergency operations. The alliance consists of a number of essential elements that together create a program in which CBOs are more prepared before a disaster and thus are better able to better serve their clients during and following a disaster. The three organizational components of the Triad Alliance are as follows:

- The City of San Leandro: The emergency services division, located in the city manager's office, is an active cofounder of the alliance and represents the city in alliance matters and

activities. A key objective of the division's mission is to coordinate emergency response and recovery efforts among city government, school districts, business, CBOs, and special districts.

- **CARD:** CARD is a cofounder of the alliance. This nonprofit organization was founded in 1994, with the support of the American Red Cross and United Way. It was formed as a result of the 1989 Loma Prieta earthquake, when a gap was seen in meeting the needs of the vulnerable populations during and following the quake. CARD's focus is meeting the needs of the community's underserved population. CARD has received local, state, national, and international recognition for its model of coordinating disaster planning for at-risk populations.
- **CBOs:** CBOs are the third principal member of the alliance. They form a direct link to the community's vulnerable population—their clients. Two CBOs are selected as lead agencies to represent the city's CBO community. These agencies have special experience, knowledge, and skills necessary to serve their clients; this unique know-how, understanding, and expertise becomes an invaluable resource during the response and recovery phases of an emergency or disaster. The city's emergency strategy becomes more responsive and effective in addressing the human services issues by incorporating CBOs into the city's emergency plan and emergency organization.

### **Emergency Network Los Angeles**

The Emergency Network Los Angeles (ENLA) is an organization that has been set up to coordinate disaster response and emergency preparedness by establishing links with Los Angeles County CBOs, the government, and the private sector. ENLA is part of Los Angeles County Voluntary Organizations Active in Disaster (VOAD). ENLA has created a list of local and national disaster preparedness and response resources (Los Angeles County Voluntary Organizations Active in Disaster 2003).

### **Voluntary Organizations Active in Disasters**

VOAD is an organization in each state or region that works to keep CBOs informed and involved during times of disaster. VOAD creates a coordinated effort of numerous agencies and

organizations and prevents the reinvention-of-the-wheel effect that limits the amount of services and the level of efficiency that each organization provides if working alone.

The National Voluntary Organizations Active in Disasters organization (NVOAD) was established in the 1970s as a way to coordinate the planning and efforts of voluntary organizations in the event of a disaster. When a disaster occurs, NVOAD members meet at the disaster sites to coordinate the many services that the community members provide. NVOAD is a nonprofit organization committed to serving its state and national VOAD member organizations through communication, cooperation, coordination, education, leadership development, mitigation, convening mechanisms, and outreach opportunities (National Voluntary Organizations Active in Disasters 2004).

During the 1980s, it became clear that individual states should have VOAD organizations to coordinate local efforts better. Thus state and regional VOADs serve the local communities in which they are established and communicate and interact directly with NVOAD. Examples of VOAD members include local churches, the Salvation Army, and the Red Cross. NVOAD is committed to serving states and regions that are interested in developing and maintaining a VOAD organization and have created a comprehensive guide for doing so.

### **National Emergency Resource Information Network**

To date, funding to organize CBOs effectively and include them in these important roles has been sporadic and inconsistent. For example, the National Emergency Resource Information Network (NERIN) was a temporary program funded in the 1990s by the Department of Commerce to determine the feasibility of a national human service network. This project focused on the role of human service responders and referral agencies, including CBOs as part of a large nonprofit service network that could work with local government agencies. Project plans included Web sites and databases with resource information that would be accessible to a variety of communities. Outcomes of the project included recommendations for network implementation. This important project was not funded beyond the initial study.

### **Community collaborative groups**

Community collaborative groups bring together local CBOs serving at-risk populations to specifically address issues related to disaster preparedness and response. Community collaborative groups vary in size, organizational structure, and procedures. Their common bond is a commitment to addressing the emergency preparedness needs of vulnerable, high-risk populations. They establish cooperative agreements among organizations that support and assist similar populations. These agreements allow such organizations to help each other when their own staff or resources are reduced or unavailable (Monterey County Emergency Food Assistance Project undated, San Francisco CARD undated, VOICE of Contra Costa County undated, Volunteer Center of Marin undated).

By participating in a local collaborative, organizations connect to a network of other service providers and a variety of resources to meet their individual needs. Community collaborative groups can provide services that the traditional emergency service providers do not, or are not permitted to provide. Participating organizations can learn how to stay open and operational after a disaster, and ensure that necessary services are provided to the people they support. Through the collaborative network, organizations can learn what resources are available to them if they are affected by a disaster and how to maintain the documentation that may allow them to be reimbursed for disaster service-related costs (Brisson and Petersen undated).

### **Information and Referral 2-1-1**

Following the September 11, 2001, terrorist attacks, an estimated 400 telephone hotlines were established in New York City, for various funds and services, creating a confusing network for victims and volunteers to navigate. A U.S. Comptroller General report on charitable aid following the terrorist attacks found that “families of victims generally believed they had to navigate a maze of service providers in the early months” and that “good information about and easy access to available assistance could help survivors in the recovery process” (Walker 2004).

In 2000, the FCC assigned the phone number 2-1-1 for community information and referral nationwide, making this scarce resource available for the sole purpose of community information and referral. The 107th Congress recognized the importance of 2-1-1 telephone service in

community preparedness and response by including use of that telephone number for public information as an allowable use of funds under grants for preparedness and response to bioterrorism and other public health emergencies. The phone number 2-1-1 provides callers with a way to access information about and referrals to human services for everyday needs and in times of crisis (United Way of Connecticut undated).

Currently established 2-1-1 systems are completely funded by the state and local government, businesses, nonprofit organizations, and other agencies. While 20 percent of the population has access to 2-1-1 telephone service in 21 states, inadequate funding prevents access to that telephone service throughout each of the states. Currently, 2-1-1 telephone service is available statewide only in Connecticut and Hawaii (United Way of Connecticut undated).

Rapid deployment of a nationwide 2-1-1 telephone service as a means of access to information about and referral to human services requires collaboration among state governments, comprehensive and specialized information and referral centers, human service organizations and service providers, emergency management and homeland security officials, telephone companies, and other relevant entities (United Way of Connecticut undated).

Working with CBOs as partners in disaster response and relief does not relieve government responsibility. It augments government efforts and forms a critical partnership with the community. DHS should value and offer funding and other incentives to encourage CBOs to become involved in disaster activities (Kailes 2000a). CBOs can do the following:

- Develop organization disaster plans that include information about how CBOs can survive a disaster and continue to serve people.
- Participate in Community Emergency Response Teams and Citizen Corps (Citizen Corps undated, FEMA undated-b).
- Participate in cross-training with disaster response personnel and disability-specific organizations personnel so both groups gain a better understanding of each other's expertise and roles and can plan together for a coordinated response.

- Assist the people they support in developing individual and family preparedness and mitigation plans.
- Preestablish contracts so that CBOs are not encumbered by procedural delays. Such contracts would allow emergency response funds—from local, state, regional, and Federal Government agencies as well as foundations and corporations—to be immediately appropriated and used. This would allow for quick deployment of disability-specific relief services. For example, relocation to shelters might not be needed if such backup services were available. Provision through contracts for backup electrical units, such as standalone or portable generators to reactivate or recharge assistive devices, elevators, and appliances, can alleviate overcrowding at shelters and help people with disabilities remain in their home or communities in potentially safer and more accessible environments.

# **Part IV. The Developing Disability-Related Homeland Security, Emergency Preparedness, and Disaster Relief Infrastructure**

## **Department of Homeland Security**

The Homeland Security Act, passed on November 25, 2002, combined 22 government agencies into the new DHS. DHS says it “streamlines and centralizes federal actions into one cohesive unit. It provides one point of contact for state and local groups and the private sector” (DHS, 2004a).

The 22 agencies are divided into five directorates:

- Border and Transportation Security
- EP&R
- Science and Technology
- Information Analysis and Infrastructure Protection
- Management

The Coast Guard and the Secret Service are not part of the five directorates because these two departments report directly to the secretary of homeland security (Stichter 2003). This government reorganization was initiated to provide a more uniform set of directions to the many departments, agencies, and units that each do a part to serve and protect the people of the United States.

## **Budget**

The budget for DHS included \$41 billion in 2004 and \$47 billion in 2005. Spending for these efforts in 2001, although not yet under the direction of DHS, totaled approximately \$21 billion. Of the 2004 DHS budget, 37 percent was allocated to support efforts by the border and transportation authorities; 30 percent was allocated to protect critical infrastructure within the country; 17 percent

was allocated for EP&R efforts; and 15 percent was apportioned for counterterrorism, defending catastrophic threats, and intelligence and warning activities (Schmit 2004).

### **Mission**

DHS's mission includes preventing and reducing the risk of future terrorist attacks; minimizing the damage if such acts do occur, as well as aiding in recovery efforts; continuing to carry out the functions of each of the individual units in the newly created department; maintaining the same level of service to nonterrorism-related items from each of the individual units in the department; ensuring that the country's economic security is not diminished in spite of the newly created department; and continuing to monitor and sever connections between drug trafficking and terrorism (Walker 2004).

### **Directorate of Emergency Preparedness and Response**

DHS's EP&R is charged with ensuring that the country is prepared for catastrophes—whether natural disasters or terrorist assaults. The directorate coordinates with first responders and oversees the Federal Government's national response and recovery strategy.

DHS builds on FEMA's long track record of aiding the nation's recovery from emergency situations. EP&R continues FEMA's efforts to reduce the loss of life and property and protect the nation's institutions from all types of hazards through a comprehensive, risk-based emergency management program of preparedness, prevention, response, and recovery.

EP&R develops and manages a national training and evaluation system to design curriculums, set standards, evaluate, and reward performance in local, state, and federal training efforts. EP&R continues FEMA's practice of focusing on risk mitigation in advance of emergencies by promoting the concept of disaster-resistant communities, including providing federal support for local governments that promote structures and communities that reduce the chances of being hit by disasters. EP&R coordinates with private industry, the insurance sector, mortgage lenders, the real estate industry, homebuilding associations, citizens, and others to create model communities in high-risk areas.

EP&R leads DHS response to all biological or radiological attacks, and it coordinates the involvement of other federal response teams, such as the National Guard, in the event of a major incident (DHS 2004a).

### **Federal Emergency Management Agency**

On March 1, 2003, FEMA became part of DHS's EP&R, which brings together, in addition to FEMA, the Strategic National Stockpile and the National Disaster Medical System (from the Department of Health and Human Services [HHS]); the Nuclear Incident Response Team (from the Energy Department); Domestic Emergency Support Teams (from the Justice Department); and the National Domestic Preparedness Office (from the Federal Bureau of Investigation). FEMA's continuing mission within the new department is to lead the effort to prepare the nation for all hazards and effectively manage federal response and recovery efforts following any national incident. FEMA also initiates proactive mitigation activities, trains first responders, and manages the National Flood Insurance Program and the U.S. Fire Administration.

FEMA has more than 2,600 full time employees. They work at FEMA headquarters in Washington, D.C., at regional and area offices across the country, at the Mount Weather Emergency Operations Center in Virginia, and at the National Emergency Training Center in Emmitsburg, Maryland. FEMA also has nearly 4,000 standby disaster assistance employees who are available for deployment after disasters (FEMA 2004a).

To understand what FEMA does, think about the life cycle of disasters. The disaster life cycle describes the process by which emergency managers prepare for emergencies and disasters, respond to them when they occur, help people and institutions recover from them, mitigate their effects, reduce the risk of loss, and prevent disasters such as fires from occurring. At every stage of this cycle, FEMA is charged with building and supporting the nation's emergency management system (FEMA 2004a).

Emergency management is not the result of one government agency. FEMA's influence is far-reaching, especially in response to a presidentially declared disaster, when FEMA may work with as many as 27 federal agencies and the American Red Cross to provide assistance. These

agencies provide state and local governments with personnel, technical expertise, equipment, and other resources, and they assume an active role in managing the response. In addition to its federal partners, FEMA works with many nonprofit and private sector agencies to assist the public in preparing for, responding to, and recovering from a disaster. Together, these players make up the emergency response team (FEMA 2004c).

To coordinate the federal efforts, FEMA recommends that the President appoint a Federal Coordinating Officer for each state that is affected by a disaster. This officer and the state response team set up a disaster field office near the disaster scene. It is from this office that the federal and state personnel carry out response and recovery functions. These functions represent 12 ESFs (emergency support functions), each headed by an agency supported by other agencies.

### **Emergency support functions**

The resources provided by the federal government are grouped into the following 12 ESFs:

- ESF 1: Transportation. Providing civilian and military transportation. Lead agency: Department of Transportation
- ESF 2: Communications. Providing telecommunications support. Lead agency: National Communications System
- ESF 3: Public Works and Engineering. Restoring essential public services and facilities. Lead agency: U.S. Army Corps of Engineers, Department of Defense
- ESF 4: Fire Fighting. Detecting and suppressing wild land, rural, and urban fires. Lead agency: U.S. Forest Service, Department of Agriculture
- ESF 5: Information and Planning. Collecting, analyzing, and disseminating critical information to facilitate the overall federal response and recovery operations. Lead agency: FEMA
- ESF 6: Mass Care. Managing and coordinating food, shelter, and first aid for victims; providing bulk distribution of relief supplies; operating a system to assist family reunification. Lead agency: American Red Cross

- ESF 7: Resource Support. Providing equipment, materials, supplies, and personnel to federal entities during response operations. Lead agency: General Services Administration
- ESF 8: Health and Medical Services. Providing assistance for public health and medical care needs. Lead agency: U.S. Public Health Service, HHS
- ESF 9: Urban Search and Rescue. Locating, extricating, and providing initial medical treatment to victims trapped in collapsed structures. Lead agency: FEMA
- ESF 10: Hazardous Materials. Supporting federal response to actual or potential releases of oil and hazardous materials. Lead agency: Environmental Protection Agency
- ESF 11: Food. Identifying food needs; ensuring that food gets to areas affected by disaster. Lead agency: Food and Nutrition Service, Department of Agriculture
- ESF 12: Energy. Restoring power systems and fuel supplies. Lead agency: Department of Energy

### **Office for Civil Rights and Civil Liberties**

The CRCL protects civil rights and civil liberties and supports homeland security by providing DHS with legal and policy advice on the full range of civil rights and civil liberties issues the department will face, and by serving the public as an information and communications channel on all aspects of these issues. Congress created the Office to review and assess allegations of abuse of civil rights or civil liberties, and racial or ethnic profiling, by DHS personnel. The office is required to report annually to Congress on any such abuses committed by DHS personnel, how much money was required to resolve these complaints, and how the complaints were resolved (DHS 2004b).

### **Leadership**

On July 22, 2004, President Bush signed an Executive Order emphasizing the importance of implementing emergency preparedness plans that accommodate individuals with disabilities (White House Office of the Press Secretary 2004). Tom Ridge, the first director of the Office of

Homeland Security, stated in November 2001 at a White House meeting with representatives from the disability community—

One of the challenges for the Office of Homeland Security—and it's a wonderful challenge—is to integrate all the Americans who want to help be part of homeland security into a national strategy.... Obviously, they've got some unique and very special challenges that we'd have to deal with, but they also have some very unique and, I think, probably helpful ideas and we want to integrate them in the process of developing a national strategy (NOD 2001a).

Like this presidential order and Secretary Ridge's statement, clear and continual strong messages and directives from multiple visible leaders must communicate and reinforce values, directions, and performance expectations.

### **Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities**

In April 2004, DHS's CRCL assembled an internal working group made up of a variety of departments and agencies. This group meets monthly and focuses on disability issues such as Section 504 and 508 of the 1973 Rehabilitation Act, ADA, and issues related to the Transportation Security Administration (TSA). The goal is to examine what is in place and to identify gaps. FEMA, the Office of Domestic Preparedness (ODP), TSA, and the Citizen Corps are some of the members. (ODP is the principal component of DHS responsible for preventing and preparing the United States for acts of terrorism. In carrying out its mission, ODP is the primary office responsible for providing training, funds for the purchase of equipment, support for the planning and execution of exercises, technical assistance, and other support to assist states and local jurisdictions to prevent, plan for, and respond to acts of terrorism.)

The July 2004 President's Executive Order on emergency preparedness for people with disabilities established an Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities, which will help agencies and private individuals and organizations take into account the unique needs of people with disabilities in their emergency preparedness planning (White House Office of the Press Secretary 2004).

The council is to submit a report to the President each year, beginning one year after the date of this order, through the assistant to the president for homeland security. This report describes the achievements of the council; the best practices among federal, state, local, and tribal governments and private organizations and individuals for emergency preparedness planning with respect to individuals with disabilities; and recommendations of the council for advancing policy that ensures that the Federal Government appropriately supports safety and security for individuals with disabilities in situations involving disasters (White House Office of the Press Secretary 2004).

### **Civil rights enforcement**

*Resources Needed.* Two key resources are required for an effective civil rights enforcement program: adequate staffing and adequate funds to support enforcement. Civil rights compliance is a labor-intensive effort. Without sufficient staff, investigations and compliance reviews may be delayed or deferred. Financial resources are required to support investigations, pay for travel, provide training and technical assistance materials, underwrite new initiatives, and provide expertise that is not otherwise available to the agency. Each federal agency that provides federal financial assistance is responsible for investigating complaints of discrimination in the use of its funds.

*Filing a Complaint Online.* A search of the FEMA home page for “filing a complaint,” “504 complaint,” or “disability complaint” quickly resulted in appropriate information. The subject “ADA complaint” did not yield any complaint-related “how-to” information. The helpline 800 number did not include a TTY number (FEMA 2003b). A search of DHS’s home page for “filing a complaint quickly” resulted in appropriate information. “ADA complaint” did not yield any complaint-related “how-to” information.

*Office for Civil Rights and Civil Liberties.* DHS’s CRCL protects civil rights and civil liberties and supports homeland security by providing DHS with legal and policy advice on the full range of civil rights and civil liberties issues. The office, which began operations in March 2003, was created by Congress to review and assess allegations of abuse of civil rights or civil liberties, and racial or ethnic profiling, by DHS personnel. The CRCL is required to report annually to

Congress on any such abuses committed by DHS personnel, how much money was required to resolve such complaints, and how such complaints were resolved (DHS 2004b). The CRCL's 2004 budget request was \$12,950,000.

*Civil Rights Program of EP&R/FEMA.* Michael D. Brown, under secretary of DHS for EP&R, has said that EP&R/FEMA's goals—

...are to protect lives and prevent the loss of property; to reduce human suffering and enhance the recovery of communities after disaster strikes; and to ensure that EP&R/FEMA is a high-performance organization serving the public in a timely and cost-efficient manner. We will not truly fulfill these goals unless we also protect precious rights and prevent discrimination. I expect support from every employee of EP&R/FEMA in carrying out our Civil Rights mandates (FEMA 2003a–i).

FEMA states that it is the policy of DHS and EP&R/FEMA to ensure that the civil rights of all persons receiving services or benefits from agency programs and activities are protected.

No person shall, on the grounds of race, color, national origin, sex, religion, age, disability, or economic status, be denied the benefits of, be deprived of participation in, or be discriminated against in any program or activity conducted by or receiving financial assistance from EP&R/FEMA. In particular, all personnel carrying out federal major disaster or emergency assistance functions, including the distribution of supplies, the processing of applications, and other relief and assistance activities, shall perform their work in an equitable and impartial manner without discrimination (FEMA 2003 a–i).

Any person eligible to receive disaster aid or other services from FEMA is entitled to those benefits without discrimination. The laws that guarantee these protections include the following:

- Section 504 of the 1973 Rehabilitation Act, which prohibits federal agencies and federally funded programs from discriminating on the basis of disability. It is designed to promote and expand opportunities for people with a broad range of disabilities and offer broad-based protection from unwarranted discrimination stemming from prejudice, social stigmas, and negative assumptions about their ability to participate fully in the mainstream of society. Section 504 covers a number of entities and federally funded activities not reached by the ADA. It is intended to make certain that tax dollars will not be used to establish, promote, or reinforce discrimination against people with disabilities (NCD 2003b). Congress also

intended the federal agencies to address and correct the ways in which recipients of these funds were discriminating against individuals with disabilities.

- Section 508 of the 1973 Rehabilitation Act, which deals specifically with access to computers and information technology.
- Title VI of the Civil Rights Act of 1964, which protects individuals from discrimination on the basis of their race, color, or national origin in programs that receive federal financial assistance.
- Section 308 of the Robert T. Stafford Emergency Management and Disaster Assistance Act, which prohibits discrimination on the basis of race, color, religion, nationality, sex, age, or economic status in all disaster assistance programs.

EP&R/FEMA's civil rights program section of the Office of Equal Rights (OER) provides the following:

- Technical assistance—policy guidance to the agency in meeting civil rights mandates. In disaster operations, staff work closely with community organizations to resolve tensions and eliminate potential complaints. The office also provides assistance to the agency and the national emergency management community in the effort to make publications, programs, and facilities accessible to people with disabilities; provides guidance to the federal coordinating officer on equal employment opportunity (EEO) and civil rights matters; and presents training on sexual harassment prevention, cultural diversity, and the EEO process.
- EEO counseling—assistance to FEMA employees, employment applicants, and managers to resolve problems quickly; guidance to supervisors through downsizing to achieve the best possible outcome; and processing of all complaints that cannot be resolved informally (FEMA 2003d).
- Complaints resolution—a contact point for anyone who believes he or she has been discriminated against in receiving services or benefits from FEMA. Disaster applicants can obtain help from an equal rights officer through the FEMA helpline. If that officer cannot resolve the issue, a formal written complaint may be filed with OER. This office is

responsible for processing complaints, acknowledgment, acceptance/dismissal, investigations, compliance reviews, and issuing final decisions (FEMA 2003d).

*Equal Rights Officer Cadre.* The equal rights officer cadre is a diverse group composed of people with backgrounds in such fields as EEO, civil rights, human resources management, conflict resolution, and community organization. They serve on the direct staff of the federal coordinating officer at the disaster field office.

In addition to technical assistance and training and EEO counseling, the equal rights officer cadre focuses on resolution of civil rights complaints. The cadre staff work proactively with community relations, public affairs, human services, and other disaster field office components to resolve individual or group civil rights issues; visit and speak with key community leaders and organizations; assess accessibility at disaster recovery centers; and distribute information about EP&R programs. They investigate disability-specific civil rights complaints and maintain contact with the disability community.

If individuals believe they or others protected by civil rights laws have been discriminated against in receiving disaster assistance, they can contact one of FEMA's equal rights officers, who have the job of ensuring equal access to all FEMA disaster programs. That officer will attempt to resolve the issues. If the matter is not resolved, individuals may file a complaint with FEMA. A signed, written complaint needs to be sent to the OER, generally within 180 days of the date of the alleged discrimination.

Once a complaint is filed, FEMA reviews it to determine whether FEMA has jurisdiction to investigate the issues raised. If the complaint is accepted, FEMA will investigate it and attempt to resolve any violations that are found. If negotiations to correct a violation are unsuccessful, enforcement proceedings may be instituted.

The civil rights program manager supervises the equal rights officers and spends approximately 45 percent of the time on disability-specific activities, such as attending national meetings,

advising other federal agencies, and providing disability-specific emergency planning and technical assistance to state and local government agencies.

*Using Funding Sanctions to Enforce Section 504 and ADA.* The CRCL is currently working on a draft document that will remind grantees of their Section 504 and ADA obligations. A more proactive approach may be needed. The CRCL also stated that the Department of Justice is actively working on guidance for state and local emergency planning departments that reinforces their legal obligation to comply with Section 504 and ADA in planning for, operating, and managing shelters and other disaster services.

Often the threat of temporarily withholding even a portion of the funds is enough to persuade a grantee to rethink its plans and attend to the assurances that are often in very small print, buried in the back of grant and contract agreements. Congress included this as an effective remedy to address discrimination on the basis of disability by recipients of federal funds.

To combat disability discrimination in the most effective way possible, it is NCD's view that federal agencies should use their sanctioning authority, including making recipients ineligible to apply for continued or new funding while they are not in compliance with federal civil rights laws. This strategy could effectively be incorporated into notices of funding availability and program eligibility requirements, so that no recipient or potential recipient can be funded while a preliminary or final finding of noncompliance is pending. This strategy should become an integral part of agencies' Section 504 enforcement efforts. DHS should also develop and apply a range of sanctions to help bring recipients of federal funds into compliance with Section 504. Additionally, DHS should publicize their efforts to maximize deterrence against violations of the rights of people with disabilities (NCD 2003a, b).

Federal funding agencies have the authority and the ability to influence their recipients' choices of how to spend their federal dollars. Recipients, for example, have used their federal funds to create separate recreation activities or swimming classes; to deny participation in employment programs to applicants who take medications for psychiatric disabilities; and to place public benefit programs in inaccessible buildings. Each of these decisions is likely to be or to lead to a

violation of both Section 504 and ADA. However, only the funding agency can withhold the amount of funding that is equivalent to the amount that would support the illegal activity. It can do much more, of course, but often the threat of temporarily withholding even a portion of the funds is enough to persuade the city to rethink its plans (NCD 2003b).

Encouraging beneficiaries to comply with civil rights obligations and agreements is a very effective way for DHS to maximize its resources and compliance. To date, DHS has not initiated funding terminations to enforce Section 504 against grantees that violate the law. NCD believes that stronger efforts should be devoted to clearly communicating to grantees that their funds can be withheld if they violate Section 504 or ADA.

Congress provided this remedy to give federal agencies the leverage they needed to force recalcitrant grantees to stop using tax dollars in discriminatory ways and to otherwise encourage voluntary compliance with the law.

*Technical Assistance, Training, and Outreach.* Encouraging the help of the public to ensure that DHS's disaster management networks comply with civil rights laws is an effective way for DHS to maximize its resources. It assists DHS by turning to the public and to DHS recipients for help in identifying discrimination and technical assistance needs (NCD 2003b).

Stronger outreach, targeted technical assistance, and training initiatives focused on ADA and Section 504 compliance issues are needed, NCD believes. A search for "504 technical assistance or guidance" and "ADA technical assistance or guidance" from the FEMA and DHS home pages resulted in only one resource:

Americans with Disabilities Act (ADA) Access Requirements, Date Published: October 26, 2000, Response and Recovery Directorate Policy Number: 9525.5. This policy provides guidance in determining the eligibility of costs for federally required ADA access compliance associated with Public Assistance (PA) program grants. This policy is applicable to all major disasters and emergencies declared on or after the publication date of this policy. It is intended for Federal Emergency Management Agency (FEMA) personnel involved in making eligibility determinations for the PA program (FEMA 2003f).

*Successful Technical Assistance Practices.* Examples of successful technical assistance practices at the HHS office of civil rights can be found at [www.hhs.gov/ocr/generalinfo.html](http://www.hhs.gov/ocr/generalinfo.html) and [www.hhs.gov/ocr/selectacts](http://www.hhs.gov/ocr/selectacts). This office has a wide array of technical assistance materials available online. The HHS Web site contains references to a large number of technical assistance materials (easily accessed through a drop-down menu that includes “civil rights” and “disabilities”), including complaint filing information, fact sheets, regulations, and case summaries. The case summaries include examples of HHS enforcement actions and summaries of several resolutions of Section 504 complaints. The civil rights resource page contains links to other federal enforcement agencies (NCD 2003b, pp. 81–82).

The Department of Education’s Web site has a number of technical assistance materials, including a short list of frequently asked questions, case decisions, a description of the complaint investigation process of the department’s office of civil rights, and a breakdown of complaints by type. The site is at [www.ed.gov/offices/OCR/disabilityresources.html](http://www.ed.gov/offices/OCR/disabilityresources.html). The Department of Education also has technical assistance materials directed at recipients, including guidance on developing a nondiscrimination policy and developing effective grievance policies and similar resources ([www.ed.gov/offices/OCR/prevention.html](http://www.ed.gov/offices/OCR/prevention.html)).

Production of ADA and Section 504 guidance materials available online and through technical assistance, including fact sheets, technical briefs, and regulation and case summaries, are very helpful in increasing compliance with civil rights laws.

*Compliance Reviews.* DHS does not conduct proactive reviews of recipients’ compliance or noncompliance with Section 504 and ADA. Agencies enforcing Section 504 have the authority to conduct proactive reviews of recipients’ compliance, or noncompliance, with Section 504. This authority is discretionary because it is not driven by complaints; it can be exercised even in the absence of complaints. Compliance reviews permit a comprehensive examination of the activities of a particular recipient for compliance with the law. A compliance review may be used to identify hitherto undisclosed compliance issues, it can provide an early alert about emerging problems, and it can be used as a vehicle for training or technical assistance.

Compliance reviews may be, and sometimes are, used as an effective enforcement tool, carrying with them the possibility of a wide variety of sanctions, including suspension or termination of funding. Compliance reviews are an effective way to conduct systematic enforcement of the law

without an individual complaint. Especially when victims of discrimination do not, or cannot, speak for themselves, compliance reviews help ensure that congressional intentions for civil rights laws are met (NCD 2003b).

A good practice, in addition to complaint investigations and actions to resolve noncompliance, involves reviewing whether an agreement actually accomplishes a Section 504 goal on a case-by-case basis. Having the flexibility to work with a recipient to modify agreements and generate better outcomes for people is the goal. It emphasizes results over process (NCD 2003b).

*Data Collection and Reports.* NCD asked FEMA and the CRCL to provide detailed information about their complaint processing and compliance review information, in general and with respect to Section 504 enforcement activities.

The CRCL has a staff of 20, including five attorneys. Staff share complaint processing responsibilities, and there is no designated individual with the sole responsibility for handling disability issues. CRCL staff felt the timing of this report was too early; they could not provide some of the information requested because the CRCL is still in the initial phases of developing initiatives and priorities.

For fiscal year 2004, the CRCL logged 60 complaints (not limited to Section 504). The CRCL has 180 days to resolve a complaint. The number of complaints resolved was not available. The CRCL reports that, given its newness, it has not developed information systems that comprehensively collect, aggregate, or summarize detailed information about complaints or compliance reviews and their outcomes.

EP&R/FEMA also has no designated individual with the sole responsibility for handling disability issues. Many of the equal rights officers have partial responsibility for this activity. In fiscal year 2003, 1 out of 85 complaints was disability related, and in fiscal year 2004, 18 out of 288 were disability-related issues.

EP&R/FEMA does not collect and analyze Section 504 and ADA program data (complaints or compliance reviews and their outcomes) for progress made, deficiencies, best practices, or

areas where DHS could provide coordination or technical assistance. It has been more than 10 years since EP&R/FEMA has issued guidance for state and local emergency planning departments reinforcing their legal obligation to comply with Section 504 in planning for, operating, and managing shelters and other disaster services. Guidance on ADA compliance has never been issued.

The CRCL and EP&R/FEMA do not get many formal complaints on discrimination related to people with disabilities and activity limitations. On first examination, there seems to be a dramatic disconnect between the experience of people with disabilities and activity limitations in disasters and the number of civil rights complaints received by DHS. There are probably multiple reasons for the low number of complaints, which may include the following:

- After a disaster many people are overwhelmed with dealing with their immediate survival needs and losses. Filing complaints can be a low priority.
- Complaints may be filed with the states as well as nonfederal partners.
- Many of the barriers experienced by people with disabilities are the result of activities conducted by states and local government and other partners. This underscores the critical importance of DHS reminding and reinforcing all of its partners, grantees, and contractors of their legal obligation to comply with ADA and Section 504 and 508 of the Rehabilitation Act in planning for, operating, and managing shelters and other disaster services. It also reinforces the importance of DHS regularly issuing guidance for state and local emergency planning departments to reinforce their legal obligation to comply with these laws.
- Many people with disabilities do not know how to make a complaint or where it should be directed for resolution.

Information systems that comprehensively collect, aggregate, or summarize detailed information about complaints or compliance reviews and their outcomes are critical to the public and to consumers and recipients of service. Among the kinds of information that should be readily available are the numbers of complaints and compliance reviews initiated, completed, and remaining for every fiscal year. Additionally, data routinely compiled should include the length

of investigations and reviews, the issues or claims reviewed and findings on each, detailed information about findings of compliance and noncompliance made, and similarly detailed information about the ways complaints and compliance reviews are resolved (NCD 2003b).

This data is important in assessing trends and themes in Section 504 and ADA issues, identifying the workload and the outcomes of cases, and assessing the quality and quantity of work done. The information is important for internal management purposes, but it is also critically important to consumers, advocates, and recipients, who rightfully expect to be informed about the types of enforcement activities being conducted and their outcomes (NCD 2003b).

People with disabilities want to read data easily about agencies' compliance with Section 504 and ADA. Such data includes complaint filings and compliance reviews initiated, specific Section 504 issues and trends in complaint and compliance reviews, and outcomes and enforcement actions. Routinely reporting Section 504 activities on the Web sites would allow DHS to publicize Section 504 and ADA accomplishments (NCD 2003b).

*Section 508.* DHS has committed to comply with the requirements of Section 508 of the Rehabilitation Act. Section 508 requires that individuals with disabilities who are members of the public seeking information or services from DHS have access to and use of information and data that is comparable to that provided to the public who are not individuals with disabilities, unless an undue burden would be imposed on DHS.

Section 508 also requires DHS to ensure that federal employees with disabilities have access to and use of information and data that is comparable to the access to and use of information and data by federal employees who are not individuals with disabilities, unless an undue burden would be imposed on DHS.

*Web Site Access.* It is DHS policy that No. 6-03, 9/2/04 reads as follows:

The Department of Homeland Security (DHS), Emergency Preparedness and Response (EP&R), Federal Emergency Management Agency (FEMA) is committed to serving all individuals equally and therefore considers accessibility to information a priority for all employees and external customers, including individuals with disabilities. Federal employees

and members of the public who have disabilities must have access to and use of information and services that are comparable to the access and use available to nondisabled federal employees and members of the public. It is directorate policy to prohibit discrimination in the accessibility of electronic and information technology (DHS 2004c).

*PDF Documents.* DHS's Web site states:

Section 508 also requires us to ensure that federal employees with disabilities have access to and use of information and data that is comparable to the access to and use of information and data by Federal employees who are not individuals with disabilities, unless an undue burden would be imposed on us. If the format of any material on our Web site interferes with your ability to access the information, due to an issue with accessibility caused by a disability as defined in the Rehabilitation Act, please contact [webmaster@dhs.gov](mailto:webmaster@dhs.gov) for assistance. To enable us to respond in a manner most helpful to you, please indicate the nature of your accessibility problem, the preferred format in which to receive the material, the Web address (URL) of the material with which you are having difficulty, and your contact information (<http://www.dhs.gov>).

FEMA's Web site states:

Some of the files are provided in Adobe Acrobat Portable Document Format. All PDF documents on the FEMA Web site are characterized by the following or similar graphic icon (). This icon is usually placed next to the document link. Download Adobe Acrobat Reader. If you have accessibility problems viewing any PDF document on these pages, go to Adobe's Online Converter to obtain the document in text format.

If you have accessibility problems viewing any PDF document on these pages, go to [http://access.adobe.com/simple\\_form.html](http://access.adobe.com/simple_form.html) and use the online conversion tools to obtain the document in text format. Once you download the files you want into the desired directory, open the Acrobat Reader program and then open the files you want to view or print. Download directions are also available with each course. It is recommended that the user download the course material files and view them off-line at their convenience, saving time and money for Internet connection charges.

If you have a disability and the format of any material interferes with your ability to access information contained on our Web site, please e-mail the FEMA/U.S. Fire Administration webmaster at [usfaweb@dhs.gov](mailto:usfaweb@dhs.gov). The webmaster will refer your request to the appropriate USFA component. The component will respond promptly to you by providing you with an alternate format of the requested material.

To enable us to respond in a manner that will be of most help to you, please indicate (FEMA 2004a):

- the nature of the accessibility problem,
- your preferred format (e.g., electronic format (Word, ASCII, etc.), standard print, large print, etc.),
- the Web address of the requested material, and
- your full contact information so we can reach you if questions arise while fulfilling your request.

The American Red Cross (one of EP&R/FEMA's private sector agencies serving as a major player in assisting the public in preparing for, responding to, and recovering from a disaster) Web site, in addition to PDF, provides most of its preparedness documents in hypertext markup language (HTML).

*Section 508 Requirements.* Section 508 requires that federal Web pages containing a PDF file include a link to a plug-in that complies with the software requirements of Section 508. In addition, it requires provision of a text equivalent for every nontext element. Many agencies use PDF files to post documents to their Web site because they create an exact representation of the original document. To view a PDF file, a user must use a browser plug-in.

DHS has two options when addressing PDF content. First, it can ensure that its PDF file is accessible and include a link to a PDF reader that conforms to the software requirements of Section 508. Or, if such a plug in is unavailable, the agency can provide a link to a duplicate file that contains the same information in an accessible format (Section 508 2002).

Adobe has made efforts to make PDF files more accessible, but many people continue to have serious difficulties accessing public information that is made available only in PDF. The many problems associated with accessing PDF documents constitute a burden on people with visual impairments that is significantly greater than the burden placed on individuals without disabilities with regard to PDF files (Sajka and Roeder 2003).

Accessible authoring is not enforced by all available authoring tools. "In fact," say Sajka and Roeder (2003), "some PDF authoring tools simply do not support Adobe's accessibility guidelines. Without a massive effort to upgrade these tools and educate authors on how to use them, or a

systematic approach to prevent the use of these tools to create documents intended for public access, the government will continue to produce thousands of pages of inaccessible documents.”

The American Foundation for the Blind, the American Council of the Blind, National Industries for the Blind, and other groups in the blind community say that “problems of access by people who are blind or otherwise print disabled and the mandates of Section 508 lead to the conclusion that documents in alternative, accessible formats must always accompany PDF for information that is intended for the public” (Sajka and Roeder 2003).

### **Grant programs**

The DHS Secretary is responsible for administering grant programs for state and local first responders, including firefighters, emergency medical personnel, law enforcement officials, and related personnel. DHS functions as a clearinghouse that assists state and local responders with planning, training, equipment, and exercise needs necessary to respond to disasters. FEMA fully or partially funds the emergency management programs and staff in all 56 states and territories and helps design and equip emergency operations in thousands of localities.

ODP is the principal component of DHS with responsibility for preparing the United States for acts of terrorism. In carrying out its mission, ODP is the primary office responsible for providing training, funds for the purchase of equipment, support for the planning and execution of exercises, technical assistance, and other support to assist states and local jurisdictions in preventing, planning for, and responding to acts of terrorism.

*Integrating Disability and Access Issues.* NCD found little evidence of DHS’s grants program encouraging potential grantees to integrate disability and access issues except for an April 2004 ODP announcement for a fiscal year 2004 competitive training grants program. One of six issue areas was titled “Addressing Training Gaps Related to Prevention and Preparedness, to Include Assistance for Special Needs Populations.”

*Procurement.* The creation and enforcement of procurement policies and procedures that are similar to, but that go beyond, Section 508 of the Rehabilitation Act can help to increase access to products and services.

DHS's procurement policies on acquiring and using accessible products and services should be integrated and enforced internally and through all contracts and funded projects.

DHS should ensure that, wherever possible, purchasing specifications reflect the most universally designed products that are accessible and usable by the greatest number of people, regardless of their capabilities. The concept helps people use products and negotiate environments they otherwise would find inaccessible or difficult to manage. For example, a group of architects, product designers, engineers, and environmental design researchers collaborated to establish the Principles of Universal Design to guide a wide range of design disciplines including environments, products, and communications. These seven principles can be applied to products. Consider adopting Principles of Universal Design as a best practice (Center for Universal Design 1997).

*Geographic Information System.* During emergencies, it is critical to have the right data, at the right time, displayed logically, in order to respond and take appropriate action. Most of the data requirements for emergency management are of a spatial nature and can be located on a map (Johnson 2000). Ensure that any surveillance systems used to assess risk include people with disabilities.

Emergency planners and others must also take into account the needs of people with disabilities who travel and may be in their community at the time of an emergency. For example, one individual reported:

In 2002 I was in a Santa Rosa, California, hotel room when I saw a graphic on an uncaptioned TV news program that warned of high winds. I didn't know if the winds were so dangerous that I should take action to protect myself. In 2003 I was at a conference in Las Vegas and uncaptioned TV news talked of the wildfires raging in California but I didn't know how close they were. I also didn't know that the smoke was being carried on the wind and that the air quality could be unsafe. In 2004 I was in Omaha at a conference when yet another uncaptioned TV news program was interrupted with a graphic warning of tornado activity and a picture of a Doppler map showing only names of counties. It was my first time in Omaha and I had no idea which county my hotel was located in (Heppner 2005).

*Proposal Selection Criteria.* Current DHS proposal selection criteria lack disability-specific indicators for evaluating proposals. Where appropriate to the grant focus, these indicators should specifically detail and show evidence of how applicants will achieve the following:

- Deal with the communications, evacuation, transportation, physical access, and health needs of people with disabilities.
- Form partnerships among first responders, emergency planners, and people with disabilities to ensure that accurate training information and usable services are developed.
- Increase communication and cooperation with the disability community.
- Appoint qualified people with disabilities to emergency planning committees, and as advisors, trainers, contractors, and consultants and project staff.
- Educate people with disabilities and activity limitations about what they can do to be prepared for any type of emergency.
- Assist localities in reviewing and, where needed, creating disability-specific policies and regulations.
- Integrate new and updated disability-specific training content into training and preparedness materials.
- Follow policies on procuring and buying accessible products and services.
- Work with CBOs.

### **Current disability-specific initiatives**

DHS has taken some important first steps in its disability-specific plan. The CRCL provides legal and policy advice to DHS related to the myriad civil rights and civil liberties issues that the Department will encounter (DHS 2004a).

CRCL has identified a number of objectives that reflect a commitment to making DHS a model workplace for people with disabilities, including the following:

- Providing paid internships for students with disabilities to gain experience and build new skills.
- Integrating people with disabilities into emergency preparedness and planning.
- Working with private organizations that have increased knowledge and information about the important issues facing people with disabilities.
- Communicating with people with disabilities about homeland security.
- Ensuring that DHS has an efficient Section 508 program (DHS 2004b).

## **Federal Communications Commission**

### **Current FCC rules**

FCC rules state that to accommodate people who are deaf or hard of hearing, emergency information that is provided in the audio portion of the programming must be provided using closed captioning or other methods of visual presentation such as open captioning, crawls, or scrolls that appear on the screen. Emergency information provided by these means should not block any closed captioning, and closed captioning should not block any emergency information provided by crawls, scrolls, or other visual means. This rule on access to emergency information for people with hearing disabilities became effective on August 29, 2000 (Federal Communications Commission [FCC] 2004).

The same information must also be provided in a manner that is accessible to persons who are blind or have low vision. Specifically, emergency information that is provided in the video portion of a regularly scheduled newscast or a newscast that interrupts regular programming must be made accessible to these people. This requires the oral description of emergency information in the main audio, such as open video description. If the emergency information is being provided in the video portion of programming that is not a regularly scheduled newscast or a newscast that interrupts regular programming (e.g., the programmer provides the emergency information through crawling or scrolling during regular programming), this information must be accompanied by an aural tone. This tone is to alert people with vision disabilities that the video programming distributor is providing emergency information, and to alert those persons to tune

to another source, such as a radio, for more information. This rule on access to emergency information for people with vision disabilities became effective February 2, 2001 (FCC 2004).

The FCC has reminded broadcasters of these rules and their obligations to comply on four occasions, the last being on May 28, 2004. In spite of these reminders, widespread problems continue.

Clear communication is the cornerstone of all successful planning and response. Access to emergency public warnings, as well as to preparedness and mitigation information and materials, must include people who receive their information orally and visually, and people who use alternative formats (e.g., Braille, large print, disks, and audio cassettes) to access print materials. There must be a national policy of public warning that includes communication access.

The FCC, in coordination with DHS, held a Homeland Security Summit on March 25, 2004, aimed at addressing emergency communications issues uniquely faced by the disability community. In addition to the ongoing interagency relationships, the FCC is exploring other communications issues related to the specific needs of the disability community that would lend themselves to other partnerships with DHS.

### **Access policy issues**

Many broadcasters and public emergency management agencies are not aware of their legal responsibilities to modify their information procedures. The following are some examples:

#### *Captioning*

- Line 21 on television screens is reserved for closed captioning. Captions are not visible unless activated by the viewer. The FCC oversees the Telecommunications Act of 1996 regulations that phase in closed captioning of TV programs by 2006. These regulations, however, do not require 100 percent captioning of all programs, including news programs. Programs shown between 2:00 a.m. and 6:00 a.m. local time are exempt. Only news programs by the four major broadcast network affiliates in the top 25 TV markets and cable

networks serving at least 50 percent of the total number of households subscribing to the program are required to have real-time captioning (Heppner et al. 2004).

- Emergency Alerting System captions use a different format. Individual television stations and networks have increased use of scrolling text and captions. In spite of FCC requirements that these forms of captioning not interfere with Line 21 captioning, reports by individuals who are deaf and hard of hearing confirm that they do. One reported that on 9/11, “Captioning began to disappear....All I could see was pictures of terror....My local and cable news had their closed captions blocking the local feeder” (Heppner et al. 2004).
- It is increasingly difficult for people to determine which information is the most recent and most important when several forms of captions and text appear on the screen (Heppner et al. 2004).

*Description of Visual Information.* The FCC oversees regulations requiring “visual presentation” of emergency information. These regulations do not specify that information must be verbatim or provided in real time. These requirements, written in pre-9/11 days, are intended to provide all crucial information in an emergency, but there are widespread reports from across the United States that emergency information is not being provided and, when it is provided, crucial information is omitted (Heppner et al. 2004).

Users report that the FCC regulation on description of visual information is not being enforced. This affects many people, but it has a much greater detrimental effect on people with no or limited vision or ability to read. These are two examples.

- Emergency text information including phone numbers is often not read (“call the number on your screen”). Logic suggests that people could switch to radios for this information. This may not work in some rural communities when radios run automated broadcasts in the evenings and weekends. In addition, some rural communities only have statewide information, and not local information, available.
- Consistent, unique, specific tones, music, and voice tags such as “this is a special report” do not always precede emergency information.

*FCC's Complaint Processing.* The FCC reports that it is continually in the process of updating all of its rules. Therefore, the commission will continue to monitor compliance with its rules on the provision of emergency information and, if necessary, initiate a rulemaking procedure to amend the rules.

The FCC Web site is clear about how to file a complaint, but it does not say how long it takes to process a complaint. Complaint procedures are found by typing in “complaint” in the search engine or by choosing the “for consumers” icon, which links to an electronic complaint filing form.

The FCC's rules currently require that accessible information be made available to members of the disability community in times of emergency. Section 79.2 of the FCC's rules requires that emergency information be provided in an accessible format. That section further requires that all critical details must be made accessible. Critical details include specific details on the areas that will be affected by the emergency, evacuation orders, detailed descriptions of areas to be evacuated, specific evacuation routes, approved shelters or the way to take shelter in one's home, instructions on how to secure personal property, road closures, and how to obtain relief assistance.

The FCC reports that it occasionally receives informal complaints from a consumer about blocking of closed captioning by emergency information crawls or scrolls or other on-screen information. Section 79.2 of the FCC's rules states that video programming distributors must ensure that emergency information does not block any closed captioning and that any closed captioning not block any emergency information provided by means other than closed captioning. Through a series of public notices, the FCC has diligently reminded broadcasters and multichannel video program distributors of their obligation to provide captioning for emergency information.

The FCC believes that its complaint process is effective. Under Section 79.1 of the FCC's rules, when consumers make informal allegations about a lack of closed captioning in video programming, the Consumer Inquiries and Complaints Division of the Consumer and Governmental Affairs Bureau contacts the broadcaster, cable, or satellite company directly, on behalf of the consumer, for the purpose of resolving the closed captioning concern. In addition, the FCC's enforcement bureau reviews these informal complaints to determine whether any

additional action is required. Consumers always receive a response from the FCC, and every complaint is taken seriously. If the enforcement bureau finds that a party is in violation of the captioning rules, the FCC may revoke the party's license, impose forfeitures, and, in the case of "flagrant" rule violations, require captioning in excess of the current hourly requirement.

The FCC welcomes specific comments and suggestions as to how to improve its processing of consumer complaints. Currently, FCC staff meet with members of the disability community on a regular basis to discuss issues affecting people with disabilities. In addition, the FCC receives consistent feedback on its complaint process through the Consumer Advisory Committee, a Federal Advisory Committee charged with providing recommendations to the FCC on consumer issues.

Some consumers do not believe, as the FCC does, that the complaint process is effective. They raise the following four kinds arguments: (1) public information provided to consumers by the FCC about their rights and the complaint process is not always clear; (2) complaints are not being passed on within the FCC and consumers have not been kept informed of the status of their complaints; (3) action on the complaints is slow when speed is required because of their emergency nature; and (4) despite numerous complaints submitted—many of them well documented and involving repeat offenders—the FCC has yet to fine a single broadcaster. Overall, according to these individuals, the message to consumers is that their complaints are not taken seriously and that their lives are not important. Furthermore, some consumers report that there is no education or enforcement regarding the need to have closed captions activated on TVs in public places. When there is an emergency, sometimes no one knows how to activate the captions on these public TVs, the remote control may be missing, and there may be several steps involved to activate the decoder. In addition, some people may be new to hearing loss or may have temporary hearing loss and not know about closed captions (Heppner 2005).

*Digital Television Closed Captioning.* In July 2000, the FCC adopted technical standards for display of closed captioning on digital television (DTV) receivers. The order incorporated sections of industry standard EIA-708-B, "Digital Television (DTV) Closed Captioning," into the FCC rules. The standard provides instructions for the encoding, delivery, and display of closed captioning information for DTV systems, with a July 1, 2002, effective date. Devices covered

under the rules include DTV sets with integrated “widescreen” displays measuring at least 7.8 inches vertically, DTV sets with conventional displays measuring at least 13 inches vertically, and standalone DTV tuners, whether or not they are marketed with display screens. As a result, viewers can choose and alter the color, size, and font of their captioning and choose between multiple streams of captioning, such as “easy reader” or alternate language captioning. The rules require that cable providers and other multichannel video programming distributors transmit captions in a format that will be understandable to the decoder circuitry in DTV receivers.

On August 4, 2004, the FCC adopted a report and order clarifying its digital closed captioning rules to ensure that those services are consistently and effectively delivered. This should allow caption users to reap the benefits of new digital technologies enabling caption viewers to customize their caption displays—location, size, font, color, and so on.

*Broadcasters’ Interpretation of “Emergency”.* Stations across the country interpret regulations requiring the captioning of emergency information to apply too narrowly to situations dealing with adverse weather conditions. As a result, key information such as airport closings and new security requirements, tightened security on major transportation routes, suspected anthrax exposure, sniper attacks, and other important news is not captioned (Heppner 2004, Heppner et al. 2004).

In April 2004, the FCC sent letters to several local television stations in the Washington, D.C., area about the failure of these stations to caption reports on the sniper shootings in the Washington area in 2002. In the letters, the FCC clarified that those sniper shootings did constitute an emergency event during which “emergency information” might have been broadcast.

The FCC interprets the “emergency information” language broadly enough to include events other than just weather-related emergencies. Emergency information is information about a current emergency that is intended to further the protection of life, health, safety, or property. Examples of the types of emergencies about which emergency information might be broadcast are tornadoes, hurricanes, floods, tidal waves, earthquakes, icing conditions, heavy snows, widespread fires, discharge of toxic gases, widespread power failures, industrial explosions, civil disorders, school

closings and changes in school bus schedules resulting from such conditions, and warnings and watches of impending changes in weather. This list of emergencies is not intended to be exhaustive. The rule may also apply to terrorism-related events and other similar instances.

In addition, through a series of public notices, the FCC has diligently reminded broadcasters and multichannel video program distributors of their obligation to provide captioning for emergency information. The FCC is continually updating all of its rules. Therefore it will continue to monitor compliance with its rules on the provision of emergency information and, if necessary, initiate a rulemaking to amend the rules.

*Telecommunications Relay Services.* Telecommunications relay services (TRS) enable callers with hearing and speech disabilities who use TTYs and other technologies, and callers who use voice telephones, to communicate with each other through a third-party communications assistant. On 9/11, TRS providers were unprepared for the volume of calls that were made, resulting in the breakdown of TRS communications in several states. It appears that none of the nation's TRS providers had clear procedures in place to inform communities about the disruption in relay services (such as 72 hours of power backup, plans that clearly identify essential staff during emergencies, use of and access to a reliable national database allowing the service to connect users with appropriate public safety answering points (PSAPS-911 Centers) in an emergency, and contingency plans for transferring calls from centers unable to operate because of overwhelming volume or damage) (Heppner et al. 2004).

PSAPS-911 Centers are not keeping up with advances in accessible telecommunications and thus may not be prepared to handle voice carry over (VCO), IP-relay (Internet protocol), VRS (video relay service), CapTel (captioned telephones), and other calls from individuals who are deaf and hard of hearing. CapTel works like other telephones but with one important distinction: users can read a captioned version of their conversations on the text screen of their phone. This is possible through voice-recognition technology, which the operator at the captioning service center uses to transcribe everything the other party says into written text. Captions appear almost simultaneously with the spoken word, allowing users access to what is said, either by hearing it or by reading.

In a TRS rulemaking initiated in June 2003, the FCC sought comment on whether TRS facilities should be part of the telecommunications service priority (TSP) program, which was created in 1988 as the regulatory framework to guide telecommunications carriers in repairing or providing new telecommunications services in the event of a disaster. The program was established to help reduce the potential chaos after a disaster when carriers may be overwhelmed with requests for repairs or new services. In accordance with the TSP rules, priorities are set for telecommunications services so that the carriers can determine which services to repair first. A service designated under the TSP program guarantees the of restoration of existing circuits or provision of new circuits before service is restored to non-TSP services. The TSP program is a voluntary program. As a general matter, “service users” may make a request that particular telecommunications services they rely on receive a priority assignment. These requests are directed to the office of priority telecommunications of DHS’s national communications system.

In a report and order (FCC 04-137) adopted June 10, 2004, the FCC encouraged TRS facilities to enroll all qualifying services in the TSP program, and agreed to sponsor such applications. The FCC believes that all appropriate steps should be taken to ensure that service to TRS facilities is made available in times of emergency, and that restoration of service to TRS facilities should occur, to the extent feasible, in tandem with restoration of dial tone service to the general public, thus ensuring that individuals with hearing or speech disabilities have service available on the same basis as individuals without such disabilities.

*Emergency Use Televisions with Screens Smaller Than 13 Inches.* Because of portability and energy requirements, most televisions selected for emergency use have screens smaller than 13 inches. The Television Decoder Circuitry Act of 1990 requires that all TV broadcast receivers with screens 13 inches or larger manufactured or imported after July 1, 1993, have the capability to receive and display closed captions.

The FCC’s rules track the statute’s 13-inches-or-greater requirement. For DTV sets, the requirement is as follows: All digital receivers with picture screens in the 4:3 aspect ratio measuring at least 13 inches diagonally, DTV receivers with picture screens in the 16:9 aspect ratio measuring 7.8 inches or larger vertically (this size corresponds to the vertical height of an

analog receiver with a 13 inch diagonal), and all DTV tuners, shipped in interstate commerce or manufactured in the United States, must comply with the minimum decoder requirements adopted by the commission in the July 2000 report and order that addressed digital captioning requirements (FCC 2004).

*Emergency E-Mail and Wireless Network.* This system lacks an emergency e-mail and wireless network (i.e., personal computers, pagers, cell phones, personal digital assistants, and test radios that caption the spoken word) that will inform people of local, regional, national, and international emergencies using the Internet and e-mail. Such a network could be effective if emergency agencies endorse and work with such a system.

The FCC says it is not clear what role the commission has in facilitating the availability of e-mail alerts. The FCC does not regulate the Internet. The FCC says it would be willing to review any concrete, written proposal about how emergency e-mail alerts fit under the FCC's authority.

*Cell Phone Compatibility with Hearing Aids.* Users of hearing aids and cochlear implants continue to experience compatibility and interference problems when using cell phones. On August 14, 2003, the FCC released a report and order that modified the exemption for wireless phones under the Hearing Aid Compatibility Act of 1988 to require that digital wireless phones be capable of being effectively used with hearing aids. The report and order requires digital phone manufacturers and service providers to take steps to reduce the amount of interference emitted from digital wireless phones and to provide the internal capability for telecoil coupling. On October 16, 2003, several interested parties filed petitions requesting that the commission reconsider and/or clarify various aspects of its decision. By public notice, the FCC's wireless telecommunications bureau sought comment on the issues raised in the petitions.

## **Part V. Conclusions and Recommendations**

While the new DHS is still in its formative stages, the opportunity is ripe for drawing on people with disabilities and activity limitations so that they can contribute to, participate in, and benefit from emergency planning, mitigation, preparedness, response, and recovery activities and services. When access for people with disabilities is designed and planned from the beginning, there is little extra cost. Attention to access and disability-specific needs contributes to a higher quality response for everybody when emergencies occur.

DHS leadership must continue to promote and model principles of nondiscrimination and inclusion by example in the behavior, speeches, meetings, planning, publications, and internal and external communications of its employees. These principles should include policy, practice, resources, research, and training—and viewing people with disabilities as contributors and collaborators, not just users.

The Federal Government’s decisions, the priorities it accords to civil rights, and the methods it adopts to ensure uniformity in the ways agencies handle their disability-related responsibilities are being established now. These efforts will continue to require sustained communication, coordination, cooperation, and collaboration with other government departments and agencies and particularly with private sector organizations. If these procedures and policies are not set on the right course at the outset, they will be much more difficult to add later.

Based on its research, NCD believes that the Federal Government needs to create and follow a clear roadmap that builds on its nascent homeland security, emergency preparedness, and disaster relief infrastructure as it relates to people with disabilities. Such a roadmap will need to rely on best practices in intergovernmental planning and communication. In addition, the Federal Government will benefit greatly from reviewing and adopting or adapting best practices of CBOs such as those described in this report. Finally, the Federal Government should consider the following key NCD recommendations in the development and implementation of its roadmap:

- DHS should establish a Disability Access Advisory Group made up of qualified people with disabilities and others with disability-specific disaster experience who meet regularly with officials to discuss issues and challenges.
- DHS's EP&R should integrate information on people with disabilities and activity limitations into general preparedness materials, and it should inform readers of those materials of how to gain access to more customized materials.
- DHS's CRCL should regularly issue guidance for state and local emergency planning departments reinforcing their legal obligation to comply with ADA and Sections 504 and 508 of the 1973 Rehabilitation Act in planning for, operating, and managing shelters and other disaster services.<sup>1</sup>
- DHS's CRCL should proactively conduct compliance reviews to identify weaknesses and problems in complying with ADA and Sections 504 and 508 of the 1973 Rehabilitation Act.
- The FCC should develop stronger enforcement mechanisms to ensure that video programming distributors, including broadcasters, cable operators, and satellite television services, comply with their obligation to make emergency information accessible to people with hearing and vision disabilities, and that violations are acted on immediately. The FCC also should be proactive on Section 255 hearing aid compatibility.
- DHS should develop and offer technical assistance and guidance materials for its grantees regarding their ADA and Section 504 legal obligations and compliance strategies.
- DHS should conduct proactive reviews of grant recipients' compliance or noncompliance with Section 504 and ADA.

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<sup>1</sup> The Department of Homeland Security states that "The Department of Justice (DOJ) is already handling this. In addition to the numerous settlement agreements that are a part of Project Civic Access, the DOJ has issued a technical assistance document to the state and local governments with this legal interpretation." See [www.usdoj.gov/crt/ada/emergencyprep.htm](http://www.usdoj.gov/crt/ada/emergencyprep.htm) (Dan Sutherland, e-mail communication of February 7, 2005).

- DHS’s CRCL and EP&R/FEMA should develop information systems that comprehensively collect, aggregate, and summarize detailed information about complaints or compliance reviews and their outcomes. This information should be made available to the public.<sup>2</sup>
- DHS should collect and analyze Section 504 and ADA program data (complaints or compliance reviews and their outcomes) for progress made, for deficiencies, for best practices, and for areas where DHS could provide coordination or technical assistance.
- To ensure the widest possible usage, PDF documents posted on all DHS Web sites should also be posted in an alternative accessible format.
- DHS should fund disability-specific initiatives.
- DHS should integrate disability-specific indicators into its proposal selection criteria.

NCD expects this report to contribute to America’s commitment to build a solid and resilient infrastructure that incorporates access to emergency programs and services and includes physical, program, communication, and technological access for people with disabilities and activity limitations. NCD acknowledges the good work that DHS has begun, as well as the work that the FCC has continued to engage in, and stands ready to assist in continuing this work so that the Federal Government can indeed serve and protect all.

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<sup>2</sup> “It would have been more accurate for the report to reflect, as we stated during the interview, that the data sought after by the [NCD] interviewers was not yet available because the office at that time was in existence for only a few months and, as we further pointed out, we were in the midst of instituting a case management system that allows CRCL to track the nature and progress of each complaint. Notably such a system has since been implemented and is now operational.” (Dan Sutherland, e-mail communication of February 7, 2005).



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# Appendix

## Mission of the National Council on Disability

### Overview and purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities regardless of the nature or significance of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

### Specific duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities in the Federal Government, at the state and local government levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services

within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.

- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

## **International**

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

## **Consumers served and current activities**

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became ADA. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that people with disabilities who are members of diverse cultures fully participate in society.

**Statutory history**

NCD was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.





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