Effective Emergency Management: Making Improvements for Communities and People with Disabilities



National Council on Disability August 12, 2009

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

Effective Emergency Management: Making Improvements for Communities and People with Disabilities

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

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National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

August 12, 2009

The President The White House Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit this report, entitled *Effective Emergency Management: Making Improvements for Communities and People with Disabilities.* NCD's purpose is to promote policies and practices that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and integration into all aspects of society. Under its congressional mandate, NCD is charged with the responsibility to gather information on the development and implementation of federal laws, policies, programs, and practices that affect people with disabilities. This report is a result of that mandate.

NCD has been interested and involved in emergency preparedness, disaster management, and recovery since 2003. NCD's first evaluation of federal government work in this area was published in April 2005 in the report *Saving Lives: Including People with Disabilities in Emergency Planning*. That report laid out a scenario of a major hurricane striking the Gulf Coast and outlined steps that the federal government should take to include people with disabilities in emergency preparedness, disaster relief, and homeland security. Hurricane Katrina struck four months later.

As a result of NCD's work, the 2006 Homeland Security Appropriations bill's Post-Katrina Emergency Management Reform Act (PKEMRA) (H.R. 5441) required FEMA to employ a National Disability Coordinator and to interact, consult, and coordinate with NCD on a list of eight other activities. These duties included interacting with stakeholders regarding emergency planning requirements and relief efforts in case of disaster; revising and updating guidelines for government disaster emergency preparedness; evaluating a national training program to implement the national preparedness goal; assessing the nation's prevention capabilities; identifying and sharing best practices; coordinating and maintaining a National Disaster Housing Strategy; developing accessibility guidelines for communications and programs in shelters and recovery centers; and helping all levels of government in the planning of evacuation facilities that house people with disabilities. Congress provided \$300,000 in the FY 2007 appropriations bill to enable NCD to fulfill our assigned duties under the PKEMRA. That funding has enabled us to complete this report.

Based on its ongoing policy and research work in the area of homeland security, NCD identified a major gap in the government's knowledge base. That gap involves the availability and use of effective practices for community preparedness and response to the needs of people with disabilities in all types of disasters. In 2008, NCD began to review the spectrum of available studies and defined a set of best and promising practices for emergency management across the life cycle of disasters (preparedness, response, recovery, mitigation) and geographic areas (urban to rural locations). In addition, NCD collected more information about promising practices from emergency management presentations, a public consultation, and public testimony received in writing and at Council meetings held throughout the country.

In this report, NCD offers information and advice to assist all levels of government in its work to establish evidence-based policies, programs, and practices across the life cycle of disasters. This report provides examples of effective community efforts with respect to people with disabilities, and evaluates many emergency preparedness, disaster relief, and homeland security program efforts deployed by both public and private sectors.

Our recommendations are based on scientific research and thorough review of policies and practices that have been tested in emergencies of all types throughout the country. It is our expectation that this report will promote a focused dialogue and communicate critical information to be used by those charged with protecting our nation's most vulnerable populations.

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 policies, programs, and practices for all Americans.

Sincerely,

An RUYA

John R. Vaughn 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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Executive Summary

The challenges faced by people with disabilities in disaster-threat situations have been made clear through events such as September 11, Hurricane Katrina, and the wildfires in Southern California. Specific problems with warning transmission and receipt, transportation, evacuation, shelter, and long-term recovery have been documented through research studies, and noted in Government Accountability Office reports, by the U.S. Congress and the White House, and by the National Council on Disability. Fortunately, the nation seems poised at a critical turning point, with greater determination than ever to move forward in reducing disasters and building capacities of those at risk. To support this trend, this report assesses scientific studies of preparedness, response, recovery, and mitigation efforts, and recommends practical, policy, and research initiatives that would maintain and expand this promising momentum. The report is divided into three segments:

- The Life Cycle of Comprehensive Emergency Management. Seven chapters review and discuss findings for a variety of hazards and the four main phases of emergency management activity: preparedness, response, recovery, and mitigation.
- *Emergency Managers and Voluntary Organizations*. The importance of connecting these two sets of resources is discussed, along with strategies to build capacities and leverage resources for people with disabilities in harm's way.
- Promising Practices. A final section outlines the implications of the empirical research assessment for the practice of disaster management for people with disabilities, identifies promising initiatives, reveals trends in policy and practice, and provides a comprehensive set of interventions for the present Administration as well as federal agencies, state and local government, and individuals.

Summary of Key Findings

NCD intends this report to be a compendium of knowledge about the challenges faced by people with disabilities in disaster situations. A lack of evidenced-based knowledge about how best to organize preparedness, response, and recovery efforts undermines efforts to reduce vulnerabilities. Consequently, what we know about the experiences of people with disabilities and disability organizations stems from a compilation of scientific studies, technical reports, after-action reports, and guidance documents. Many are of recent origin.

Preparedness efforts—including education and training, planning, designing warning systems, and evacuation protocols—is the area where most work has been conducted. Still, many emergency managers and people with disabilities remain unprepared for a disaster, in part because of the extra burden placed on minimal staff or the already difficult circumstances of many people with disabilities. Further, despite mandates to do so, most disaster planning occurs without the consultation or participation of people with disabilities or disability organizations. This report calls for greater inclusion of these key stakeholders in all types of preparedness efforts to push forward the necessary work that must be done.

Response remains problematic in part because of the clear lack of research validating best practices. This is especially troublesome for search and rescue of people with disabilities. When people with disabilities are remembered, such as with warnings, they are often grouped into one homogeneous population and provided with instructions that are not appropriately communicated or that are impossible to follow. Considerations for the special needs of residents in nursing homes, transportation for those who lack personal vehicles, search and rescue procedures that aid people with disabilities, and both general population and functional needs shelters that can accommodate disabilities are all issues that must continue to be addressed with the disability community and then put into practice by emergency management professionals.

Recovery is an area in which minimal research is available, particularly in the area of disabilities and disasters. Reports, testimony, and other evidence clearly suggest that recovery is drawn out and problematic for people with disabilities. Problems with securing accessible temporary housing, failure of insurance to cover disability-specific needs and gaps in federal assistance, loss of access to health care, and disruption to caregiver networks all undermine the abilities of people with disabilities to return home.

Mitigation efforts represent the single best strategy to reduce the impacts of disasters. Such measures may involve securing items within a household or construction of a large safe room. However, such efforts appear to be minimal at best across the nation. Efforts to redress this situation require the involvement of voluntary organizations to mitigate risk at the household level, as well as federal mandates to involve people with disabilities in mitigation planning, revision of guidance documents to increase accessibility in safe rooms, and funding to provide disability-specific mitigation measures.

Emergency managers and voluntary organizations often work side by side in a disaster context to provide relief and recovery assistance. Yet these same key resources often remain distant from people with disabilities and disability organizations. This report calls for greater connectedness among emergency management and the full range of voluntary organizations, including disability organizations, agencies, and advocates. Such collaboration can make a difference by leveraging collective resources to solve the problems faced by people with disabilities in a disaster situation.

Summary of Key Interventions

The assessment in this report culminates in a series of intervention strategies designed to reduce the impact of disasters for people with disabilities. A summary of those recommendations for the Obama Administration—as well as for federal, state, and local levels of government and individuals—follows. More detailed recommendations can be found in Chapter 11 (Interventions).

The Obama Administration

The Obama Administration agenda provides a number of compatible areas through which transformative change could occur. Key initiatives to launch such change include the following:

- Convening a Disabilities and Disasters White House Summit that includes government and nongovernment organizations, including disability organizations and leaders.
- Appointing and empowering a permanent staff position to handle only disabilityrelated matters inside the White House, including issues on disasters and disabilities.
- Funding capacity-building programs that tap community-based organizations linked to and actively involving people with disabilities in disaster preparedness, response, recovery, and mitigation activities.
- Involving disability organizations with expertise in disaster management in the President's Advisory Council for Faith-Based and Neighborhood Partnerships.
- Viewing the exclusion of disability issues in emergency management as a civil rights issue.
- Ensuring that health care remains available, accessible, and affordable after a disaster, including providing additional funds through Medicare Part D for lost medications and additional resources for health care support.
- Offering tax incentives for preparedness and mitigation measures at the household level as well as for businesses that significantly enhance their evacuation planning, signage, and procedures for customers and employees with disabilities.

President Obama's agenda also coincides with funding initiatives in the 2009 American Recovery and Reinvestment Act. Strategies to leverage that funding for disaster and disability issues could include the following:

- Funding affordable housing with more accessible features and mitigation measures, such as safe rooms.
- Strengthening America's infrastructure with accessible transportation features that increase evacuation options, as well as stronger levees and dams that mitigate risk for populations unable to evacuate easily.
- Applying homeland security and emergency management funds toward increased protection of people with disabilities, through funds for Public Transportation Security Assistance, Port Security, and Railroad Security Assistance. This might include evacuation planning, accessible seating and pathways, evacuation devices, warning systems for a diverse range of disabilities, and training of first responders in disability issues.
- Connecting reconstruction projects to efforts in schools that afford greater preparedness and mitigation of local hazards, including attention to state schools that support people with disabilities, as these are often key locations of postdisaster support for residents as well as for the larger community.

Federal Recommendations

- Continue strengthening efforts to enforce compliance with Federal Communications Commission (FCC) policies regarding emergency broadcasting to reach people with disabilities.
- Complete the Federal Emergency Management Agency (FEMA) Comprehensive Planning Guide (CPG) series—including 301 Special Needs and 302, which includes service animals—in sync with other CPG series guides.
- Hire disability coordinators at the FEMA regional offices.

- Fund research streams that push forward scientific evidence of best practices for disaster management and disabilities.
- Establish a national clearinghouse for disability and disaster information and resources organized to meet the needs of emergency managers and disability organizations.
- Involve disability organizations and people with disabilities in federal exercises, after-action reports, and federally funded recovery planning.
- Expand disaster recovery funding to cover disability issues, including health care disruption, loss of durable medical equipment and assistive devices, caregiver support expenses, service animals, transportation costs, and additional expenses arising from living in temporary housing.
- Revise FEMA guidance materials for safe room construction to include disability access; fund mitigation projects that target people with disabilities.
- Enhance accessibility features in federal buildings to strengthen evacuation planning, evacuation devices, and warning systems.

State-Level Interventions

- Task a state official with disability and disaster issues.
- Involve disability community organizations and state offices or agencies in all state efforts regarding natural hazards, terrorism, technological or hazardous materials concerns, and pandemic planning.
- Conduct disability training for first responders.
- Strengthen code requirements for public places, including alternative warning systems and signage.
- Conduct evacuation planning for all state offices, to include people with disabilities. Require exercises and debriefings that involve people with disabilities.
- Develop recovery plans before disaster strikes that address disability issues.

• Establish state task forces on disaster housing that are consistent with the new National Disaster Housing Strategy and that involve disability organizations.

Local-Level Interventions

- Local jurisdictions should create working groups to review and revise emergency operations plans, mitigation plans, and recovery plans to address the issues of people with disabilities. Special attention should be paid to warning systems, evacuation planning and other protective actions, shelters, and temporary housing.
- Cross-training on disability and disaster issues should be conducted among emergency managers, first responders, voluntary agencies, and disability agencies.
- Funding should be secured to launch preparedness and mitigation programs that address the safety of people with disabilities.

Individual-Level Interventions

- Accept personal responsibility for preparedness in a disaster context; where that is challenging, involve caregivers in such efforts.
- Create contingency plans for evacuation and other protective action, shelter life, medical care, and service animals. Purchase insurance, implement mitigation measures, and set aside personal funds to offset the impact of disaster.
- Be alert for warnings and actively seek information on recommended responses; be prepared to take action.
- Advocate for people with disabilities with local emergency managers.

Introduction

The challenges faced by persons with disabilities (physical, sensory, cognitive, psychiatric, etc.), seniors, and residents of low-income households (among which considerable overlap exists) in all disaster-threat situations have been made even more clear through events such as September 11, Hurricane Katrina, and the latest wildfires in Southern California. Problems with warning transmission and receipt, transportation, evacuation, shelter, and long-term recovery have been documented through both research studies and government investigations, as noted in several GAO reports, inquiries by the U.S. Congress and the White House, the National Council on Disability (NCD), and other organizations, such as the National Organization on Disability. Lack of planning and lack of inclusion of persons with disabilities and others with unique disaster-related needs for these issues remains a problem across the nation, despite recognition in Executive Order 13347, the Nationwide Plan Review, post-Katrina legislation, and U.S. Department of Justice Shelter Guidance, to list but a few.

Those who seek to address disaster-related vulnerabilities of persons with disabilities and build capacities of people at risk face a significant challenge because of a lack of evidence-based knowledge about how best to organize preparedness, response, and recovery efforts. Wading through the literature is problematic for those seeking guidance, because the evidence is scattered across multiple disciplines, buried in journals and reports, and often written in scientific jargon. The volume of material specifically pertaining to the disability population and to other groups within the traditional definition of "special needs," when deconstructed to the core, represents a fraction of the general research topics in the field of emergency management. Fortunately, this trend seems to be at a critical turning point, with greater recognition of disability and disaster issues, as well as increased determination to address those concerns and enhanced efforts to produce both empirical and practical materials.

This report is based on the available literature, including empirical research as well as practical guidance materials. It is divided into three main parts, all related to disability issues. The first part explains key terms and scenarios, and examines the life cycle of

comprehensive emergency management. This life cycle includes four phases: preparedness, response, recovery, and mitigation. The second section looks at strategies for working with emergency managers and maximizing the contributions of voluntary organizations. The third section reviews and summarizes policies, programs, initiatives, and trends; it culminates in a comprehensive set of interventions at the federal, state, local, and individual levels. Appendices provide supporting materials.

A list of terms and acronyms is presented so readers will understand definitions of key terminology and acronyms. Chapter 1 presents scenarios to sensitize readers to the contexts that need to be considered. A variety of scenarios are addressed, including rapid onset events, isolating circumstances (such as pandemics), power failures, and large-scale events. Geographic locations are considered as well, including rural settings, urban concentrations, the rural-urban interface (where wildfires present threats), as well as coastal and regional threats. Situational concerns include high-rise buildings, congregate care facilities, schools, adult day care centers, senior housing, and public housing. Types of disability and specific needs associated with certain conditions are discussed next, followed by a discussion of the implications of these varying and often overlapping scenarios.

Chapters 2 through 7 examine the empirical literature, technical reports, and guidance materials. Each chapter concludes with recommendations for policy, practice, and research. In Chapter 2, the topic of preparedness is presented. Coverage includes planning and the significance of participatory processes that involve people with disabilities as well as the legal ramifications of planning that is exclusionary. Preparedness also includes efforts to educate those at risk and to train those who respond to act in ways that are appropriate for people with disabilities. The importance of predesigning effective warning systems is also discussed, along with planning issues involving both slow and rapid onset events. Protective action issues are also examined, particularly those related to evacuation planning and sheltering in place. The preparedness chapter concludes with a presentation of useful educational and training tools. Additional materials are in the appendices.

The full range of the response cycle is assessed in Chapter 3, including problems involved in issuing warnings (e.g., providing accessible communications, problems with receipt, and socio-behavioral response). Disability-specific research on general warnings for people who are blind, deaf, hard-of-hearing, or living with mobility or cognitive disabilities reveal significant problem areas. Sections follow that address technologies and other tools used during the response period. Insights into disability-specific evacuation procedures are presented along with consideration of ADA requirements. Tools such as registries, buddy systems, and search and rescue techniques are discussed, along with concerns about the lack of empirical research to document best practices in these critical areas. Coverage of nursing homes is included, as well as a section on shelters. Additional material on shelters can be found in other chapters as well.

Chapter 4 moves into the recovery phase. While scant literature exists on disabilities and disasters in general, even less is available on the topic of recovery. This chapter addresses what is known empirically as well as areas of concern that are beginning to emerge through NCD quarterly meetings and other sources. Topics include issues with federal recovery assistance programs in areas ranging from coverage to accessibility. The process of accessing aid in general is presented, along with an overview of the traditional disaster case management process and how organizations address unmet needs. Capacity-building through involvement of people with disabilities and relevant organizations follows next. Coverage continues with recovery-specific issues that may influence the opportunities to recover fully, including exclusionary recovery planning efforts, debris removal, infrastructure, financial and business impacts, medical and mental health care disruptions, and housing issues (such as temporary trailers, health hazards, rental issues, problems with rebuilding for homeowners, and issues with public housing). New efforts in these areas undertaken since Hurricane Katrina conclude Chapter 4.

In Chapter 5, the important topic of mitigation is introduced. Again, scant evidence suggests that the mitigation phase is underaddressed when it comes to serving people

with disabilities. Anecdotal evidence suggests that mitigation certainly provides safeguards for the general public, including people with disabilities, but that some mitigation measures may fail to afford sufficient protection or be disability-specific. Disability-specific mitigation measures are certainly underfunded. Both structural and nonstructural mitigation measures are discussed. The importance of inclusive mitigation planning is emphasized, as is the need for funding that provides disability-specific mitigation measures. Building a more disaster-resilient disability community is the overall goal of the recommendations at the end of Chapter 5.

Chapter 6 addresses emergency managers and what they and disability organizations can do together to foster a more collaborative and productive disaster management relationship. The chapter walks a disability organization through the challenges facing emergency managers and offers suggestions on how to interface with emergency management agencies more effectively. Concrete suggestions for providing additional training and education for emergency managers complete the discussion. Appendix B directs the reader to additional resources.

Chapter 7 describes the contributions and value of voluntary organizations when it comes to emergency management, disability organizations, and people with disabilities. Effective disaster management involves voluntary organizations that can link resources to clients and support efforts to improve the circumstances of people with disabilities. This chapter offers examples and tools to accomplish exactly that by discussing the potential roles of faith-based, community-based, civic, and social service organizations. The value and importance of including people with disabilities as volunteers is a key principle of this chapter. Appendix B offers more information.

Chapters 8–10 weave the information from the empirical chapters into increasingly practical content. Chapter 8 summarizes the overall theme of previous chapters under the heading "Implications from the Research." The chapter organizes and presents the principles of best practices as related to the phases of preparedness, response, recovery, and mitigation as they could be practiced by emergency managers, disability organizations, and others. Chapter 9 (Initiatives in Progress) offers illustrations of

exemplary policies, programs, and practices already in place or recently under way and links them to the best practices principles. This chapter is a guide to the kinds of efforts for the four phases that could be modeled by others. Chapter 10 (Policy, Program, and Practice Trends) describes where the field of emergency management appears to be heading with regard to disabilities and disasters, with examples that provide insight into promising trends. In this chapter, it is clear that although much work remains to be done, much promise exists, and the nation is on the verge of pushing forward, with potential for significant change. To continue those trends and support the identified principles for best practices, Chapter 11 identifies interventions at the federal, state, local, and individual levels. This chapter lays out recommendations that have the potential to make the field of disaster management more inclusive and accessible.

The result is the first comprehensive assessment of what we know about disabilities across the life cycle of emergency management, coupled with principles identified for best practices and a set of transformative recommendations. The document contains many examples that can inspire those who seek to achieve greater protection and safety for all our citizens.

Key Terms and Acronyms

- Activities of daily living. Also called ADLs, this term encompasses eating, bathing, dressing, and other basic functions.
- ADA. Americans with Disabilities Act.
- Assisted living center. Allows for independent living with some degree of support as needed.
- **Assistive device.** Something that provides support or helps a person with a mobility impairment to be mobile, like a walker, or to complete tasks, such as a dressing stick.
- **Buddy/buddy system.** An individual or set of individuals who provide support to a person with a disability when it comes to warnings, evacuation, or other types of protective actions as needed.
- **Case management.** The process through which a client and case manager work to identify disaster recovery concerns and find solutions and resources.
- **CBOs.** Community-based organizations, often linked to specific populations. CBOs offer local insights and capacities that can be useful in disasters.
- **Civic organizations.** Community service groups, such as the Lions, that organize around particular concerns and can extend their expertise, time, and resources during a disaster.

Closed captioning. Broadcast messages that can be received with special equipment.

- **Cognitive disability.** A disability that may affect a person's ability to "listen, think, speak, read, write, do math, or follow instructions" (National Organization on Disability definition). See also *developmental disability* below.
- **Congregate care facility.** A facility where groups or larger numbers of residents or patients live, such as a nursing home.
- **Cross-training.** Efforts to teach organizations about each others' missions and capacities, such as linking emergency management agencies with disability organizations.
- **Debris.** Items left behind by a disaster; they may include hazardous materials and must be managed carefully to avoid contamination or exposure.
- DHS. Department of Homeland Security. Oversees FEMA.
- **Developmental disability.** A term that has broadened beyond cognitive development to include people who may not develop fully because of a disability.
- **Disability navigator.** An employee, usually at the state level, who helps people with disabilities find and apply for disability programs.

Disaster. An event that disrupts community functioning and social structures.

- **DME.** Durable medical equipment such as oxygen equipment, wheelchairs (manual and electric), catheters, walkers, and transfer boards.
- **DOJ.** U.S. Department of Justice.
- **DRC.** Disaster Recovery Center—a temporary center set up by FEMA to allow the public to access a wide range of services.

- **Education.** Courses and content typically offered through a college or university degree program.
- EMA. Emergency Management Agency. See also *emergency manager*.
- **Emergency manager.** An individual hired (or who may be working as a volunteer in some jurisdictions) to coordinate preparedness, response, recovery, and mitigation activities for local hazards.
- **Emergency shelter.** Shelter usually taken for a short period, such as in a vehicle, on a bridge, or in a temporary location. See also *general population shelter*, *temporary shelter*, and *special needs shelter*).
- EO. Executive Order from the Office of the President of the United States.
- **EOC.** Emergency Operations Center—a temporary center from which coordinated response activities are conducted.
- **ESF.** Emergency Support Function; a planning area within the National Response Framework. See also *NRF*.
- **ESF #14.** The NRF functional area that addresses recovery.
- **ESF #6.** The NRF functional area that addresses mass care, particularly with voluntary agencies.

Evacuation. Movement from an area of risk to an area of safety.

- **FBO.** Faith-based organization. FBOs are based on a specific faith but offer assistance to all.
- FCC. Federal Communications Commission.

FDC. Federal Disability Coordinator, a position within FEMA; sometimes referred to as NDC, National Disability Coordinator.

FEMA IS Series. FEMA's free, online independent study series of courses.

FEMA. Federal Emergency Management Agency.

FESHE. Fire and Emergency Services Higher Education initiative.

Functional needs. A management approach that focuses on functional areas that must be covered, such as evacuation assistance, communication, or medical support.

GAO. U.S. Government Accountability Office.

- **General population shelter.** An evacuation location set up for the general public; ADA and DOJ require these shelters to accommodate people with disabilities.
- **Higher Education Project**. A FEMA initiative designed to encourage the development of college and university courses and programs on the topic of emergency management.
- **HUD.** U.S. Department of Housing and Urban Development, which develops a National Housing Locator Database for disasters.
- **ILC.** Independent Living Center—a service organization that provides support to people who want to live independently; it can serve as a resource and advocate for clients.
- **Individual Assistance.** FEMA program that provides grants and funds for rental housing, reconstruction, temporary repairs, and other needed assistance.

- Interfaith. A coordinated effort among faith-based organizations that typically addresses unmet needs and can serve as a key resource. See also *long-term recovery committee*.
- JFO. Joint Field Office; set up by FEMA after a disaster to coordinate response efforts.
- **Katrina Aid Today.** A consortium designed to provide and encourage careful case management protocol for disaster survivors.
- **Knowledge transfer.** Efforts that attempt to move scientific research to practitioners or to share information among practitioners.
- Long-term recovery committee. An organization set up to coordinate voluntary agencies and address unmet needs; may also be called an interfaith or unmet needs committee.
- **Mass care.** Efforts to provide food, clothing, shelter, and basic medical support to those in need.

Mitigation. Activities/measures that reduce loss of life, injuries, and property damage.

- **Mitigation planning.** A community-based effort to identify hazards and prioritize nonstructural and structural risk-reduction measures.
- **Mobility disability.** This term encompasses people who use "wheelchairs, scooters, walkers, canes and other devices as aids to movement" (National Organization on Disability definition).
- **National Disaster Housing Strategy.** A FEMA plan for restoration of housing after a disaster event.
- NCD. National Council on Disability.

NDMS. National Disaster Medical System.

NIDRR. National Institute for Disability and Rehabilitation Research.

- **Nonstructural mitigation.** A less tangible measure, such as insurance or codes, that aims to reduce disaster threats.
- **NRF.** National Response Framework; the organizing plan for emergency response at the federal level.
- **NSF.** National Science Foundation.
- **NVOAD.** National Voluntary Organizations Active in Disaster; an umbrella organization under which many faith-based and community-based organizations provide coordinated disaster assistance to survivors.
- **Pandemic.** An illness that spreads rapidly and threatens the lives of significant numbers of people.
- **Paratransit.** Accessible vehicles for people with disabilities whose needs are not met by public or other transportation systems.

Permanent housing. A housing situation in which no further moves are necessary.

- **Planning.** An activity that develops a set of standard operating procedures designed to organize and direct activities during an emergency or disaster.
- **Preparedness.** Actions taken before an event to encourage proactive response during an emergency in order to save lives. Examples include education, outreach, planning, and exercises.
- **Rapid onset event.** An emergency that occurs with little warning, thus challenging abilities to respond and survive.

- **Recovery.** The process or series of steps or stages that someone moves through from the impact of disaster until restoration of key functions, which can involve housing, health care, work, transportation, and other critical areas.
- **Registry.** A list designed to identify those in need of support or evacuation assistance during an emergency.
- **Residential living.** A location where groups or larger numbers of residents are living with support, such as a group home for people with developmental disabilities.
- **Response.** "Actions taken a short period prior to, during, and after disaster impact to reduce casualties, damage, and disruption and to respond to the immediate needs of disaster victims" (Tierney, Lindell, and Perry 2001).
- **SBA.** The U.S. Small Business Administration. Individuals apply through SBA for a loan; if rejected, they may qualify for an individual assistance grant.
- **Sensory disability.** A person "with hearing or visual limitations, including total blindness or deafness" (National Organization on Disability definition).
- **Service animal.** An animal specially trained to provide support to a person with a disability.
- **Shelter in place.** A protective action strategy that requires minimal relocation and is typically used in a rapid onset event.
- **SNAP.** Special Needs Advisory Panel; a term used in some areas to designate a council or board that addresses disability concerns in relation to disasters.
- **Social service organizations.** Designed to provide specific kinds of assistance to a set of clients, such as housing assistance or unemployment services.

- **Special needs shelter.** Also referred to as functional or medical needs shelters, these locations provide specialized medical support. See also *general population shelter*, *emergency shelter*, and *temporary shelter*.
- **Structural mitigation.** A tangible, built feature, such as a levee or dam, that helps to reduce disaster threats.
- TDD. Telecommunication device for the deaf. See also TTY.
- **Temporary housing.** A location that allows an individual to return to carrying out basic functional needs, including cooking, sleeping, laundry, and other activities of daily living.
- **Temporary shelter.** A location set up by organized efforts and trained staff that remains open to provide food, shelter, and medical care. See also *general population shelter*, *emergency shelter*, and *special needs shelter*.

TOP-OFF. Top Officials; federal exercise for Homeland Security.

- **Training.** Courses and content typically offered in an agency or organizational setting that may involve certification or similar recognition.
- **TRS.** Telephone relay service.
- TTY. Teletypewriter. See also *TDD*.
- **Unmet needs committee.** Specifically addresses people who fall through the cracks of existing assistance programs. See also *long-term recovery committee*.
- **Unmet needs.** Term used to describe issues and concerns that have not or cannot be addressed by standard programs and efforts.

USFA. U.S. Fire Administration.
- VAL. Voluntary Agency Liaison; a FEMA staff member who connects voluntary agencies and leverages their capacities to address recovery needs (particularly unmet needs) of low-income households and families.
- VMAT. Veterinary Medical Assistance Team.
- **Voluntary organization.** Several types exist; see *FBO*, *CBO*, and *civic organizations* and *social service organizations*.
- **Volunteer.** An individual who, ideally, is trained and affiliated with an experienced disaster organization.
- **Warning.** A message sent to alert those at potential risk and designed to motivate them to take protective action.

CHAPTER 1: Scenarios

This chapter addresses a wide range of mass emergencies and disasters. Consideration is given to specific hazards that may have implications for people with disabilities, such as sudden onset events (e.g., wildfire, terrorist attack) or drawn-out, isolating events (e.g., influenza pandemic). The target population is persons with disabilities, but care is taken to acknowledge the *diversity* of disabilities and the range of independence in which persons with disabilities live, function, and contribute to society. This chapter identifies studies that address overlapping and complex situations. For example, a senior with a new disability living on Medicare may face challenges with securing resources to evacuate. Similarly, an employee with a mobility disability could face limited evacuation options from a high-rise office building. Or a congregate-care facility could house a diverse set of dependent patients and clients who would require diverse means for taking protective action. In short, it is not enough to simply think of accommodating a disability. Rather, it is necessary to understand the complexity of emergency situations facing a diverse range of people with disabilities, people of all ages and incomes. There is no one-size-fits-all approach to disaster management when considering disability issues.

This chapter examines various scenarios in order to understand the range of challenges and problems associated with protecting, responding to, and supporting people with disabilities. The chapter approaches these challenges by examining four conditions: (1) the hazard or disaster agent; (2) areas of geographic concern; (3) situational contexts; and (4) the complex, interacting nature of disabilities. To conclude the chapter, we suggest implications for the practice of emergency management and related professions as an introduction to subsequent chapters. The overall purpose of this chapter is to provide a context for the challenges of trying to protect people with disabilities and to pave the way for the chapters that follow, which address those challenges systematically.

Hazards/Disaster Agents

Throughout the field of emergency management, an all-hazards approach is generally recommended. Such an approach assumes that a general planning effort can be launched that applies across various types of hazards. For example, effective disaster management requires interorganizational coordination and communication regardless of whether the event stems from natural (e.g., flood, hurricane), technological (e.g., chemical spill, nuclear plant accident), or terrorist origins. Most events demand the dissemination of some type of warning to the general public, which is usually handled through various forms of technology (e.g., sirens, reverse 9-1-1) and media outlets. Search and rescue activities are initiated, in which first responders step into anticipated and familiar roles. Short-term recovery efforts involve broader sets of partners, such as utility companies; these efforts can be prearranged through mutual aid agreements and standard operating procedures or SOPs (e.g., prioritization for hospitals, then residences). For most scenarios, it is assumed that planning can encompass all hazards through the creation of a basic Emergency Operations Plan (EOP), with annexes for specific hazards and/or events. Annexes may include, for example, specific terrorism plans (e.g., anthrax procedures, water contamination) or functional areas such as handling donations or managing volunteers. Yet rarely are the concerns of people with disabilities embedded into EOPs, SOPs, or even annexes without specific legal mandates.

Although it is possible to develop an EOP that integrates planning for people with disabilities into SOPs using an all-hazards approach, doing so requires an understanding of how particular hazards or disaster agents may affect the abilities of people with disabilities, and how agencies and organizations can provide adequate protection. What arises from the scientific body of knowledge and from an examination of practices in operation, however, is that even the typically appropriate all-hazards approach may not always work when it comes to people with disabilities. Nursing homes, for example, report considerable communication problems in disaster situations (Saliba, Buchanan, and Kingston 2004), suggesting that they lack appropriate resources and are outside the local emergency management partnership. And, although the all-hazards approach generally offers a streamlined approach to dealing with most mass

emergencies and disasters, it is true that some types of hazards represent heightened areas of concern for people with disabilities. Consider these scenarios:

- Rapid onset events. Although warnings continue to improve, there are significant concerns about rapid onset events, especially for people with disabilities, who may require additional time to shelter in place or evacuate to a safer location. A tornado may occur with little warning, especially during supercell thunderstorms that escalate and de-escalate within minutes. Wildfires travel at incredible rates, even overrunning experienced firefighters. And existing warning systems may be inadequate for rapid onset events, such as sirens that cannot be heard during high-wind events.
- Isolating events. Several types of events can produce isolating conditions that prevent first responders and emergency managers from reaching people with disabilities, in addition to preventing those at risk from reaching safe shelter. A pandemic is one such condition, an event that could specify quarantine as an appropriate countermeasure. Other potentially isolating events are biological, chemical, or nuclear accidents or attacks. Hazardous materials spills that require sheltering in place also prevent rescue and require accessible resources that can be used for protective action.
- Power failure events. Many people with disabilities need electricity to power durable medical equipment (DME), support oxygen, and maintain cool temperatures for medicines. Blackouts and storms (e.g., ice, tornadoes, and hurricanes) as well as earthquakes that destroy infrastructure undermine the abilities of those at risk to survive. Individuals who live in residential areas are among those who could potentially be affected by such an event; individuals who live in congregate facilities (nursing homes, hospitals, assisted living centers, residential schools) are just as vulnerable, and an event may affect large numbers in these facilities. Coupled with other conditions, such as the situational circumstances mentioned below, an event could potentially put thousands of lives at risk.

- Large-scale events. As witnessed during Hurricanes Katrina and Rita, and during terrorist events, evacuation of those at risk can strain resources. Sufficient and appropriate vehicles might not be available. Laws and procedures might allow facility administrators to make site-specific decisions with deadly consequences. Traffic flow patterns might impede exiting. Individuals who rely on buddy systems to evacuate might find their plans disrupted if that person is not available or simply forgets. Shelters might not be ready to receive people with disabilities or those at risk might not believe shelters are ready; both conditions can deter evacuation by those at risk (van Willigen et al. 2002). Minimal research has been conducted to date on disaster recovery, and none of it is specific to people with disabilities. However, organizational reports indicate that, for example, the goal of returning home to areas devastated by the Katrina storm surge in 2005 may be impossible for some people with disabilities.
- No event is "safe." Although these general types of events represent particular concerns that bear increased attention, any event can affect people with disabilities in times of disaster. It should not be assumed that only the events mentioned here should be considered.

Areas of Geographic Concern

Some hazards occur repetitively in certain areas more than others. Coastal areas bear the burden of hurricanes and tropical storms, while the plains states suffer from rapid onset tornado activity. Winter snowstorms isolate households in the northern and mountainous parts of the country, while ice storms may incapacitate entire cities, even in southern states. Some geographic areas bear up well given their experiences with hazards, while others suffer through unexpected or unplanned-for events. What is common though, is a clear need to improve emergency preparedness efforts with and for people with disabilities. Although each state and local emergency management agency bears responsibility for conducting hazard assessments and initiating appropriate planning, it is worthwhile to briefly examine some general areas that represent geographic concerns.

- Isolated rural locations. All states, tribal areas, and U.S. territories include rural, potentially isolating locations. Rural areas may fail to prepare adequately; this is usually due to a lack of resources and experienced personnel. Indeed, many rural areas rely solely on volunteer departments and coordinators or on personnel who are fairly new to the field of emergency management. The addition of staff, including those with expertise relevant to people with disabilities, may not be an option. Consequently, emergency management efforts may not expand much beyond a basic state of planning and preparedness. Beyond the initial phase of preparedness, the phases of response, recovery, and mitigation may be logistically and realistically difficult to undertake. In such conditions, mutual aid agreements may be the main source of resources and expertise, although some states may access these at considerable distances.
- **Urban concentrations.** Urban populations present particular challenges because of the sheer numbers of people. After Hurricane Katrina, for example, it was clear that many seniors, people with disabilities, and caregivers could not evacuate from New Orleans and other impacted areas. It is also clear that increased numbers of people with disabilities may mean that a number of people simply do not get the warning messages. Stories of people with sensory, mobility, and cognitive disabilities who were unable to leave their residences or who were surprised by the magnitude and intensity of the storm were common. Because of a lack of transportation, failure to send transportation, and perhaps unwillingness to evacuate to unfamiliar shelters and locations (which may not be able to support a particular need), many people died. According to the Centers for Disease Control and Prevention, 60 percent of those who died were senior citizens, and the Kaiser Foundation reports that many caregivers remained behind to help those with mobility issues. The same is true of other hazards; for example, a major power outage that lasts for hours or days at a time can seriously disrupt necessary support, including oxygen supplies and power for durable medical equipment. Large concentrations of people with disabilities may mean that available resources cannot keep up with life-saving measures.

- Coastal areas. Coastal areas bear a disproportionate risk for tropical storms. These areas also tend to draw those who may be more at risk, including senior citizens, who often live either part of the year or permanently in warm climates. Because the prevalence of disabilities increases with age, coastal areas are a particular area of concern (Heinz Center 2002). Some of those areas, such as the entire State of Florida, do a good job in evacuating and responding to vulnerable populations, while others clearly require additional effort. The West Coast hosts populations at risk for a significant earthquake event. People with disabilities may experience particular difficulty in such events because of objects falling and blocking pathways or causing injuries (Rahimi 1993).
- Urban/rural interface. As noted in recent reports (e.g., California State Independent Living Center 2004), people with disabilities may not fare well in wildfires. Such events may allow for some evacuation time, but they can also be rapid onset events, in which evacuation is difficult. Because of the increasing encroachment of human populations on the urban/rural interface, it is anticipated that wildfire threats will continue to grow. Efforts to control risks associated with wildfires have been increasing as well, although these initiatives have not necessarily been applied to or conducted in concert with the needs of people with disabilities. Even when they are coupled with typical preparedness measures, such as special needs registries, efforts to evacuate people with disabilities have failed in wildfire scenarios (California State Independent Living Council 2004).
- Regional concerns. Sometime in the next several decades, large-scale earthquake events are anticipated to occur on the West Coast (e.g., San Andreas and/or Hayward Faults) and in the middle part of the nation (e.g., New Madrid Fault). While the West Coast has been preparing for such events for some time, the middle part of the nation appears to be less well-prepared. For example, California buildings, infrastructure, and utilities have benefited from varying degrees of mitigation measures, including retrofitting of residential and commercial properties. Further, emergency planning has been conducted extensively in California, but some states face potentially catastrophic impacts if the New Madrid earthquake strikes an area where retrofitting efforts have not

been made. Areas at risk might include Memphis or St. Louis (Shinozuka, Rose, and Eguchi 1998). The unevenness of emergency preparedness in the face of these risks is a particular area of concern for people with disabilities and for the emergency management community in general.

• No area is immune. As these brief scenarios demonstrate, certain geographic locations represent particularly challenging issues for protecting people with disabilities. Understanding that some specific areas bear repetitive risks is a good starting point to understand how vulnerability develops. However, it is clear that no geographic area is immune from hazards. Unexpected events occur routinely as well. For example, terrorism can strike anywhere and in any form. In 2007, a tornado damaged Brooklyn, New York—an event that had not occurred for over 100 years; a rare February tornado killed nine people in Oklahoma in 2009. Floods are the single most common hazard in the United States, but a "100-year flood" might not occur for 300 years or it could happen twice in one month, as it did in Grand Forks, North Dakota, in 1997. The lesson to be learned is the importance of preparing all communities in all locations, but with comprehensive coverage for geographic areas that include significant risk.

Situational Concerns

Vulnerability to disasters and mass emergencies can stem from physical location. People are not stationary. They travel from home to work to recreational spots, where they may face very different situations for taking protective action. These situational concerns may include the following:

 High-rise buildings. As first responders well know, any building over seven stories tall is difficult to evacuate. Ladders do not reach that high, and alternative escape devices are not common and, for the most part, are untested. For people with disabilities on any floor, an emergency plan may be "go to the designated area and wait for assistance." High-rise buildings are one of the single most challenging locations requiring a high level of commitment for preparedness, response, and mitigation efforts. Both residential buildings and commercial structures require special attention. A number of studies simulating such evacuations are under way and should be followed in the coming years (Christensen, Blair, and Holt 2007).

- Congregate care. Assisted living facilities, nursing homes, and similar locations proved seriously unprepared during the 2005 hurricane season. Even in areas that used evacuation resources, critical problems occurred, including injuries, emotional distress, inadequate staffing, loss of medical records, disruption to medical care, loss of caregivers and social networks, lack of appropriate reception shelters, and even the deaths of dozens of nursing home residents evacuating prior to Hurricane Rita. Because the administrators of such facilities typically make the decision to evacuate, evacuation may be delayed because of a lack of resources or staff, communication issues, lack of understanding, unavailability of beds at a comparable facility, utility failures (e.g., see Fernandez et al. 2002; Saliba, Buchanan, and Kingston 2004), or negligence.
- Schools. Several types of school systems are areas of concern. In general, school systems are tasked with ensuring the safety of their students. However, many institutions (including those in higher education) conduct only the most routine kinds of preparedness efforts, such as fire drills. Specific directions on how to support students with disabilities do not appear to be part of routine protocols across most institutions. School systems that support students who are blind or deaf, or have a cognitive disability require considerably more planning; yet, scant attention has been paid to such collective locations, the nature of their planning, the amount of staff available to provide adequate support during an emergency, the nature of the training offered to staff and students, or how well that training works in an actual event.
- Adult day care. Only recently have day care centers become a focus of attention for mass preparedness, and the focus is primarily on centers for young children. Adult day care centers for people with Alzheimer's and other cognitive disabilities

are off the radar for many emergency management agencies, especially those with limited staff and expertise.

- Senior housing. Elderly residents may live in several types of housing. Housing designed specifically for seniors may be one of the areas most open to emergency preparedness, in part because such locations are linked to various service providers. However, service providers supporting the elderly (such as home health care agencies) may not be well linked to the emergency management community. Further, it is not clear to what extent those responsible for senior housing should provide preparedness information other than the requisite smoke alarm. Since the 2005 hurricanes, a number of workshops and seminars have been held across the country to address emergency preparedness at nursing homes. Unfortunately, most of the workshops held to date do not seem to incorporate senior housing where concentrations of elders with disabilities may be living. As another example of the diversity of senior housing, naturally occurring retirement communities (NORCs) also require attention.
- Public housing. Public housing provides affordable living options. Sadly, this type of housing also appears to suffer considerable damage in times of disaster, perhaps because such housing in many locations is older. While the U.S. Department of Housing and Urban Development (HUD) in recent years has labored to secure postdisaster housing vouchers and to assist with relocations, these activities may remove people with disabilities from familiar locations and from the service providers and social networks necessary to maintain their activities of daily living (ADLs), especially during an emergency event. The extensive damage to public housing and the controversial decision to alter that environment to a mixed-income area may undermine efforts to establish more affordable housing. No research has been conducted on the role of public housing when it comes to people with disabilities and disaster events.
- No place is immune. The previous examples describe where people might be during an emergency, but it is important to remember that people travel during the day and might also be on public transportation, in shopping malls, at work, or

in other locations, such as the doctor's office. Consequently, it would not be appropriate to focus exclusively on residential situations and omit other locations. Recent lawsuits, for example, have prompted reconsideration of evacuation procedures at shopping malls and football stadiums.

Type of Disability

The National Organization on Disability (NOD) identifies three types of disabilities of concern for emergencies and disasters: sensory, mobility, and cognitive. This report uses the NOD definitions given below (<u>www.nod.org</u>, see Emergency Preparedness Initiative):

- Mobility. This term refers "primarily to persons who have little or no use of their legs or arms. They generally use wheelchairs, scooters, walkers, canes, and other devices as aids to movement." Concerns for people with mobility disabilities might include:
 - Sheltering expeditiously for a rapid onset event, such as a chemical spill.
 - Losing durable medical equipment during an evacuation.
 - Returning home from a shelter over debris-covered roads.
 - Tearing out damaged wallboard, carpeting, and the like from the effects of floodwaters.
 - Reoccupying a home before it has been cleared of items shaken loose by an earthquake.
 - Returning home at all to a structure in the floodplain and consequently being forced to relocate or enter a congregate care facility, leading to a loss of independence.
- **Sensory.** This term refers to "persons with hearing or visual limitations, including total blindness or deafness." Particular concerns that might arise for someone with a sensory disability could include the following:

- Being able to read educational and training materials on emergency preparedness that were developed in a format that is not accessible; FEMA materials, for example, while available online, are unusable for many people with sensory disabilities.
- Hearing warning messages or seeing the area of concern on televised weather maps.
- Understanding what the meteorologist is saying if he or she turns his or her back or fails to offer closed-captioned information.
- Navigational and other challenges in shelters and in temporary housing.
- Being among the last to learn of recovery programs and resources that fail to disseminate information in accessible formats.
- **Developmental/cognitive.** The terms "developmental" and "cognitive" most commonly include conditions that may affect a person's ability to listen, think, speak, read, write, do math, or follow instructions. Concerns that may arise for people with developmental or cognitive disabilities include the following:
 - Difficulty understanding instructions, including those that vary from source to source.
 - Fear of a first responder or other person with whom the individual is unfamiliar.
 - Isolation in a shelter environment if separated from a family member, friend, or caretaker.
 - Confusion over how to use a given prophylactic, for example, in a pandemic.
 - Having an official assume that the individual does not understand procedures or messages when in fact he or she does.
 - Lack of access to needed resources because of a location's failure to provide ADA-specified accommodations.
- Intersecting disabilities. Although the NOD materials focus on separate circumstances, it is important to remember and understand that disabilities often intersect and overlap. An individual may, for example, have both mobility and

sensory disabilities. Coupled with issues of income, age, gender, and culture, the goal of ensuring safety in the context of disaster becomes increasingly complex. Accordingly, it is not appropriate to think of preparing just for a person who uses a walker. Realistically, one must think in terms of where people are located in their life circumstances. For example, is the person a hard of hearing senior citizen with a low income, living alone in senior housing? It is easy to understand that such an individual would find it difficult to shutter a home against an impending hurricane, to receive warning of a rapid onset tornado, or to afford any means of evacuation other than that provided by the broader community. In addition, stockpiling extra food, water, and emergency supplies is probably out of the question because of the person's limited income.

Disabled does not mean incapacitated. As the emergency management community continues to progress toward better support and inclusion of people with disabilities, it is important to bear in mind that vulnerable populations do not necessarily lack capacity. Stereotypes and assumptions among the broader public, including those in positions responsible for life safety, remain prevalent: people with disabilities must be taken care of, protected, and looked after. However, as a number of studies in the following chapters will document, people with disabilities also bring tremendous capacities, insights, and resources to those involved in the businesses of safeguarding the public. This document, accordingly, travels the path that both acknowledges risk and affirms capability.

Implications for the Practice of Emergency Management

As this chapter demonstrates, understanding vulnerability is complex. It is not sufficient or appropriate to simply state that people with disabilities are "at risk." For the practice of emergency management and others involved in trying to accord a higher degree of public safety, the implications are immense and challenging. One study, for example, discovered that only 20 percent of all emergency managers included content on disabilities in their EOPs (Fox et al. 2007). As noted earlier, officials in certain areas and regions of the country face considerable obstacles. In rural areas, staff members are more likely to lack expertise and resources for even basic efforts, often relying on the willingness of volunteers to aid their efforts. Urban areas could be overwhelmed by the sheer number of people they seek to serve. Coastal areas face annual, slower onset events, whereas plains states typically brace in March for rapid onset tornado outbreaks. Each scenario requires different kinds of attention to the needs of people with disabilities.

Understanding risk starts with examining the many places and points at which vulnerabilities intersect, then targeting those areas using good science and effective practices. Empirical scientific work on this topic is limited, although it has been improving. The purpose of this report is to identify and systematically work through that body of scientific knowledge, to assess current practices and make some basic recommendations for research, practices, and policies in a chapter-by-chapter review. Toward that end, the chapters are organized around what is called the Comprehensive Emergency Management Framework (National Governor's Association 1979):

- Chapter 2: Preparedness. Preparedness includes actions taken to reduce injuries, deaths, and property loss before disaster strikes; it can include planning, training, education, drills and exercises, and designing warnings/communication systems. Content in this chapter reviews the literature that addresses these topics.
- **Chapter 3: Response.** Response activities include those that reduce the risk to lives and property through direct action while an event is under way. Accordingly, this chapter examines evacuation, search and rescue, transportation, sheltering, and concerns regarding residences and workplaces.
- Chapter 4: Recovery. Recovery is defined in many ways, including return to normalcy, reconstruction, rehabilitation, and even restitution. In this report, we focus on enabling displaced people to return home. Both short-term and long-term recovery periods are examined. Short-term includes restoration of utilities, road clearing, and movement from shelter into temporary housing (if and as needed). Permanent housing challenges will be examined, as well as

employment and workplace concerns. Issues related to the return home including those of mobility, transportation, health care, and social and support services—will be covered.

• **Chapter 5: Mitigation.** Structural mitigation measures include those that are built into the surrounding environment, including levees, seawalls, safe rooms, and even fire alarms. Structural mitigation measures include nontangible measures that also make a difference, such as insurance, zoning, ordinances, and even self-help groups. Mitigation measures have the potential to afford greater safety but may also unintentionally change the recovery pattern of people with disabilities. For example, along the Gulf Coast, elevations to safeguard lives from a storm surge mean that people with disabilities cannot easily return home.

CHAPTER 2: Preparedness

Introduction

This chapter provides an overview of relevant scientific literature and technical reports on the life cycle of emergency management, including preparedness, response, recovery, and mitigation. Scant scientific evidence exists to provide crucially needed guidance at this point, beyond pointing out gaps in our knowledge and problem areas, and suggesting general solutions. Technical reports offer anecdotal evidence that may be disaster-specific and difficult to translate across varying jurisdictions. To remedy this situation, this report documents what is known and what is believed to work, elucidating principles for best practices and possible interventions. Each chapter, starting with this one, offers recommendations to transform research, practice, and policy to push forward an agenda of safety for people with disabilities who may be in harm's way.

The preparedness phase of emergency management is a cyclical process that focuses on proactive behaviors and actions aimed at lessening the impact of a disaster. McLoughlin (1985) suggests that preparedness encourages the development of emergency response capabilities on several fronts (p. 166). This development should take place at the individual, organizational, community, and state/federal levels. In fact, the Federal Emergency Management Agency (FEMA) IS-1 tool kit suggests that preparedness allows us to offset the complexity of most disasters, including those that are known for their rapid onset, by determining our actions beforehand (FEMA 2007, p. 4-1). These actions include establishing authorities and responsibilities for emergency actions, accumulating the resources to support them, and developing plans to link these areas so that emergency preparedness plans flow seamlessly (FEMA 2007, pp. 4-1 & 4-2).

Preparedness efforts, which range from educating the public to planning comprehensively across a variety of organizations and issues, offer the potential to dramatically reduce the impacts of disaster on people with disabilities.

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 its staff, most of whom have limited or no vision. The Associated Blind wanted a plan for staff members that covered the range of problems that could occur during a disaster. On September 11, 2001, their efforts paid off. The entire staff calmly and safely evacuated the building's ninth floor, a success they attribute directly to customized advance planning and drills. (National Organization on Disability 2005)

Tierney and colleagues (2001, p. 5) offer the following thoughts on preparedness:

Emergency preparedness encompasses actions undertaken before a disaster that enable social units to respond actively when disaster does strike. Organizational preparedness activities include developing emergency response plans; training employees and response personnel on what to do in an emergency situation; acquiring needed equipment, supplies, and materials; and conducting drills and exercises. Household preparedness activities include developing an emergency plan for the household, storing food and water, making sure there is a battery-powered radio on hand, and taking other steps to anticipate whatever problems a disaster might create.

Ultimately, everyone, including people with disabilities, is personally responsible for his or her own safety and must prepare actively for a disaster. This may be difficult. To illustrate, people must use discretionary income to pay for emergency kits, transportation costs for evacuation, temporary shelter expenses, and recovery needs. However, because incomes for people with disabilities fall below the national norms, it may be a hardship to keep extra food and water on hand. Further, disasters preparedness often ranks low in most people's priorities (Tierney et al. 2001, p. 44). For people with

disabilities, preparedness may be yet another task in a long list of needs that must be met. Furthermore, many people with disabilities are routinely excluded from the preparedness process, particularly planning efforts, exercises, and drills.

However, many people with disabilities are fully capable of responding in an appropriate manner if alert systems are put in place to warn them during times of crisis or if a disaster is expected to occur. Such systems can also help them take protective action, evacuate, shelter, and recover. However, some people with disabilities may be physically unable to respond during disaster situations because of a variety of barriers. These individuals could include quadriplegics, people with Alzheimer's, or children with cognitive disorders, to name a few. Those who fall into this category must overcome extraordinary barriers just to accomplish ADLs (usually with assistance) and may experience life-threatening challenges if they are not assisted during disasters. Thus, emergency management, disability, and other advocacy organizations and communities have a moral obligation to specifically include people with disabilities in emergency plans for their organizations and communities. If organizations and agencies ensure that people with disabilities receive adequate instruction and assistance in creating personal preparedness plans, the overall impact on their organizations and capacities is reduced. In short, preparedness requires attention to people with disabilities to build individual capacity and the ability of organizations to respond.

Summary of Key Findings

While a number of documents provide recommendations for working with people with disabilities on disaster preparedness, very few sources actually show evidence of having implemented or evaluated these strategies. Furthermore, people with disabilities are often grouped together as a unit in disaster preparedness recommendations, which does not account for the differences that exist between disabilities or the range of issues that emergency managers must prepare for to successfully respond to a diverse population in a disaster. Although a number of promising preparedness efforts have emerged in recent years, much remains to be done. Executive Order 13347 recommends the inclusion of people with disabilities in planning and exercises.

Recently, a DHS TOP-OFF exercise included consideration of disability issues. Examples of pending documents include FEMA's *Comprehensive Preparedness Guide 301* on special needs planning and *Guide 302*, which includes content on service animals. Both are currently in draft or development status. FEMA recently released its National Disaster Housing Strategy, which calls for national and state efforts to plan for accessible disaster housing. A wide range of educational preparedness materials exists, but dissemination appears to be limited primarily to disaster organizations, when it is disability and other service organizations that are best positioned to distribute these materials. A few exceptions to this trend exist, such as efforts that involve independent living centers in education and training. Consideration of the literature—including scientific studies, technical reports, and guidance documents—indicates that while much remains to be done, the spirit of willingness to take action seems to be at a higher level than in the past.

Review of Scientific Literature and Technical Reports

While technical reports are increasing in number, the scientific literature on emergency preparedness for people with disabilities is still quite sparse. In scientific studies and technical reports, recommendations are often made about what should be done; however, few articles describe how to apply their recommendations on a large scale. This leaves emergency planners and organizations throughout the nation with a list of suggestions and no concrete plan for implementing them.

In the pages that follow, this report addresses particular areas of concern, including planning, education, training, warning systems, and protective action.

This review also notes a gap between researchers and practitioners in the area of working with people with disabilities on emergency preparedness. Although some research is being conducted in this area and some recommendations have been made, many of the suggestions do not provide practitioners with specifics on how to put these proposals into place. If this gap is not bridged, frustration will continue to grow on both sides, and people with disabilities will remain underserved and in harm's way during times of disaster.

Preparedness in General

People receive constant reminders of the importance of preparing for a fire. Almost everyone knows someone who has been affected by a fire and understands that the same thing could happen to them at home or in the workplace. However, the same is not true for catastrophic events like Hurricane Katrina. While people understand the significance of such a major event, various factors may lead an individual or household to defer action. These factors may include income issues, abilities, resources, lack of experience, or even the belief that such an event is not likely to happen again. A Harris Poll in 2001 revealed that 61 percent of people with disabilities have not developed a home emergency evacuation plan (NOD 2001). Tierney and colleagues (2001) argue that the low salience of disasters in people's lives is one of the "most significant impediments to enhancing emergency preparedness" at the individual level (p. 29). They suggest three conditions that might act as a catalyst to encourage disaster preparedness:

- There is a high near-term threat of disaster. Households appear reluctant to prepare when they believe the near-term probability of an event is low.
- A credible source is disseminating the hazard and preparedness information.
- Preparedness information is given repeatedly, through multiple channels, and in a form that is easy to remember and use (Tierney et al. 2001, p. 43).

Additionally, preparedness behavior is based on personal hazard knowledge, perceived responsibility for taking action, and perceptions about correct preparedness activities (Tierney et al. 2001, p. 45). Using these criteria, individuals with disabilities might be most open to preparedness messages that come from credible sources within trusted networks, such as disability organizations, workplaces, professional associations, faith communities, or personal social networks. Using a wide set of conduits to reach people with disabilities would thus be advisable.

On the organizational level, Waugh (1988) identified five general impediments to preparedness programs:

- Overall intractability of the disaster problem.
- Lack of clear and measurable performance objectives.
- Insufficient resources.
- Inadequate levels of support.
- Inadequate guidance and expertise from higher levels of government.

These types of problems plague many jurisdictions. Particular problems include lack of staffing, expertise, time, and resources. Many local jurisdictions in particular struggle to engage in general preparedness efforts and planning.

Planning

Planning is possibly the most important, albeit the most difficult, stage in the emergency management process. This is due, in part, to the unpredictable nature of disasters, including natural and technological disasters, and bioterrorism. Although some disasters allow plenty of time to execute emergency plans, others do not. The unexpectedness that accompanies these sudden onset disasters necessitates a quick response from those in its path. According to McLoughlin (1985), the ability to take "prompt and effective action" during a disaster is grounded in the planning process (p. 169). This implies that a sense of urgency must be built in to preparedness activities. Thus, the planning process must work in a holistic manner while anticipating potential rapid onset situations. McEntire (2001) describes the holistic mindset as one that considers "multiple causal sources, catalytic processes and the compound interaction of physical, built, technological and social systems" (p. 190). In layman's terms, the holistic approach demands that we consider both the event and its effect on all sectors of society, especially vulnerable populations. Emergency plans addressing preparedness for catastrophic events are less commonly developed than plans for higher probability hazards, like fires, for example (Parr 1987, p. 151).

According to Parr, people with disabilities are often a "neglected minority" during the development of disaster plans (Parr 1987, p. 148). Instead of including people with disabilities in the planning process, emergency planners often rely on traditional assumptions about the needs of this group. However, these assumed needs might not be the same as the actual needs of people with disabilities. The 2003 Southern California wildfires reaffirmed Parr's claim, and the events surrounding these fires underscored the fact that this exclusionary practice continues (California State Independent Living Council 2004, p. 3).

The problem may be systemic and rooted in organizational challenges. As noted in a study of 30 disaster sites (Fox et al. 2007), "people with disabilities were poorly represented in emergency planning" and only 27 percent of emergency managers had completed available training on disabilities (p. 196). Fully 66 percent of the counties had "no intention of modifying their guidelines to accommodate the needs of persons with mobility impairments" because of problems stemming from costs, available staff, awareness, and other concerns (Fox et al. 2007, p. 196). This conundrum challenges emergency management organizations as well as people with disabilities and disability organizations.

The needs of people with disabilities must be included in emergency plan development. Otherwise, as Litman (2006, p. 14) argues, emergency planners may appear insensitive to people with disabilities and thus lack credibility. The solution is likely to be embedded in a partnership approach to preparedness efforts and joint planning with emergency managers and disability organizations both at the planning table. Bringing such expertise from disability organizations into the planning process is likely to result in more sophisticated and realistic planning.

The generic, one-size-fits-all approach to disaster planning does not work. Each type of disability presents its own unique set of barriers during disasters. For example, people with hearing disabilities may not receive weather warnings that broadcast only over audible technologies. Wood and Weisman (2003) argue that multiple avenues of communication are necessary to close this gap in the warning system for people with hearing disabilities. Another example would be the difficulty people with mobility

disabilities experience negotiating the stairs of a fire escape during evacuation. Emergency planners must construct solutions that enable people with disabilities to overcome these barriers (Loy and Batiste 2004; Parr 1987). In Executive Order 13347: Individuals with Disabilities in Emergency Preparedness (HHS 2005), President Bush called for emergency managers to "consider, in their emergency preparedness planning, the unique needs of agency employees with disabilities and individuals with disabilities whom the agency serves" (Executive Order 13347, para. 3). Indeed, addressing barriers created by the "unique needs" of people with disabilities, rather than focusing narrowly on the disability itself, can serve to better protect all people during times of disaster. Children, seniors, and people with disabilities all benefit from a fuller set of options to support those at risk during an event.

The exclusion of people with disabilities during plan development often leads to increased injury and death rates among this segment of the population during disasters (Parr 1987). People with disabilities are entitled to the same protection as those who do not have disabilities (FEMA 1995, 2002; DHS 2005, p. 3; DOJ 2007, Section I.B; Parr 1987, p. 149). Planners must compensate for their increased vulnerability by addressing, specifically, the needs of people with disabilities during the planning process.

Participatory Planning Process

Preparedness activities are less effective without the participation of vulnerable populations (Newport and Jawahar 2003). People with disabilities must be actively involved in the planning process for several reasons:

- First, their knowledge of potential barriers is invaluable. People with disabilities are excellent choices to serve as consultants or advisors during emergency plan development (Loy and Batiste 2004; Parr 1987, p. 153).
- Second, their personal experience in overcoming these barriers adds tremendous validity to plan solutions.

• Third, the empowerment experienced through participation may prompt people with disabilities to take preemptive actions on their own and encourage others to follow suit (Wisner 2002).

Invited participants must be representative of all types of disabilities. Equal representation is imperative, as each disability can present unique challenges to consider during emergency plan development. For example, people with only mobility disabilities can receive warnings via ordinary technology, but they may not be able to self-evacuate; whereas people with hearing disabilities may be able to self-evacuate, if they are properly notified. Advocacy groups that work for people with disabilities should also receive an invitation to the planning table. The collective knowledge gained by including these individuals and organizations is invaluable to plan development. In addition, the individuals or groups responsible for implementing the plan, such as first responders, should also be involved in the process (May 1985, p. 95). The insight gained through working side by side with people with disabilities during the plan development process will enhance everyone's understanding of the plan's purpose.

Planning, Preparedness, and the Law

Emergency planners and others need to know their legal and ethical responsibilities for planning for people with disabilities. Two laws are of primary interest, the Americans with Disabilities Act (ADA) and the Health Insurance Portability and Accountability Act (HIPAA), which covers patient confidentiality.

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) was enacted into law on July 26, 1990. It stipulates that "governments [as well as some private and commercial businesses] be accessible to people with disabilities" (DOJ 2007a, p. 1). Accessibility includes physical access but also addresses "how programs, services, and activities are delivered" (p. 1).

Disability is defined by the ADA as a "mental or physical impairment that substantially limits one or more major life activities" (DOJ 2007a, p. 5). Barriers to accessibility can

include architecture, policies and procedures, and communication methods. "Effective communication means that whatever is written or spoken must be as clear and understandable to people with disabilities as it is for people who do not have disabilities" (DOJ 2007b, pp. 1 & 2). "Effective communication" is determined by the situation. For example, a passing situation may require only minimal assistance, such as a written note, instructions that are read aloud, or personal assistance in finding a location. Other situations—those that are "more complex or lengthy"—require more assistance, such as qualified interpreters, captioning, or the use of computer terminals (DOJ 2007b, p. 4). Regardless of the auxiliary aid or service used, primary consideration must be given to the method that provides the person with a disability the greatest sense of security and understanding.

According to the Office for Civil Rights ADA Fact Sheet (<u>www.disabilityinfor.gov</u>), public entities must serve people with disabilities and eliminate barriers to ensure that programs, services, buildings, and communication are accessible to people with disabilities.

The ADA recommends planning ahead for effective communication with people with disabilities, and identifying resources for auxiliary aids and services. This includes determining early on how to copy documents into Braille, find qualified interpreters, and train all employees to recognize the need for effective communication with people with disabilities (DOJ 2007a). All Public Safety Answering Points (PSAPs), such as 9-1-1 and other emergency services, "must directly receive TTY calls without relying on an outside relay service or third-party services" (DOJ 2007c, p. 2). Telephone emergency services are required to be as effective for users of TTY as they are for nonusers. This is measured in relation to "response time, response quality, hours of operation, and all other features offered" (p. 2). Furthermore, the ADA requires that PSAPs must maintain and provide backup capability for all TTY equipment.

Emergency planners must plan ahead to effectively provide services and communicate with people with disabilities before, during, and after an emergency. Emergency planners must also advocate for policies that best protect and maintain the independence of people with disabilities as they prepare for and navigate emergency situations.

HIPAA

The federal Health Insurance Portability and Accountability Act of 1996 (HIPAA) protects the health information of all individuals, regardless of whether they have a disability (HHS 2008). HIPAA asserts the protection of patients' rights, including patient access to medical records, notice of privacy practices used by covered entities, limits on how personal medical information may be used, limits on the use of patient information for marketing, and confidential communication between patients and covered entities. Although HIPAA has often been the subject of controversy as emergency managers have worked to use as much information as possible in disaster preparation, steps have been taken to allow the release of patient information for emergency preparedness activities. According to the "At A Glance" chart offered through the Office of Civil Rights, public health authorities (PHAs) may disclose information, including that which pertains to emergency preparedness activities (HHS 2008).

HIPAA allows state laws to assert stronger privacy protection than what HIPAA regulates and provides information to patients who seek to make complaints about the privacy practices of covered entities (HHS 2008). Covered entities must provide patients with a copy of their privacy procedures in writing. They must also conduct employee training and have a designated privacy officer. Finally, HIPAA allows covered entities to disclose protected health information for "specific public responsibilities" (HHS 2008, para. 14). Covered entities are permitted to use their "professional judgment to decide whether to make such disclosures based on their own policies and ethical principles" (HHS 2008, para. 14).

The HIPAA Decision Tool assists emergency planners in determining what information may be used to aid individuals during an emergency. Protected health information may be disclosed to a covered entity, which can include a health plan, a health provider, or a health care clearinghouse. PHAs are often involved in emergency preparedness activities and may receive protected health information. PHAs include the following:

An agency or authority of the United States Government, a State, a territory, a political subdivision of a State or territory, or an Indian tribe that is responsible for public health matters as a part of its official mandate, or a person or entity acting under a grant of authority from or contract with such agency. (HHS 2008, para. 4)

According to the At A Glance chart, PHAs may disclose information, including that which pertains to emergency preparedness activities (HHS 2008).

In an Office for Civil Rights bulletin dated September 2, 2005, the HIPAA Privacy Rule was reviewed to demonstrate how patient information could be shared during disasters, such as Hurricane Katrina. Providers are allowed to share patient information in order to treat a patient, refer a patient for treatment, or coordinate treatment care with other providers, or to seek payment for providing health care services (HHS 2005). Providers may also notify family members, guardians, or other responsible parties about a patient's "location, general condition, or death" (HHS 2005, para. 6). When working with agencies, such as the American Red Cross, it is not necessary for a provider to obtain permission to share health information "if doing so would interfere with the organization's ability to respond to the emergency" (HHS 2005, para. 9). Furthermore, providers may share information with anyone necessary in order to "prevent or lessen a serious and imminent threat to the health and safety of a person or the public," and they may alert family members, guardians, or other responsible parties as to the location and condition of a patient at their facility (HHS 2005, para. 10).

Emergency planners must plan ahead for sharing protected health information during and following a disaster. By knowing the HIPAA Privacy Rule and how it should be applied in emergency situations, planners are better positioned to serve the public, especially people with disabilities.

Planning Tools

Recently, the federal government has offered some guidelines for emergency and disaster situations to assist with the planning process. As described in several chapters in this report, the Department of Justice has offered ADA-based guidelines for shelters that provide both planning principles and specific guidance for cots, doorways, and other areas requiring accessibility or adaptation. FEMA released its National Disaster Housing Strategy in January 2009 (FEMA 2009b). FEMA is also in the process of creating a Comprehensive Planning Guide (CPG) series. CPG 101 is poised for release in the spring of 2009. Follow-on guides will include CPG 301 on special needs planning and CPG 302, which will include service animals. These tools should be reviewed and implemented when developing emergency operations plans, shelter plans, and recovery plans.

Education

Written plans identify the particulars of how emergency response activities should unfold (McLoughlin 1985, p. 169). However, these disaster plans are useless unless people and responders are aware of their existence and educated on their content. Following the devastation of Hurricane Katrina in 2005, interviews with New Orleans police officers revealed that few knew the city had developed a catastrophic flood plan in 2004 (Cashen 2006, p. 8). This lack of awareness may have contributed to the chaos that New Orleans experienced in the aftermath of Hurricane Katrina.

Since most people have limited experience with disasters, educational programs are essential components of effective preparedness planning (Parr 1987, p. 153). Educational programs provide information and instructions that individuals can use to develop personalized emergency preparedness plans. Increasing the awareness of people with disabilities through disaster-related education programs should lead to increased confidence and self-reliance (Newport and Jawahar 2003). Armed with an increased awareness of their vulnerability during disasters, people with disabilities must assume responsibility for their own safety and act accordingly. Sudden onset events can be particularly problematic for people with disabilities. People with mobility disabilities may experience difficulty trying to hide or evacuate during rapidly developing

disasters, such as earthquakes (Fernandez et al. 2002). Taking ownership in planning for your own safety will not only increase resilience to the impact of a disaster but should further equip an individual to deal with the challenges of everyday life.

Education programs should instruct individuals and families how to prepare for disasters, especially sudden onset events. The materials and formats used in these disaster education programs must be developed in such a manner that they are accessible to people with disabilities in both format and content. Periodic reviews of the information are essential to ensure that instructions reflect current research and practices. Avenues of distribution for this information include the following (Natural Hazards Center 2005):

- Organizations: People with disabilities may rely on a wide range of organizations, including social service, health, advocacy, community-based, disability, and other organizations. Professional associations for people with disabilities and disability community groups (music, dance, poetry, theater) can also be used. It is most practical to attempt to distribute information to people where they live, eat, work, worship, recreate, and socialize.
- Public meetings and workshops: These can be used not only to formally
 present information but to encourage the exchange of information among
 attendees. Public meetings work best when the number of attendees is relatively
 small. A neighborhood meeting is a good example of this method.
- Brochures, door hangers, and other printed materials: Printed materials are a rather simple but effective method of dispersing information. These materials should be available in Braille as well as other languages to ensure that everyone has access to the information.
- Issue presentations and panel discussions: These are similar to public meetings but could involve larger audiences, as attendees are primarily there to receive information. Examples include professional associations, civic clubs, and advocacy organizations.

- Radio talk shows, chat rooms, social networking sites, disability blogs, and email blasts: These informal mediums are less intimidating to most people and are generally accessible from any location via phone or computer.
- Web-based information: The Internet is fast becoming the information source of choice. In most cases, people are able to quickly access multiple references to almost any topic without leaving their homes.
- Degree programs: Colleges and universities should be encouraged to integrate an awareness of the needs of people with disabilities into their degree programs, especially emergency management, fire sciences, social sciences, social services, and gerontology, to name a few.

Training

By integrating participatory preparedness strategies and conducting public outreach, it is possible to spur personal preparedness, build local capacity, and create new partners in preparedness. Jim Davis, the emergency management coordinator in Pittsylvania County, Virginia, worked to increase the safety of people with hearing disabilities. Davis first worked with a local college to obtain a \$5,000 grant to buy radios and then engineered them to vibrate pillows as a warning mechanism. As a result of his efforts, local citizens who were deaf requested additional training. To respond to their request, Davis provided community emergency response training (CERT) with sign language interpretation. For his efforts, Davis received the 2007 Clive Award at the National Hurricane Conference.

Training offers an avenue to evaluate the concepts and measures or recommended procedures contained in an emergency preparedness plan while simultaneously enhancing the proficiency of participants, both individuals and organizational representatives or staff. Examples include practice sessions, live drills, and tabletop exercises. These events should take place in a controlled environment that both teaches and tests emergency procedures. On an individual level, practicing and adapting a personal evacuation plan is vital to ensuring that protective actions work and become familiar. The development of responsive habits is the first line of defense against any type of disaster, especially rapid onset events.

Emergency responders also need training in recognizing and understanding the needs of people with disabilities (Parr, 1987, p. 153). Most emergency responder training comes from practical exercises or emergency simulations. For example, firefighters practice search and rescue techniques while using simulated smoke training inserts in their self-contained breathing apparatus face piece to limit visibility. This simulates the lack of visibility encountered in a smoke-filled environment without exposing firefighters to the risks associated with an actual fire. In similar fashion, firefighters should use tools, such as the etiquette guide developed by Oklahoma Able Tech and Fire Protection Publications, during training sessions to increase their awareness of the needs of people with disabilities. Additionally, people with disabilities must be actively involved in preparing, conducting, and overseeing training exercises. Their expertise in proper lifting techniques, ways of communicating, and handling other barriers that are often overlooked will greatly benefit emergency responders in their response preparations. This perspective and insight into the unique needs of people with disabilities will enhance the effectiveness of training simulations and identify areas for improvement (HHS 2005, p. 38, Recommendation #2; FEMA 1995, 2002; NOD 2005; Parr 1987, p. 153).

The following excerpt, taken from the April 2005 International Association of Emergency Managers *Bulletin*, reinforces the need to include people with disabilities in all preparedness activities following analysis of the Interagency Chemical Exercise:

The fact that difficulties and deficiencies became evident when disability issues were injected into such a complex and significant exercise only means that solutions can be addressed so those same deficiencies, over time, will be resolved. During I.C.E., the disabilities represented were not indicative of a comprehensive and all-inclusive list. Every disability presents slightly different issues, so it is clear the most effective planning can be done by including people with

disabilities from your own community, testing the responses honestly during drills, and adjusting future protocol accordingly.

Preparedness Materials

The American Red Cross (n.d.) stresses that "everyone," including people with disabilities, should prepare to be able to survive on their own for a minimum of three days following a disaster; this statement is consistent with FEMA's recommendation that people prepare to be self-sufficient for up to 72 hours after a disaster. This includes maintaining an adequate supply of food, water, medicine, and other essential items at all times. Additionally, personal preparedness should include planning for events that may happen while an individual is not at home. This would include instances when a person is working, shopping, or traveling. Communities, organizations, and first responders must also be actively engaged in preparedness planning to ensure their readiness when a disaster strikes.

A number of helpful brochures and guides are available in print and electronic format to assist with developing a personal preparedness plan. Adherence to the personal preparedness information contained in these guides should lessen the impact of any disaster, especially sudden onset types. Information is also available to help communities and emergency personnel prepare to respond to the needs of people with disabilities during disasters. Although each guide differs somewhat in its approach, the basics remain consistent across the board. We will summarize the content of several of these guides in an effort to illustrate what is available.

Individuals

• Prepare in a Year

Available @ http://emd.wa.gov/preparedness/documents/PE_PIY_Booklet.pdf

The State of Washington's Emergency Management Division has developed a simple method of encouraging people to prepare for a disaster. This booklet separates personal preparedness into 12 easy-to-accomplish tasks. Families are

encouraged to commit one hour each month to achieving a specific task. If they do this, their personal emergency plan will be complete in a year. Although this guide is generic in nature, it could easily be adapted to address the needs of people with disabilities.

Easy-to-follow instructions are provided as each step is introduced. The checklists and illustrations that accompany the instructions enhance the user-friendliness of the guide. The 12-step process makes it less intimidating than most preparedness guides and encourages the participants to spread the costs across an entire year. An added bonus to this approach lies in the fact that emergency preparedness receives ongoing attention, which should result in increased participation.

One point of concern is the omission of information about smoke alarms in the fire safety section. A discussion of this life-saving technology must be included in any discussion about fire safety and would be the place to discuss audible and visible alarm systems. Additionally, this guide focuses on disasters common to the Washington area instead of employing an all-hazards approach.

• Emergency Preparedness: Taking Responsibility for Your Own Safety: Tips for People with Disabilities and Activity Limitations

Available @ http://lacoa.org/esppub.htm#Spec

This personal preparedness guide from the Los Angeles County Office of Emergency Management is designed specifically for people with disabilities and is available in Spanish. The guide begins with a short discussion of who should use the guide, how to use it, and why personal preparedness is necessary, especially for people with disabilities. Personal preparedness is divided into six general steps. The discussion of each step is brief but informative. These short, information-packed discussions provide quality instructions instead of clouding the issue with lengthy dialogue. The selfassessment checklist and bulleted points of emphasis in each section contribute to the guide's simplicity and user-friendliness.

A unique feature of this guide is its description of four different emergency kits (carry-on, grab-and-go, home, and bedside) that each person should create. However, the short description of each kit may leave some individuals at a loss concerning the desired contents. The discussion in this section identifies a variety of potential kit items but leaves the decision up to the individual. This lack of specific direction may lead to the omission of an essential item or complete failure to create the kit. A list of some suggested items for each kit would strengthen this step.

• Emergency Readiness Wheels

Available @ www.eadassociates.com/products.html#wheels

EAD and Associates, LLC has developed a unique preparedness tool— *Emergency Readiness Wheels*. Currently, there are two versions of this tool: one for people with disabilities and another for seniors. These two-sided wheels provide both preparedness and response information. These tools could be translated into other languages depending on the volume of requests.

The preparedness side of the tool guides the user through an eight-step process toward personal preparedness. Each slice of the wheel provides short, yet clear, instructions to the user, making it manageable to work with. The face of the wheel provides summarized emergency information, additional resources, and space for emergency contact numbers. The preparedness side of the tool focuses on evacuation. Preparing for Disaster for People with Disabilities and Other Special Needs
 Available @ www.fema.gov/plan/prepare/pubs.shtm.

This personal preparedness guide is designed to help people with disabilities create their own unique emergency plans. The guide stresses that people know their own strengths and weaknesses better than anyone else and can build their own plan around their unique needs. Participants are first instructed to develop a personal support network and perform a self-assessment. Then a four-step process leads participants through the development and maintenance of their personalized emergency plan. The guide is also available in Spanish.

• OK-WARN for the Deaf and Hard-of-Hearing

Available @ http://www.ok.gov/OEM/Programs & Services/Preparedness/OK-Warn for the Deaf and Hard-of-Hearing/index.html

This program offers a method for people with hearing disabilities to receive notification of weather-related hazards in Oklahoma. Warning notifications are sent via alphanumeric pagers and emailed to everyone listed in the database. Each person can choose the type of warnings he or she wishes to receive. People can also limit their notifications to selected counties within the state.

• Safe Escape

Available at www.safeescape.org

This family-oriented program provides online videos and other tools, such as an assessment checklist, to help families plan for evacuation in various scenarios.

• Emergency Preparedness and People Who Are Blind and Visually Impaired

The American Council of the Blind offers this consumer handbook in accessible formats, linked to the specific interests and needs of people with visual
challenges. The guide can be found at <u>www.acb.org/washington/emergency-</u> preparedness-final.doc.

• State Agency Created CDs (Massachusetts EMA)

To better serve people with vision impairment, the Massachusetts Emergency Management Agency (MEMA) partnered with community services for the blind to develop CDs that contain the same emergency information provided on its website. These CDs were distributed to public libraries and throughout the community. They "describe procedures for sheltering-in-place, evacuation, mass care shelters, the Emergency Alert System, pet safety, and special needs information" (p. 1).

Ready America

Available @ www.ready.gov/america/getakit/disabled.html

The Department of Homeland Security website, <u>www.ready.gov</u>, offers a vast array of emergency preparedness information. The site's *Ready America* selection offers a preparedness planning brochure specifically designed for people with disabilities. This two-page brochure contains emergency planning information for people with disabilities and guides the participant through a threestep process: Get a Kit, Make a Plan, Get Informed.

Organizations and Communities

• Project Safe EV-AC

Available @ http://evac.icdi.wvu.edu/library

Project Safe EV-AC was developed under Department of Education Grant Number H133G040318. These materials address two distinct issues that affect people with disabilities during emergencies. First, there are no effective training materials that address the fear and anxiety caused by emergency planning. Second, there is no cohesive set of safe evacuation "best practices" that includes people with disabilities.

This project offers suggestions for overcoming personal anxiety and fear when developing emergency plans. These materials also examine the unique difficulties associated with various disabilities. A discussion of various disaster situations and site-specific evacuation needs is also included in the project's materials.

• An ADA Guide for Local Governments

Available @ www.ada.gov/emergencyprep.htm

This document provides guidance in making emergency preparedness and response activities accessible to people with disabilities. Illustrated suggestions accompany a series of action steps that address planning, notification, evacuation, and sheltering activities. The instructions in this guide are brief and to the point, making it an excellent introductory piece to the needs of people with disabilities.

• Emergency Planning and Special Needs Populations (G197)

Available @ http://training.fema.gov/EMIWeb/pub/register.asp

The U.S. Fire Administration developed this course to increase the skill and knowledge of emergency planners with respect to the needs of people with disabilities. This course aims to educate any group that is responsible for the safety of people with disabilities. This includes first responders, nonprofit organizations, community service organizations, and health care providers. The information contained in this course could also benefit those who develop emergency plans as a profession.

Emergency Procedures for Employees with Disabilities in Offices Occupancies
 Available @ www.usfa.dhs.gov/downloads/pdf/publications/fa-154.pdf

Every employee, including people with disabilities, deserves the right to work in a safe environment, and that responsibility falls on the shoulders of the employer. This guide will help employers fulfill their responsibility to create a safe working environment. Employers are encouraged to include people with disabilities in each phase of their emergency planning process. This guide is very informative and would be beneficial for individuals as well. However, the multicolumn layout of this guide takes away from the quality of its content.

First Responders

• Orientation Manual for First Responders on the Evacuation of People with Disabilities

Available @ www.usfa.dhs.gov/downloads/pdf/publications/fa-235-508.pdf

First responders may be called to assist people with disabilities at any time. Therefore, preparing for these situations is an essential element of their training. This guide encourages first responders to include people with disabilities in planning evacuations and when selecting assistive evacuation technologies. In addition, writing guidelines and appropriate terminology are provided for first responders to use during plan development and when assisting people with disabilities.

• Sign Language Booklet for Emergency Medical Situations

The Western Pennsylvania School for the Deaf in Edgewood, Pennsylvania, developed a sign language booklet for use during medical emergencies. Baldwin EMS in Pittsburgh has been using the book for several years (Assistant Chief Curtis Neill, personal communication, May 16, 2008). Chief Neill said the booklet contains the universal sign language alphabet, along with specific signs to describe medical terms or conditions. He said the booklet was tested during mock emergency scenarios involving the students who developed this tool.

• Social Etiquette—Tips for Firefighters

Available @

www.ok.gov/abletech/Fire_Safety/Fire_Safety_Solutions_Grant_Etiquette_Guide. html

Oklahoma Able Tech and Fire Protection Publications developed this guide to help firefighters understand and interact with people with disabilities. First responders are given advice on what to expect in the homes of people with disabilities and how to communicate and react in various situations. The guide offers basic instructions on social etiquette, greetings, providing and requesting information, working with service animals, and serving as an interpreter.

Warnings

In 2005, the National Council on Disability issued a report entitled *Saving Lives: Including People with Disabilities in Emergency Planning.* In this report, NCD found that warnings did not adequately reach people with disabilities during disasters, specifically those "who cannot depend on sight and hearing to receive their information" (NCD 2005, p. 12). Adequate and timely information is essential to disaster preparedness activities. The lack of this vital information is a contributing factor to the limited disaster preparation among people with disabilities (McEntire 1999). Most disaster warnings broadcast via conventional media avenues only, which may not be accessible to people with hearing or vision disabilities. Advance efforts are needed to preplan and test messages, purchase and test warning systems, and educate the public on how the systems work and how to respond when they receive a warning.

A number of barriers impede the ability of people with hearing disabilities to access hazard information. These barriers include audible-only weather warning systems, a lack of closed captioning during television weather warnings, and the absence of information sources while driving (Wood and Weisman 2003). New technologies may soon address these barriers. Specially adapted weather radios, text messaging, and weather pagers provide hope that this problem is solvable (Wood and Weisman 2003). However, these new technologies will not be effective sitting on the shelf. The problem lies in getting these assistive technologies into the hands of those who need them. This may be difficult, as people with disabilities are less likely to have disposable income and may not be able to afford such devices (van Willigen et al. 2002). Other, more innovative practices tap directly into specific disabilities:

- OK-WARN is "a new way for people who are deaf and hard-of-hearing to receive timely notification of weather hazards in the State of Oklahoma. The program was created to help ease the fears of individuals who are deaf and hard-of-hearing who may have difficultly receiving life-saving warnings. OK-WARN is a customized database program that sends out critical weather information to alphanumeric pagers and email addresses" (go to www.ok.gov/OEM/OK-WARN). Participants are instantly notified when the National Weather Service issues an alert. The system attempts to deliver the message using multiple data sources.
- The WGBH National Center for Accessible Media (NCAM), a division of Boston's public broadcaster WGBH, "is uniting emergency alert providers, local information resources, telecommunications industry and public broadcasting representatives, and consumers in a collaborative effort to research and disseminate approaches to make emergency warnings accessible. This project, funded by the Department of Commerce's Technology Opportunities Program (TOP), is addressing a most urgent need—the one to develop and encourage adoption of standardized methods, systems and services to identify, filter and present content in ways that are meaningful to people with disabilities leading up to, during, and after emergencies"

(http://ncam.wgbh.org/news/pr_20050915.html).

In 1998, the Rehabilitation Act was amended to require federal agencies to make electronic and information technology accessible to people with disabilities. "Section 508 was enacted to eliminate barriers in information technology, to make available new opportunities for people with disabilities, and to encourage development of technologies that will help achieve these goals" (<u>www.section508.gov</u>, Section 508, para. 1). The General Services Administration (GSA) uses the Section 508 website to provide current information and resources to meet Section 508 requirements.

The Federal Communications Commission (FCC) continues to remind broadcasters of the regulations that must be met to assist people with disabilities during emergencies. This included writing letters to television stations in the Washington, D.C., area during the sniper shootings in 2002. The FCC regularly meets with members of the disability community to discuss emergency warnings and how they might be improved (NCD 2005). It is clear, however, that compliance with FCC policies lags considerably in terms of implementation. Stations report a lack of closed captioners and note the high cost of such services and the lack of availability of captioners during an emergency.

Friends, family, neighbors, and coworkers are all important conduits for information dissemination. By simply adding a few sentences, warning messages could include instructions for neighbors and family members to support people with disabilities (Daley et al. 2005). One way to accomplish this is by encouraging social networks to assist people with disabilities during disasters. Another step could be taken by organizing through work units, neighborhood associations or watches, or community organizations. Participants in social networks should know the location, contact information, and evacuation instructions for people with disabilities in their neighborhoods (Litman 2006, p. 16). This idea is similar to the buddy system, in which an individual plans with another person to initiate protective action upon receipt of a warning. For both types of efforts, Parr (1987) suggests establishing a backup network of alternative sources of assistance for people with disabilities during disasters (p. 152) to fill the gap if the primary source of assistance is unavailable or out of town. For more information on warning messages, see Chapter 3.

Evacuation Planning

The decision of whether or not to evacuate can be a complicated issue. The time and resources needed to evacuate people with disabilities is often greater than what is required for individuals without disabilities (Rubadiri, Ndumu, and Roberts 1997). Thus, pre-event evacuation planning is crucial. Calls for evacuation must allow sufficient lead time to ensure the safe evacuation of people with disabilities, and the evacuation message must explicitly describe the risks associated with not evacuating to encourage greater compliance with evacuation orders (Burnside, Miller, and Rivera 2007, p. 730).

Timing is not the only issue associated with evacuating people with disabilities. The U.S. Government Accountability Office (GAO) documented a number of challenges during recent evacuation events, including identifying people who need evacuation assistance, securing adequate transportation, and coordinating the evacuation effort (GAO 2006a; Phillips, Metz, and Nieves 2005). To illustrate, a lack of adequate transportation impeded evacuation efforts before Hurricane Katrina. Family members and caregivers refused to leave relatives or clients behind who could not walk to bus locations or were not provided with accessible transportation (Elder et al. 2007, p. S127). Experts concur that "a coordinated effort between government agencies and nonprofits can create an environment of information sharing that will allow transportation planners to accurately account for carless populations" (Renne, Sanchez, and Litman 2008, p. vi). As these researchers observe, "Little dialogue exists regarding the medical needs of the carless society as it pertains to evacuation planning" (p. 6).

Transportation assets must also be organized, particularly those with accessible features. As Professor Lex Frieden from the University of Texas at Houston noted after Hurricane Ike, "There are more than a hundred paratransit vehicles operated by the Metropolitan Transit Authority of Houston.... A hundred percent of the several hundred mainline service vehicles in Houston are wheelchair accessible. We used those vehicles, both the paratransit vehicles and a number of the city buses, to go down along the coast outside of their jurisdiction to pick people up and evacuate them." FEMA has recently established regional agreements with paratransit services to provide support as

well (see Chapter 9). Evacuation protocols are still emerging and lack empirical validation through scientific studies. As of February 2009, the Federal Highway Administration was reviewing draft guidance for special needs evacuation.

The development of evacuation modeling programs is a step in the right direction. Kuligowski presented an overview of advances in these technologies during a 2004 Department of Education (ED) conference on evacuating people with disabilities. Kuligowski stated that evacuation simulators are making strides in the inclusion of evacuation impediments, such as disabilities, in their prediction models, including those for high-rise buildings (ED 2005). These models should enhance the effectiveness of emergency planners/plans by identifying predictable human behaviors and areas of congestion, but they are still being developed.

The development of various forms of registries that identify people with disabilities has received some support in recent years. However, the California wildfires in 2003 exposed several problems with registries that should receive consideration before expanding the use of this technique. First, the California State Independent Living Council (SILC) (2004, p. 5) reported that individuals in charge of these registries were unable to access them because of power outages and lack of access to their work sites. Second, lists that had been distributed to local fire stations remained locked in cabinets, as everyone was out fighting the fire and no one was staffing the station (California SILC 2004, p. 4). A related problem is that many registries are "static" and list only a home location, and the person may be at work, out shopping, or in another location. Because people with disabilities may not be able to evacuate, registries could be used to assist those left behind. However, as Dr. Margaret Nosek (2008) noted after Hurricane Ike, "I had registered earlier with 211 as a person with a critical medical need, but found it impossible to get through to them after the storm.... In addition to assisting with evacuation, a mechanism should be in place that will contact individuals registered." Registries have not been evaluated by objective scientific means for their effectiveness. Evidence suggests that "few carless individuals are effectively utilizing registry systems" (Renne et al. 2008, p. vi).

Employers are subject to meeting the ADA provisions and must address the needs of people with disabilities in evacuation plans (Loy and Batiste 2004). Although little research was found documenting widespread progress in this area, many employers have rewritten their evacuation plans to include provisions for people with disabilities. Such provisions may be limited to designating a temporary location of refuge while waiting for rescue or could include buddy systems for helping people out of buildings or evacuation devices. Such systems are understudied for their effectiveness and use.

Rapid Onset Evacuation

Rapid onset evacuation can prove difficult under the best of circumstances. Adding to the state of urgency, the need to communicate instructions and directions that are appropriate for all populations, including people with disabilities, creates a situation that is even more problematic. The 2004 California SILC brief titled *The Impact of 2003 Wildfires on People with Disabilities* found that people who were deaf were not notified adequately of the wildfires. Emergency personnel raced ahead of the fast-moving fires and announced evacuation orders using car loudspeakers. Few reports on television were close-captioned.

Similarly, people who were blind often went without notification as well. Many remote areas did not have television or radio access and none had reverse 9-1-1 capabilities (California SILC 2004). According to the report, sometimes "those notified to evacuate were not advised which direction to flee, or what location could be used as an emergency gathering point" (p. 3). SILC brought forth the following recommendations regarding notification during rapid onset events:

Activate enhanced 9-1-1 and/or reverse 9-1-1 systems. These systems can
incorporate compatibility problems with telecommunication devices for the deaf
(TDDs). When such technology is purchased, this must be factored into
decisions about which systems to buy.

- Ensure that notification systems are in place, including reverse 9-1-1 systems that can reach individuals with disabilities through the use of text telephones (TTYs), if necessary.
- Ensure that local news related to evacuation announcements is presented on television stations that cover an expanded area. Some people in San Bernardino County were unable to receive notifications about county conditions during the 2003 fires, as Los Angeles stations were not targeting news outlets in those areas.
- Volunteer organizations serving people with disabilities and seniors should assign members to maintain and operate a "phone tree" to notify association members in the event of area emergencies (p. 7).

Again, little research was found on rapid onset evacuation in the workplace, which suggests an immediate priority area for scientific investigation.

Sheltering in Place

An alternative to evacuation when faced with a rapid onset disaster, such as a hazardous material release, is to seek refuge inside a structure. This is known as sheltering in place. The object of sheltering in place is to limit, if not eliminate, exposure to the outside air. Instructions for creating this type of shelter are available through a number of sources. While these shelters are relatively easy to set up, the individual will need to purchase enough material to seal the selected room. Further, most shelter-in-place protocols and studies focus on individuals, not recognizing the extensive challenges that exist.

Sheltering in place may be problematic for people with disabilities for several reasons. First, as Phillips, Metz, and Nieves (2006, p. 131) noted, people in the "lowest income quartile [are] less likely to want to attend classes on creating a home shelter environment and to have a family plan or preparedness kit" in place to do so, and people with disabilities often fall into this lower income quartile. Second, people with disabilities may experience difficulties with the physical labor necessary to create a home shelter. The limitations of their disability could prevent them from setting up a shelter or increase the amount of time necessary to do so, leaving them vulnerable to airborne contaminants for an extended period. A separate but similar issue may occur among individuals with cognitive disabilities, who may have difficulty understanding instructions for sheltering in place. This includes people with significant cognitive disorders and those with Alzheimer's. (Chapter 3 provides additional information on this topic.) A third problem with sheltering is the lack of accessible options; for example, most underground safe rooms in tornado alley are not accessible.

Informal observations of recent warnings for rapid onset events requiring sheltering in place in Oklahoma revealed that on-air meteorologists and weather services did not offer any instructions other than going to an interior room or going underground. This lack of information specific to people with disabilities and their social networks is likely to delay or deter them from taking protective action. Without specific warning messages about what to do, compliance with sheltering in place is less likely (Mileti 1999). Warning messages regarding specific action must be directed to the populations at risk. (For more on this topic, see Chapter 3.)

Conclusion

Historically, people with disabilities have been marginalized by the emergency management community. Instructions relating to the unique needs of people with disabilities have typically been limited to a few lines in an emergency plan, if they are mentioned at all. "Disabilities" were generally placed into one large category, without consideration for the unique needs associated with each type of disability. Emergency planners often decided what people with disabilities needed without consulting those people. This practice further alienated people with disabilities and increased their vulnerability during disasters. In recent years, Congress and the White House have demanded that people with disabilities be afforded the same consideration during emergency planning as all other individuals. Although some improvement in this area is evident, catastrophic events, such as Hurricane Katrina and the California wildfires, exposed the gaps that still exist in many emergency plans and preparedness efforts.

These events reinforce the need for additional action to protect the lives of people with disabilities against the destructive nature of disasters.

Research Recommendations

- Develop an understanding of how to assist people with disabilities during disasters. This study should rely heavily on the experiences of people with disabilities and should make sure to include all types of disabilities.
- Develop, test, and confirm effective training procedures for a range of people with disabilities across the life span.
- Thoroughly research the current best practices of buddy systems and registries for their viability as tools in the preparedness tool kit.
- Assess the extent to which substantive content on people with disabilities is incorporated into emergency management, fire science, and related disciplines in institutions of higher education.
- Investigate the extent to which schools, independent living centers, and other congregate-type organizations prepare for mass emergencies and disasters, and what insights they can offer for best practices.
- Identify and evaluate strategies that encourage the participation of people with disabilities in emergency planning sessions and first responder training sessions.
- Evaluate the existence and composition of emergency plans for catastrophic events. Specifically, note how these plans address the diverse challenges facing people with disabilities.
- Survey emergency managers, first responders, and others tasked with handling preparedness plans involving people with disabilities to assess their levels of understanding about issues, strategies, and tools for improving these preparedness efforts.

Practice Recommendations

- Disseminate preparedness information widely through a broad range of partners across the community. Procure and disseminate materials in multiple accessible formats for a range of disabilities.
- Increase the inclusion of people with disabilities in training exercises. People with disabilities should be involved in the development, execution, and review of training exercises to ensure that their knowledge and experiences are passed on to first responders and emergency managers.
- Observe and evaluate drills and exercises for inclusion and adherence to current practices; identify alternative strategies for inclusion of people with disabilities in such events.
- Develop or acquire tools, such as sign language booklets, to help first responders understand the needs of people with disabilities during an emergency. Make these tools available to first responders across the country using mediums such as the website for Lessons Learned Information Sharing (recently connected through Twitter, a social networking tool).
- People with disabilities must be invited to the emergency planning table. Their direct inclusion in the development of plans should increase the effectiveness of emergency plans when it comes to properly addressing the unique needs of different disabilities.
- Gather together, in one accessible location, easy-to-use materials and ideas for improving the practice of emergency management and first response to people with disabilities across the life cycle of emergency management (preparedness, response, recovery, and mitigation), with subsections relevant to the activities of each cycle.
- Design warning messages so that they incorporate instructions for people with disabilities on how to take protective action for the impending hazard.
- Involve people with disabilities and disability organizations in critiques of existing plans as well as exercises, training, debriefing, and after-action reports.

- Involve disability organizations in helping people understand the importance of preparedness; develop emergency kits and protective action strategies, including evacuation.
- Update specific disaster agency online educational and outreach materials (for example, those of FEMA) for best practices and ensure that materials (1) are accessible in multiple formats; (2) target individual, organizational, and government users; and (3) cover all phases of disasters, including preparedness, response, recovery, mitigation, and relevant subsections of these cycles.

Policy Recommendations

- Policies focusing on disaster preparedness should strive to protect and maintain the independence of people with disabilities. This includes addressing issues such as appropriate warning systems, transportation services, and sheltering options—to name a few.
- Re-issue Executive Order 13347 to require that people with disabilities and their advocates be integrated into local preparedness and planning efforts.
- Establish policies that provide for mass emergency and disaster curricula across all levels, disciplines, and types of educational institutions and federal agencies.
- Strengthen compliance with FCC policies on emergency communications, closed captioning, and similar tools for disseminating warning messages.
- Require federal agencies to include disability organizations as partners in all preparedness and outreach efforts, funds, grants, and programs.
- Encourage adoption of universal design principles as a means to increase evacuation options for people with disabilities (Steinfeld 2006).

CHAPTER 3: Response

Introduction

Entry into the response phase indicates that some type of disaster is occurring and demands immediate action. Preparedness, recovery, and mitigation activities primarily occur during the downtime between disasters or following an event. Response, on the other hand, kicks into action when some people are experiencing the worst day of their life.

Tierney, Lindell, and Perry (2001, p. 5) define emergency response as the "actions taken a short period prior to, during, and after disaster impact to reduce casualties, damage, and disruption and to respond to the immediate needs of disaster victims." The National Fire Protection Association (NFPA) adds that the response phase focuses on the "immediate and ongoing activities, tasks, programs, and systems to manage the effects of an incident that threatens life, property, operations, or the environment" (NFPA 2007, p. 1600-5). The use of words such as "immediate" and "threatens" indicates that a sense of urgency accompanies the response phase. This is not the time to plan or reflect. Emergency response calls for quick and decisive action.

Emergency response is not an exact science. According to Drabek (1985), the initial period following a large-scale disaster "present[s] a complex array of organizational demands that constitute a unique managerial problem" (p. 85). Local, state, and federal governments spend considerable time and resources developing response strategies for various natural and manmade hazards. However, even the best plans and preparations can be overwhelmed in an instant by the unpredictability and variation of a particular disaster. This becomes immediately clear during catastrophic events, such as Hurricane Katrina; however, it does not imply that response planning is useless. In fact, quite the opposite is true. Planning for an effective response is extremely valuable. The strategies discussed in these sections raise awareness of gaps in the response network and identify recommendations for research, practice, and policy.

Emergency management stages do not have a definite beginning or end; they frequently overlap. For instance, warning messages and related training and education may be part of the preparedness phase, while issuing and responding to warnings occurs during the response phase. Neal (1997) points to the irrelevance of disaster phases and suggests that distinct phases may not even exist. While not advocating for the elimination of phases, he suggests that the following should be better understood:

(1) disaster phases are mutually inclusive, (2) disaster phases are multidimensional, (3) disaster phases should reflect social rather than objective time, (4) disaster phases should include multiple perceptions of the event (e.g., those of disaster managers, emergency responders, and victims), (5) disaster phases should consider how various cultures adjust to disasters and hazards, (6) disaster phases are explicitly tied to notions of social change, (7) disaster phases are tied to assumptions of determinism, and/or (8) the phases of disaster are not relevant. (Neal 1997, p. 260)

The way in which response is handled affects the other phases, particularly how recovery progresses. For instance, emergency road clearance allows for immediate rescues and also creates a safe means for an eventual return home. It is important to note that the perspectives of people with disabilities have not routinely been considered in response planning nor has consideration been given to the effects of response actions for recovery. This lack of inclusion not only affects what is known about the physical needs of people with disabilities but also fosters a response that at times is culturally inappropriate.

FEMA lists five stages of disaster response: "alert and notification; warning; protecting the citizens and property; providing for the public welfare; and restoration" (FEMA 2007, p. 5-2). As with the major stages of emergency management, phases of response often overlap. Two phases of response are of particular importance in discussing vulnerable populations. These are alert and notification, and warning.

During the alert and notification phase, two groups are notified: "the general public and emergency response personnel who will respond" (p. 5-2). Emergency personnel are encouraged to connect with media to ensure that clear messages are provided on television and the radio (FEMA 2007). Unfortunately, these communication mechanisms often circumvent or completely ignore the needs of people with disabilities. Kailes and Enders (2006) report, "Typically, disaster preparedness and emergency response systems are designed for people for whom escape or rescue involves walking, running, driving, seeing, hearing and quickly responding to directions" (pp. 16 & 17).

During the warning stage, the public is notified about a dangerous, usually impending event. Occasionally, because of unforeseen events in which there was little time to alert and notify emergency personnel and the general population so they could be ready for a disaster, the warning stage is the first stage of response. FEMA advises emergency personnel to assess and strengthen their warning systems to better prepare for this stage (FEMA 2007). This chapter will address the measures that must be taken to provide adequate warning and protection to vulnerable populations, which may include people with disabilities.

In addressing response needs among people with disabilities, Kailes and Enders (2006) note that "some limitations are quite visible, while others—such as heart disease, emotional or psychiatric conditions, arthritis, significant allergies, asthma, multiple chemical sensitivities, respiratory conditions, and some visual, hearing and cognitive disabilities—may be less readily apparent" (p. 9). Conditions that may affect response capabilities include the following:

- Mobility disabilities, which interfere with walking or using stairs (e.g., joint pain, paralysis, and use of a mobility device, such as a wheelchair, cane, crutches, or walker).
- Reduced stamina or a tendency to be easily fatigued, owing to a variety of temporary or permanent conditions.

- Respiratory conditions resulting from heart disease, asthma, or emphysema, as well as those triggered by stress, exertion, or exposure to small amounts of dust or smoke.
- Emotional, cognitive, thinking, or learning difficulties.
- Vision loss.
- Hearing loss.
- Temporary limitations resulting from, for example, surgery, injuries (sprains, broken bones), or pregnancy (p. 10).

Summary of Key Findings

Research that seeks to improve disaster response among people with disabilities appears to fall into two categories. The broadest category focuses on improving the delivery of information and the response time of individuals so they can safely react to an impending disaster or emergency. This approach results in improved warning systems and policies for effective communication, as well as recommendations to individuals with disabilities regarding their responsibilities and choices (i.e., suggesting that people with disabilities arrange for someone to personally warn them of an approaching disaster rather than providing a mechanism to ensure that all people with disabilities receive effective and immediate communication of warnings). Critics of this approach note that it tends to contribute to blaming the victim and often ignores problems in the built environment (i.e., manmade surroundings that provide the setting for daily living), as well as issues of exclusionary planning and limitations of responding organizations.

The second category of research focuses on the built environment and seeks policy changes to create public environments that will increase the safety of everyone, regardless of ability. Christensen, Collins, and Holt (2006, p. 24) note that "emergency evacuation research, policy, and practice will continue to be ineffective until premised on the understanding that disability is a product of the environment rather than inherent in the individual." Hemingway and Priestly (2006, p. 57) agree: "Traditional perspectives, based on assumptions of individual limitation, have shaped the

construction of disabled people's vulnerability to natural hazards as tragic yet unavoidable." Ignoring the built environment further alienates people with disabilities and jeopardizes the safety of everyone who is responding to an emergency or disaster.

In an interview with Holt regarding her research with Christensen on the "problem of evacuating victims with severe mobility impairments" (p. 13), Wagner (2006, p. 13) reports on the response needs still faced by people with disabilities. Contributing to this issue of the built environment is the fact that "the most accessible entrances tend to be the best route out of the building for everyone; nondisabled people head there first in an emergency, thus clogging those exits intended for the disabled, who have no alternative exits." Researchers in this area promote the need to address the built environment as accessible to everyone, thus promoting safe disaster response rather than relying on individuals to understand and act on detailed instructions in an environment that is not supportive of their functional needs.

Litman (2006, p. 12) addresses lessons learned during Hurricanes Katrina and Rita. In reviewing the City of New Orleans' guidelines—"Emergency Guide for Citizens with Disabilities"—Litman notes that "it contains little practical support, placing most of the responsibility for safety and evacuation on individuals." Litman is among the researchers who are discovering that a great many of the recommendations currently available to people with disabilities promote personal responsibility over and above social responsibility, and create an environment of victim blaming when systems fail to adequately assist people with disabilities during the response phase.

Tierney, Petak, and Hahn (1988) address the consequences of following a traditional "medical model" in setting policies for people with disabilities. Use of the medical model puts the focus on "fixing" people and, ultimately, promotes personal responsibility over social responsibility. This model focuses on a person's limitations rather than the contribution that the social context provides. On the other hand, the socio-political approach situates the problem within the larger society. Using this model, "a disability is [viewed as] the consequence of environmental and social factors that interact and restrict the capabilities of some individuals" (Tierney, Petak, and Hahn 1988, p. 16).

This viewpoint considers "the broader social, cultural, economic, and political environment that 'creates' the disability" (p. 16). The authors conclude that adoption of this approach promotes people with disabilities as members of a minority group whose "functional limitations and incapacities" are directly related to the existing discriminatory practices and policies surrounding the built environment and social norms of society.

Many of the problems incurred by emergency personnel during the response phase of a disaster could be addressed if planning included people with disabilities. It is imperative that people with disabilities have a voice and be at the table for all stages of disaster planning, including the development of policies that impact the built and social environments and, therefore, influence a person's ability to respond appropriately to disaster. Yet, the report from the Special Needs Assessment for Katrina Evacuees (SNAKE) project found that many emergency shelter planners had little interaction with the disability community prior to Hurricane Katrina (NOD 2005). The following findings were presented in the SNAKE report:

50% of those interviewed had policies, plans and guidelines for accommodations in place prior to Hurricane Katrina. Only 36% had someone with expertise onsite to provide guidance regarding appropriate accommodations.

54% of the respondents did not have any working agreements with disability and aging organizations prior to the event. 50% made contacts with those organizations as a result of their Hurricane Katrina experience.

The gap between emergency management and disability- and agingspecific organizations widened when the organizations serving these populations tried to connect with the emergency management community—85.7% of these community-based groups answered that they did not know how to link with the emergency management system. (NOD 2005, p. 7) In addressing emergency response among people with disabilities, Kailes and Enders (2006) advocate the broad inclusion of people with a variety of needs and abilities. To serve the general public in the best possible way, they say that—

People with disabilities should not be viewed as one more special interest group that drains resources from the common pool. Accommodating this large group often translates into being better equipped to serve all people. Anyone, at any moment, can incur a disability, particularly during emergencies. (Kailes and Enders 2006, p. 13)

Review of Scientific Literature and Technical Reports

To better meet the needs of all people, including people with disabilities, emergency managers must understand how people respond during a disaster warning. Knowing how to provide a warning message that will be well received and using a credible "voice" to deliver it are major steps toward motivating community members (including people with disabilities) to respond appropriately. By better understanding the steps taken by individuals who receive and hopefully respond to warning messages, emergency personnel can improve the likelihood that crucial instructions are followed.

Overview of Warning Receipt and Socio-behavioral Response

During the 1990s, the Natural Hazards Center at the University of Colorado at Boulder convened 100 expert researchers and practitioners to assess the state of knowledge in the field of disasters and mass emergencies. As noted by then-director Dennis Mileti (1999, p. 174) in the summary volume of that body of work, "The United States has no comprehensive national warning strategy that covers all hazards in all places." Separate warning systems exist in a decentralized and quasi-coordinated manner across jurisdictional levels, units of organization, and communities. Coordination among these various levels determines how effectively the warning is disseminated. Without understanding or integrating the perspectives and needs of people with disabilities, warnings may be ineffective and safety compromised. However, as noted in Chapter 1

(Scenarios), many jurisdictions lack any level of expertise regarding how to accommodate people with disabilities. As a further complication, emergency management agencies and organizations have not fully incorporated people with disabilities or their advocates or caregivers into emergency planning within and across local, state, and even national levels (DHS 2005).

Warning systems, which are crucial before or during the onset of the response phase, may vary in their effectiveness for the general public, particularly among people with disabilities. Reliance on some technologies, such as sirens, may lead to a false sense of security, although research demonstrates that warning systems fail frequently as devices intended to motivate the desired behavioral response (Sorenson 2000). How people behave when warnings are issued provides crucial insights. Mileti describes seven steps people tend to go through when they receive a warning (Lindell and Perry 2004; Mileti 1999; Mileti and Sorenson 1990).

The first step involves "hearing" the message. Researchers have largely assumed that the public is hearing and have therefore failed to use inclusive language; however, the assumption that officials issue audible warnings is probably correct. These sources typically include television, radio, sirens, loudspeakers (fixed or mobile), and tone-alert radios (TARs). Additional sources may include print media, websites, open or closed captioning, roadside electronic signs (similar to the Amber Alert), placards (such as those seen at airports for transportation security), email, text messaging, and even social networking websites. Thus, the existing and decentralized warning system in the United States, though offering extensive means for warning dissemination, largely relies on audible (possibly supplemented by visual) messages that are often transmitted through an intermediary. Thus, even if a message has been written by a professional, the interpretation and reiteration of the message may vary as the information moves along from one person to another. Accuracy is often lost. As a case in point, consider the effort of a radio station that had to translate the written warning of an impending tornado into Spanish. Failing to properly do so, the station only reported on the *news* of the tornado, which contributed to the lack of warning dissemination (Aguirre 1988). Most

warning messages say absolutely nothing about how to warn people with disabilities and often fail to provide instructions on how to take protective action specific to disabilities. This is especially important in rapid onset events.

A second step requires the recipient to believe that the message is credible. A number of barriers interfere with credibility. Cultural and language differences are common barriers. Messages might not be transmitted across culturally diverse communities because of segregation, lack of trust, and historic patterns of intergroup conflict (Lindell and Perry 2004). Disseminating information into a culture that uses another language is particularly problematic; for example, limited access to or abilities to use American Sign Language (ASL) can lead to misinformation or no information dissemination at all. Furthermore, many authorities have little credibility in the disability community, owing in part to a history of circumventing the disability community in planning for disasters.

Experts contend that the best way to extend warnings is through the use of people who are as similar to the target population as possible, using well-established officials familiar to the community to enhance credibility (Fothergill, Maestas, and Darlington 1999). For example, emergency management professionals can build their credibility among the disability community by involving people with disabilities in all stages of disaster response; this also helps achieve effective response in the community during times of disaster. Another strategy is to use public service announcements (PSAs) and warning messages disseminated by people who are known and trusted in the disability community (Phillips and Morrow 2007). Shields, Boyce, and Silcock (1997) note that staff trained in emergency evacuation should provide guidance to people who are evacuating public facilities. Familiar and trusted staff can alert a significant portion of the public in such instances and ensure an efficient evacuation.

The third step involves a warning recipient (which, of course, presumes actual receipt) who decides that a threat does exist. Known as social confirmation, this behavior is common in nondisaster situations as well (Fazio 1979; Kruglanski and Mayseless 1987). People have a tendency to want to confirm their attitudes, beliefs, and opinions to ascertain that they are correct. Such behavior could be seen with Hurricane Katrina

as local residents talked to each other about the seriousness of the event and whether to evacuate. For many, the decision was delayed until an official evacuation was ordered by city and state officials. For thousands of people who lacked transportation or needed accommodation, it was too late. And the first two steps must have already occurred. If warning transmission is delayed or the warning is not received, social confirmation is delayed even further, thereby increasing the danger. Some people with disabilities require additional time to respond to an emergency; therefore, emergency managers, meteorologists, and members of the media need to provide warnings at the earliest possible moment to better accommodate these individuals.

The fourth step occurs when warning recipients personalize the message to themselves, understanding that they are personally at risk. Such personalization may not occur if people believe the threat is not as serious as predicted or if previous experience suggests that this one won't be as bad as what they have already endured. Elderly residents along the Louisiana coast, for example, delayed evacuation after comparing the impending event with their experiences with Hurricanes Betsy or Camille. Believing that nothing could be as bad, some did not evacuate. A related aspect of the fourth step is confirming that others are heeding warning messages. Being able to see, hear, or understand that other people are taking shelter increases the likelihood that a person will take action. For people with sensory, cognitive, or psychiatric disabilities, taking shelter may be further delayed if confirmatory cues are not present. Solutions include PSAs that show people with disabilities taking protective action, outreach efforts by people with disabilities or advocacy organizations, and direct appeals to people with disabilities, their families and friends, and service organizations.

In the fifth step, people decide whether protective action is needed. For example, people may assume that a tornado will continue on its route and not require protective action because they do not understand that supercells can back-build, tornadoes can change direction rapidly, and radar may not detect a risk. Or a household may decide that they do not need to evacuate for a flood because they do not understand the risk of a potential dam failure and its consequences, or an agency may fail to explain that risk.

Making a decision thus depends on understanding the information and risk assessments presented to the public. Hurricane forecasters struggle with this routinely when they talk about the "cone of uncertainty" that predicts potential hurricane landfall and the possible magnitude vis-à-vis tides and storm surges. Helping people who are at risk understand the need for protective action under conditions of uncertainty is problematic for the public in general. Because of the challenges associated with the multiple steps that occur in the warning process for some people with disabilities, the desired response may be further delayed.

The sixth step may be the single most important one for people with disabilities in the warning dissemination and response phase. In this step, those who are at risk determine whether protective action is feasible. As seen in east coast hurricanes, some people with disabilities do not evacuate if they believe that shelters are not ready for them or if a partner in the preplanned buddy system is out of town (van Willigen et al. 2002). Without accessible transportation, people may not be able to evacuate (GAO 2006a; Kaiser Family Foundation 2005). With limited mobility, people may not be able to shelter in place. In the absence of appropriate places to shelter (such as an accessible safe room), lives may be lost.

Finally, those receiving warnings determine what action to take and then take it. This step often depends on effective training and education (during the preparedness phase) so that people can assess their options and choose the most expedient and effective route. For some people with cognitive or psychiatric disabilities, this may be more difficult. Warnings that do not explain options in ways that inspire action fail to achieve the intent of the effort. Although much research remains to be done in this area, the current status of warnings for people with disabilities seems woefully inadequate.

Ken Fisher, New Orleans operations section chief for the Office of Emergency Preparedness, provided an overview of issues to consider at the January 30, 2008, NCD quarterly meeting (NCD 2008a). Fisher noted that one of the goals of emergency preparedness for the City of New Orleans was supporting citizens with special needs by addressing medical needs, hospitalized and elderly people, and people without transportation to shelters. Fisher noted that it was important to "create and maintain an environment where the decision to evacuate becomes more desirable than remaining behind" (NCD 2008a). He proposed that this could be done by creating friendlier sheltering plans and providing information earlier so individuals could develop their own evacuation plans.

Problems with Warning Receipt Among People with Disabilities

Providing an appropriate warning that is clearly understood (and then correctly followed) largely depends on the communication needs of the receiver. People with disabilities make up an increasingly broad and diverse community, and communication needs differ depending on individual circumstances. People who may have special communication needs for disaster warning messages include people who are deaf, deaf-blind, blind, or visually impaired; the frail elderly; and those with cognitive disabilities. Kailes and Enders (2006) note that individuals with communication needs include those "who are ethnically diverse; have limited or no ability to speak, read, or understand English; have reduced or no ability to speak, see, or hear; and have limitations in learning and understanding" (p. 14). Furthermore, according to Kailes and Enders (2006, p. 14),

[M]ost people who have limitations that interfere with the receipt of and effective response to information are self-sufficient but need information provided in methods that they can understand and use. This is a very large and diverse population of those who will not hear, see, or understand, in addition to those who cannot hear, see, or understand.

Deaf and Hard of Hearing: Closed Captioning

Inclement weather warnings often go unheard (and therefore unnoticed) by deaf or hard of hearing individuals (Wood and Weisman 2003). Many people who are deaf or hard of hearing are left to speculate about weather conditions when the audible systems in place do not adequately communicate warning messages in a format that can be easily understood and followed. Civil Defense sirens are another method of concern. Many

individuals who are deaf or hard of hearing cannot hear the siren, although their tax dollars help fund this service for the general population.

As noted by Wood and Weisman (2003, p. 188) there is a "'hole' in the nation's weather warning system." The Federal Communications Commission (FCC) revised Section 713 of the Communications Act to include a requirement that broadcasters communicate emergency details in a "visual format" (Wood and Weisman 2003, p. 188). Before the 2000 FCC ruling, emergency weather alerts often crawled along the bottom of the television screen. These crawls were often obliterated by closed captioning and were therefore ineffective for deaf viewers. Under newer guidelines (which began August 29, 2000), captioning and weather crawls must be able to be viewed without blocking each other. Research has not confirmed the effectiveness of these new guidelines, but general observation of media coverage suggests that the guidelines are not yet well implemented.

For example, Phillips and Morrow (2007) observed that despite the FCC guidelines, many emergency broadcasts still fail to provide live (or real-time) captioning. While realtime captioning is not an FCC requirement, many individuals who are deaf or hard of hearing prefer it. Also, there is a range of other options that serve the same purpose (see the section on technological devices in this chapter). Finally, the FCC did not begin to enforce its regulations aggressively until after the 2003 California wildfires. A recommendation included in the SNAKE report states, "The FCC must immediately issue strong statements that remind video programming distributors, including broadcasters, cable operators, and satellite television services that they must comply with their obligation to make emergency information accessible to people with hearing and vision disabilities" (NOD 2005, p. 12).

Because weather crawls on television begin with a beeping tone, many viewers who are deaf or hard of hearing miss emergency weather information either partially or entirely. Real-time captioning of unscripted material (e.g., breaking news, weather reports) are mandated by the FCC; however, it is "expensive, time critical, and labor intensive" (Wood and Weisman 2003, p. 191). While those surveyed prefer real-time captioning, it can be difficult for smaller markets to afford the services of stenocaptioners. Stations

may contract with real-time captioning firms or purchase voice recognition technology to translate breaking news and weather reports. While the Weather Channel provides realtime captioning at all times, local information is not provided for viewers in rural areas using satellite. Again, other options may exist for viewers in these areas; they are discussed in the technological devices section below.

Alternatives to Closed Captioning

Are there other strategies to disseminate warnings to people who are deaf? Warning research in general demonstrates that people will secure information from trusted sources. In Wood and Weisman's research, 81 percent of those surveyed stated that they had "experienced a fear of being unprepared for weather emergencies" (p. 189). Wood and Weisman discovered that individuals who are deaf or hard of hearing preferred to obtain severe weather information from television, followed by personal notification by family, friends, or coworkers. This method requires that individuals who are deaf or hard of hearing remind those who can hear audio warnings to alert them when severe weather is forecast. This may be an unreliable method, in part because it relies on others. As noted by van Willigen and colleagues (2002), reliance on a buddy to help with evacuation may not work if the buddy is unavailable. Similarly, relaying information or remembering to do so depends on a dedicated social relationship that may not always exist. However, it is clearly advisable to involve social networks in disseminating warnings as part of a broad and diverse warning effort.

Another dimension relates to the interpersonal effects of fostering dependence on others by not providing adequate and diverse warnings. A post-9/11 report from the Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN) and the Northern Virginia Resource Center for Deaf and Hard of Hearing Persons (NVRC) said that many deaf and hard of hearing individuals were left to speculate about the emergency at the World Trade Center during the event. Many deaf professionals learned of the event through their coworkers, sometimes with mixed results.

One state agency employee wrote, "It is demeaning and undignified to depend on hearing coworkers to tell us when an announcement was made and what it was in reference to. Sometimes they are not around." This employee suggests a visual public announcement system so that people with hearing loss will be alerted to any emergencies or emergency drills that arise. (DHHCAN 2004, pp. 32 & 33)

Another problem may occur when information is transmitted from one person to another through a serial form of transmission: accuracy is lost. If people with disabilities rely on those who do receive the message (such as people who are hearing or not visually impaired), the serial transmission process from a weather service to a media outlet to a "buddy" to a person with a disability may introduce a number of errors, including interpretation of risk, location and magnitude of the hazard, recommended action, and possible consequences.

Phillips and Morrow (2007) note that deaf or hard of hearing individuals often lose emergency information when meteorologists turn their backs to the camera while talking, making it impossible to read their lips. The authors state that "simply transmitting the warning is insufficient, because message content is interpreted within the receiver's sociocultural context" (p. 62). Few studies are available that demonstrate how "deaf persons receive, interpret, and disseminate warning messages …" (p. 62). Sole reliance on lip reading among the deaf and hard of hearing population during emergency response can have disastrous effects. Heppner (2005, para. 8) says that "only 35% of the English language is visible on the lips" (para. 8).

Alternative strategies may be an option, although none is without pros and cons. Wood and Weisman (2003) note that while some deaf and hard of hearing individuals report that they use the Internet to track weather conditions, this may be an inaccurate source of information for severe weather emergencies. Even if Internet sites provide timely and dependable weather information, power outages are a concern when using this method.

Multiple and diverse means of disseminating warnings benefit people in general and certainly benefit people with disabilities. Audio alerts, text messages, Internet information, social networking, well-written warning messages, and well-trained message communicators are key to successfully delivering warning messages. Diversifying warnings supports people without disabilities, too. The post-9/11 report by DHHCAN noted that "hearing people benefit from captions too" (p. 18). In areas with loud noise or crowded conditions during emergency situations, captions can help those who are not hard of hearing better understand the emergency and respond appropriately (DHHCAN 2004).

Warnings, Response, and People with Visual Disabilities or Limitations

While there is little research on the effectiveness of warning communications when it comes to people who are blind or visually impaired, the American Foundation for the Blind (AFB) provides some discussion regarding key issues. A blog posted by Carl Augusto (2005) on the AFB website (www.afb.org/blog/blog posts.asp?FolderID=24) states that while radio has historically been an excellent communication method used by people who are blind or visually impaired, many individuals with vision loss are now relying more heavily on television to meet their communication needs. He notes that the television format, however, creates difficulties among people who are blind owing to its reliance on graphics and crawling text to communicate disaster warnings. Augusto says that media reports on the events surrounding Hurricane Katrina confirm that cell phones and similar technology can be helpful for obtaining information when television and radio are no longer available. However, he recognizes that "the problem is [that] much of this technology is still not user-friendly for people with vision loss, which can leave people who are blind or who have low vision in a dangerous predicament" (para. 4). On-air meteorologists seem to assume that the consumer has good vision and can see the radar images. It is not unusual to listen to an emergency weather broadcast in which a meteorologist describes the path of a storm without proper audio cues as to its location or trajectory. More recent technologies that project a storm path, location, and time may be useful, but only if they are offered through audible means as well as through visual graphics.

Augusto notes that these issues are being addressed through a partnership between AFB and the FCC Media Security and Reliability Council. According to Augusto, these entities are working to develop standards to address the needs of individuals with vision loss during times of disaster. Furthermore, Augusto reports that "the Carl and Ruth Shapiro Family National Center for Accessible Media at WGBH (NCAM) is working on a project to identify the gaps that exist between alert systems that deliver information and to find a way to fill in those gaps" (para. 5).

Individuals who are deaf-blind have more diverse needs but often "prefer large print displays when available" (DHHCAN 2004, p. 33). Furthermore, "they cannot rely fully on visual cues or audible cues. Instead, they rely more on tactile cues. This puts them more at risk during an emergency" (p. 34). Communication with individuals who are deaf-blind can range from sign language near the person's face to sign language in the palm to words written on the palm with a finger (DHHCAN 2004). According to Huebner (1995), "The universal symbol for an emergency that an adult who is deaf-blind usually responds to is the tactile symbol 'X,' 'drawn' on his or her back by the person who is alerting him or her" (p. 22). This signifies that an emergency has occurred and that it is imperative for the person receiving the message to follow directions and not ask questions at this time. Yet, few if any preparedness materials or training workshops incorporate this or similar information.

While current practices have been addressed here, it is important to note that there is no evidence of the effectiveness of such practices. Research is needed to better plan and assist in the efficient and safe evacuation of people in the deaf, deaf-blind, and visually impaired communities.

Warnings, Response, and Mobility and People with Cognitive Disabilities

Dyer and colleagues (n.d.) point to the frail elderly as a vulnerable population whose members often have physical and cognitive disabilities that must be taken into account when planning for recovery. Mobility disabilities may hinder response, extending the time it takes for individuals to move through Mileti's steps after they receive the message and take action. As previously mentioned, mobility disabilities may be hidden and thus overlooked when emergency personnel communicate response instructions to the general population. According to Dyer and colleagues (n.d.), during Hurricane Katrina, the frail elderly were especially hard hit. Many refused or were unable to evacuate, and many drowned as a result. Emergency managers must keep in mind that this population suffers disproportionately from dementia, stroke, and other diseases, such as Parkinson's disease, which can affect cognitive ability. Many also "require varying degrees of [physical] assistance with activities of daily living…" (p. 4).

Research regarding individuals with cognitive disabilities tends to focus heavily on evacuation or psychological recovery (which are covered in a later chapter). Please see the evacuation section below for additional information regarding individuals with learning disabilities.

Technology Overview

Crandall and colleagues (n.d.) reported on the California State Fire Marshal's Emergency Evacuation Information Task Force for People Who Are Blind or Visually Impaired. Findings of the task force suggest that "some mixture of audible and tactile format is best for reaching the largest number of visually impaired individuals" during emergency response from public facilities (para. 13). The task force notes the need to provide emergency information that is equivalent "to that offered (to) sighted people" (para. 14). Pre-emergency options include—

providing handouts in the form of tactile maps; Braille, raised, and large print or devices such as portable recorders, auditory push-button devices, and infrared signs built into all EXIT route signs as potentially being appropriate mechanisms of preparing occupants for [emergency response]. (para. 14)

The task force made three recommendations for technology and assistive devices:

1. All exit signs shall be in Braille, raised print, and large print in high contrast.

- 2. Exit route signs shall be accessible through an infrared system using a receiver, and shall have an emergency power backup system. During an emergency, an audible indicator (sound or word) shall be provided at the point of the exit. This would be considered an approximation of equivalency.
- Emergency procedures information shall be available, on request by consumer option, in the following formats: large print, Braille, and an audible form. The audible form may include but shall not be limited to a personal tour. A personal tour along with an alternative, audible format would fulfill this requirement. (para. 17)

California SILC (2004) made the following recommendations regarding notification:

- Activate enhanced 9-1-1 and/or reverse 9-1-1 systems. These systems can have compatibility problems with TDDs. When such technology is purchased, this must be factored into the decisions about which systems to buy.
- Ensure that notification systems are in place, including reverse 9-1-1 systems, that can also advise individuals with disabilities through the use of TTYs if necessary, including advice to purchasers about placement of TDD messages.
- Ensure that local news related to evacuation announcements is presented on television stations that cover an expanded area. This recommendation relates to the inability of people in San Bernardino County to receive notification concerning county conditions during the 2003 fires, as Los Angeles stations were not targeting news in those areas.
- Volunteer organizations serving people with disabilities and seniors should assign members to maintain and operate a phone tree for notifying association members in the event of area emergencies (p. 7).

The FCC has continued to remind broadcasters of the regulations that must be met to assist people with disabilities during emergencies. This has included letters to television stations in the Washington, D.C., area during the sniper shootings in 2002. The FCC

also regularly meets with members of the disability community to discuss emergency warnings and how they might be improved (NCD 2005).

Kailes and Enders (2006) provide the following list for better addressing communication needs and improving response among people with disabilities:

- Posting content of oral announcements in a specified public area so that people who are deaf, hard of hearing, or out of hearing range can go there to get or read the announcements.
- Designating a specific time of the day and place where foreign language and sign language interpreters will be available to communicate information.
- Employing trusted community-based organizations that can effectively communicate with the communities they serve (pp. 14 & 15).

Technological Devices

Wood and Weisman (2003) point to the potential of a special needs weather radio, released in 1999, as a device to help with warning receipt in the deaf and hard of hearing community. This technology is ideal for someone with hearing loss.

The receiver includes a strobe light as well as an auditory signal that alerts a deaf or hard of hearing person; a liquid crystal display that shows what type of watch, warning, or advisory has been issued, along with duration of watch or warning; and a pillow vibrator/bed shaker that awakens the person from sleep in case of a local weather warning. (p. 192)

An adapter for a car cigarette lighter allows this radio to be used on the road as well. Other adaptations, such as weather alert messages in large print or Braille, are also available for individuals who are blind or have a visual limitation. Wood and Weisman note that while this technology is a step in the right direction, some issues still exist with the special needs weather radio. For instance, full text is not yet available when a warning is given, so the recipient is unable to identify the source of the information, the types of hazards expected, or the suggested safety measures. Also, this service is not available throughout the nation at this time. Furthermore, deaf and hard of hearing individuals generally do not think that a radio is a device they will use; therefore, education is needed in the deaf and hard of hearing community about this new technology and its possibilities for improving emergency response. This technology is typically less portable compared with newer devices to which the general public has become more accustomed.

Weather pagers are a viable option for alerting deaf and hard of hearing individuals during severe weather warnings (Wood and Weisman 2003). Full-text warnings are sent to the pagers, causing a vibration and notifying the wearer that a message has been received. While the benefits of this technology are obvious, the service is not free. It should be noted here that deaf and hard of hearing taxpayers pay into the Civil Defense warning systems that alert all hearing citizens when severe weather alerts are issued. However, this service is not provided to the deaf and hard of hearing community. Costs for using a weather pager include the pager itself plus a monthly service fee. To address this issue, some municipalities have secured private funding or offer this service to deaf or hard of hearing individuals at a free or reduced cost. The Oklahoma School for the Deaf piloted this program in the State of Oklahoma. Because of its success, the project was expanded statewide. Deaf and hard of hearing individuals who sign up for the free program must provide their own wireless device with email communication. All individuals enrolled in the program receive an instant message when a tornado warning goes out in their county.

Weather Alert 2000 provides text to wireless phones and pagers during inclement weather (Wood and Weisman 2003). "The device can activate a strobe light and an alarm tone when it receives warnings via a satellite signal, and can be programmed to receive weather alert information for up to 16 counties anywhere in the United States" (p. 193). While this technology is more expensive than the monthly fees incurred by weather pagers, it is able to transmit messages during storms, when weather pagers cannot.

Oklahoma's Weather Alert Remote Notification (OK-WARN) for deaf or hard of hearing residents offers emergency alerts through email, pager, or text messages. Using a FEMA grant, the Oklahoma Office of Emergency Management (OEM) was able to provide this service free to deaf and hard of hearing individuals who have their own pager, email address, or cell phone, and who fill out an application form on the Oklahoma OEM website. Critical messages are delivered repeatedly and are also archived for the long term (http://www.ok.gov/OEM/Programs & Services/ Preparedness/OK-Warn for the Deaf and Hard-of-Hearing/index.html).

In addition to traditional relay service, Internet-based relay calls can be made using an Internet connection in conjunction with technology such as a "videophone, webcam, text pager, or computer" (National Emergency Number Association [NENA] 2008, p. 9). When using video relay, a caller can communicate with someone using sign language or by reading lips. Voice Carry Over (VCO) can also be used, if the caller prefers. "With VCO in use, the telecommunicator will hear the caller's voice and not the voice of the video interpreter (VI)" (NENA 2008, p. 10). NENA is documenting "guidelines for Public Safety Answering Points (PSAPs) and recommendations to the FCC" for video relay usage (NENA 2008, p. 11). Video relay message services are often provided free of charge.

Recently, social networking sites have been used to distribute emergency preparedness information, and they could be used for dissemination of warnings for slower onset events. Universities, emergency management agencies, the Department of Homeland Security, and FEMA have initiated experiments using Twitter, Facebook, and similar tools. The extent to which these sites are used or may influence the disability community is unknown, but this area should be explored as one of the tools for warning dissemination.

Evacuation

During their research on hurricane evacuations, van Willigen and colleagues (2002) found that people with disabilities were routinely overlooked, and they cautioned emergency managers against assuming that their needs had been addressed. While
some organizations have taken huge strides in assisting people with disabilities during evacuation, most place responsibility for this problem on the individuals themselves—a variation on the medical model (Tierney, Petak, and Hahn 1988). On the basis of census results, Morrow (1999, p. 5) argues that a "sizable segment" of any community's population will need additional assistance during evacuation. Add to this number those who may be experiencing temporary disability, such as a broken leg, and the difficulty in predicting the number who will need assistance is evident (FEMA 2002, p. 3). In the Houston area alone, at least 40,000 people required power for wheelchairs, ventilators, and similar equipment before Hurricane Ike (Frieden 2009).

Fox and colleagues (2007) argue that most first responders assume that everyone is able to evacuate safely without any additional assistance. This assumption can prove problematic when the evacuation scenario includes people with disabilities. Although people with disabilities are not always helpless, many do face unique evacuation barriers that must be addressed during the development and execution of evacuation plans.

Christensen and colleagues (2007) point to the need for better "understanding of the complexity of evacuation issues" (p. 249). They address evacuation responses (i.e., protective, preventive, rescue, and reconstructive) as well as factors that "affect all emergency evacuations: (1) the behavior(s) of the individual, (2) the planned systems active in the event, [and] (3) the environment in which the event occurs" (p. 250).

ADA and Legal Issues

In 1995, after years of inappropriate institutional placements, two women with cognitive disabilities filed suit against Georgia for involuntary institutionalization even after psychiatric professionals recommended that they receive community-based care (Center for an Accessible Society n.d.). The case, *Olmstead v. L.C. and E.W.*, was appealed and went to the U.S. Supreme Court. In 1999, citing Title II of the Americans with Disabilities Act of 1990 (ADA), the Supreme Court ruled 6–3 that people with disabilities have the right to live in the community in a noninstitutionalized setting with proper services and support as deemed appropriate by professionals (Center for an

Accessible Society n.d.). According to Cornell University Law School's Legal Information Institute:

In the Americans with Disabilities Act of 1990 (ADA), Congress described the isolation and segregation of individuals with disabilities as a serious and pervasive form of discrimination. <u>42 U.S.C. §</u> <u>12101</u>(a)(2), (5). Title II of the ADA, which proscribes discrimination in the provision of public services, specifies, *inter alia*, that no qualified individual with a disability shall, "by reason of such disability," be excluded from participation in, or be denied the benefits of, a public entity's services, programs, or activities. §12132.

What this means is that more people are living in the community and are less likely to have supports from institutions during disasters.

Title II of the ADA requires that public entities provide services to people with disabilities in the most integrated settings possible, or as appropriate to the needs of the individual with a disability (also referred to as "integration regulation") (Cornell University Law School Legal Information Institute n.d.). This ruling has significant implications for people with disabilities who both choose to and are capable of living independent lives within their community. Many disability advocates cited cases in which people with disabilities do better living independently while receiving appropriate community-based services and support. The implication in the construct of emergency planning is clear since the landmark ruling, it is prudent to assume that every community is made up of individuals with disabilities living independently and that these individuals may be less likely to have the support of institutions during disaster. Thus, plans must take this demographic knowledge into account.

In reviewing the design requirements of the ADA Accessibility Guidelines for Accessible Egress (ADAAG), Christensen and colleagues (2007) note that the document recommends evacuation procedures that "[do] not create an accessible environment... [but rather only indicate] the presence or lack of an accessible environment" (p. 251).

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For instance, signage or alarms highlighting areas of rescue assistance or accessible means of egress (as outlined by ADAAG) do not necessarily provide accessibility to people with disabilities. Christensen and colleagues assert that such recommendations further victimize vulnerable populations and do not meet "the intent of the ADAAG, [which] is to ensure an accessible built environment..." (p. 251). ADAAG recommendations "are essentially planned evacuation systems" as they do not focus on the built environment (p. 252). In contrast to this, FEMA and the United States Fire Administration (USFA) have developed a guide, *Emergency Procedures for Employees with Disabilities in Office Occupancies*. Page 13 of this guide provides an example of areas of refuge as well as horizontal exits.

The problems mentioned above in government evacuation requirements for meeting the needs of people with disabilities further perpetuate disability for the very population they attempt to serve. Christensen and colleagues say that such policies require "individual responsibility and preparation to adapt to barriers in the environment in lieu of removing the environmental barriers that contribute to the increased risk" (p. 253). Recommendations for future research include the need to address the built environment when studying evacuation and response procedures among people with disabilities. A shift in focus will help create policy that concentrates on the underlying environment and responds by limiting features that pose greater risks to vulnerable populations. By seeing to it that the built environment better meets the needs of the most vulnerable populations, policymakers can create an environment that improves response and evacuation outcomes for all populations. Several federally funded studies are under way on this important research.

In Savage v. City Place Limited Partnership, et al., a settlement was reached that forced Marshalls, a major retailer in 42 states and Puerto Rico, "to provide accessible evacuation routes for shoppers with disabilities in all of its stores…" (Gardner and Hollman 2005, para. 1). Katie Savage, who uses a wheelchair, filed a lawsuit after being trapped in a mall when Marshalls employees tried to force her to exit via an inaccessible path during an emergency evacuation. Savage became trapped in an underground

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portion of the facility, where she was unable to use the elevators. The Circuit Court for Montgomery County, Maryland, "found that the ADA requires places of public accommodation to consider the needs of people with disabilities in developing emergency evacuation plans" (Gardner and Hollman 2005, para. 3). According to Elaine Gardner, director of the Disability Rights Project at the Washington Lawyers' Committee for Civil Rights and Urban Affairs—

The ADA always has been understood to help get people with disabilities into places of public accommodation. Now, for the first time, it also works to ensure that public places try to get those same people <u>out</u> in the event of a fire, terrorist attack, or other emergency. (para. 4)

Evacuation for People with Physical Disabilities

Dave Beste, a captain with the Bellevue Fire Department in Bellevue, Washington, spoke at the NCD quarterly meeting in Seattle, Washington, on July 15, 2008 (NCD 2008c). Beste described the mission of the Emergency Evacuation Task Force as well as the partner organizations and representatives that were active in the group (NCD 2008c). According to Beste, the Emergency Evacuation Task Force includes the following:

The National Institute of Safety and Technology, the American Society of Mechanical Engineers, the fire service, the International Code Council, the Government Services Agency, the elevator industry, [representatives of] both Canada and the United States, human behaviorists, and, finally, [representatives of] the disability community. (NCD 2008c)

The task force is performing a hazard analysis on high-rise office buildings and identifying building code policy to prevent collapses similar to the one that occurred at the World Trade Center. Furthermore, the group is proposing new protocols and technologies that would allow elevators to be used during a fire for people with disabilities. Such technology would allow people with physical disabilities to evacuate themselves "without the [direct] help of the fire service" (NCD 2008c).

Elevators would be programmed to stop running once a smoke detector sounded; however, they would go to the affected floors. Once there, individuals trained to use the elevators would aid people with disabilities in evacuating the floors affected by fire. The fire department would be able to use all the elevators for this purpose or only some of them. Furthermore, with the use of "pressurized stairwells," air pressure would prevent the smoke from leaving the floor and going into the elevator or lobby (NCD 2008c). Finally, audio and video signage would direct evacuees from the building in a safe manner. A two-way communication system would be installed in every elevator lobby, and a person on any floor could call fire control for assistance. According to Beste, this code change has been submitted to the International Building Code and will soon move forward for public comment and a committee vote.

An ADA Guide for Local Governments (DOJ 2006b), suggests policy development that plans for the safe evacuation of people with disabilities. Such policies include transit buses with wheelchair lifts, early evacuation, and voluntary registries. Accessible transportation should be identified early and made available during evacuation.

Evacuation for People with Intellectual Disabilities

Interestingly, although mobility disabilities have been addressed in disaster response activities much more often than other disabilities, many of the "invisible" disabilities are overlooked when it comes to sending out warning messages during the period of response. Even obvious mobility disabilities are sometimes disregarded during this stage. In the California wildfires, SILC reported that "many individuals who require mobility aids to walk or move themselves were evacuated without those items" (California SILC 2004, p. 5). In the same report, SILC found that the Mountain Area Rural Transit Agency (MARTA) drivers were aware of those individuals who were in greatest need of transportation assistance and were able to evacuate many people with mobility disabilities. However, when they returned to assist in evacuating more people, many roads were closed, resulting in "several hours' delay in the evacuation process" (p. 5).

Historically, evacuation studies have focused on individuals with mobility disabilities, rarely addressing evacuation needs among people with severe learning disabilities (Shields, Smyth, Boyce, and Silcock 1999). In a few small studies in the United Kingdom, evacuation behaviors of people with learning disabilities have been measured. For the purposes of these studies, an individual must have had an intelligence quotient (IQ) score below 70 (Santrock 20078) and additional deficiencies in age-appropriate behavior, including "impairments in adaptive functioning, such as social skills and responsibility, communication, daily living skills, personal independence, and self-sufficiency" (Shields et. al. 1999b, p. 336). Through meta-analysis of the existing literature, Shields and colleagues reviewed training programs among individuals with intellectual disabilities and drew the following conclusions regarding evacuation considerations among this population:

- Of the adults with a disability in a given population, a considerable percentage may have cognitive disabilities and may be without assistance in public facilities.
- Residential life (including group homes) for people with mental disabilities provides a host of safety issues related to emergency evacuation, particularly unannounced nighttime evacuation behavior.
- Separate research by Shields and colleagues (cited in the same article as the information above) found that individuals with cognitive delay failed to warn or assist others in an unannounced nighttime emergency evacuation drill. In fact, expected behaviors exhibited by individuals without cognitive disabilities during times of evacuation were not consistently followed by those with learning or cognitive disabilities. These behaviors included seeking additional information, finding help or calling the fire department, preventing the spread of fire and smoke, looking for others in the building, warning and assisting others in the building, preventing property damage, and meeting at a safe area.

According to the meta-analysis provided by Shields and colleagues (1999b), individuals with cognitive disabilities may have difficulty understanding or processing evacuation messages. This may occur even when daytime training has been provided but the

evacuation procedure takes place at night. Instructions need to be clear, repetitive, and straightforward. The authors conclude that daytime evacuation practice for people with mental disabilities may not effectively translate into nighttime evacuation success (p. 342). For instance, people with cognitive disabilities do not consistently follow evacuation directions and response times at night, even after easily maneuvering such tasks during daytime drills. Additionally, Shields and colleagues (1999b) note that employees of public facilities should be actively engaged in evacuation drills that include the public so they can practice assisting individuals with a variety of needs based on age or disability.

The Nobody Left Behind (NLB): Disaster Preparedness for Persons with Mobility Impairments research study identified six emergency management sites that had guidelines in place for meeting the needs of people with mobility disabilities during disasters (White, Fox, and Rooney 2007). According to the authors, these sites "took a comprehensive approach to addressing the needs of persons with disabilities, including mobility impairments" (p. 3). If they include people with disabilities in planning efforts, emergency management sites are better able to plan for and carry out evacuations. Specific guidelines that distinguished the six sites included these:

- Administering and maintaining a surveillance system, usually a self-identified registry system of persons needing assistance during a disaster or emergency.
- Identifying accessible transportation vehicles and guidelines to evacuate persons with disabilities needing assistance.
- Establishing a shelter to meet needs.
- Conducting training and exercises on evacuation of persons with disabilities.
 (p. 4)

After the 2003 Southern California wildfires, SILC (2004) provided the following recommendations for evacuation of people with disabilities:

- Transit agencies need to play a key role in local and statewide emergency planning.
- Paratransit rider lists should be available for emergency services personnel to use to contact transit-dependent individuals in the event of an emergency.
- Transit vehicles need to be treated as emergency vehicles for purposes of evacuation.
 - Driver training certification programs need to be established.
 - Transit vehicles need access to fire zones for emergency purposes, even after roads have been closed to nonemergency vehicles.
 - Emergency services personnel should be willing to escort one or more transit vehicles through danger areas in the event of an emergency.
 - Transit agencies should be reimbursed for excess costs related to emergency services and evacuation.
 - Transit agency dispatchers should relay updates about emergency situations received from drivers to media or family members of passengers living in affected zones.
 - Transit vehicles should be stocked with emergency preparedness and evacuation brochures and similar safety-related materials.
 - Paratransit dispatchers should routinely call regular riders when emergencies occur to ensure that they are aware of the situation and to schedule rides if needed. If they are unable to contact the riders, emergency services personnel should be notified. (pp. 8 & 9)

According its website, Project Safe EV-AC is "a three-year developmental project" that seeks to improve evacuation from multiple settings for people with disabilities (<u>http://evac.icdi.wvu.edu</u>, para. 1). The project provides free materials for people with disabilities and emergency management personnel. Project Safe EV-AC has a training library for individuals and emergency responder teams as well as a short guidebook on evacuation techniques for people with disabilities and a train the trainer program.

Registries

To hasten evacuation efforts, some registries can identify the location of people with disabilities who will need additional evacuation assistance if they are specifically set up to do so, including the location of group living facilities (Morrow 1999, p. 10). For example, in response to two teenagers who identified a potential response need for their cousin with autism, the "Wexford Volunteer Fire Company in Pine, Pennsylvania, developed a registry for residents who require special accommodation in an emergency" (DHS n.d., p. 1). The program is called First Look, and it allows people with disabilities or their family members to register their information and specific needs with the program at any time.

Registries vary considerably in terms of how they are set up and used. A registry may be as simple as a paper list of people who may need assistance during a response effort or as detailed as an Internet-based database with multiple layers of information. Registries can include a wide range of potential registrants, from congregate care populations to individuals at home. Lists can also include broad categories of those in potential need of assistance, including people with mobility, cognitive, and sensory disabilities; people with medical needs; the elderly; children home alone (latchkey children); pregnant women; and individuals with either chronic or temporary conditions. Registries can range from short lists to extensive compilations. However, although registries have become popular strategies in recent years for untoward events, scientific research has not yet been conducted to specify the types of registries that exist and the conditions under which those lists operate best.

Discussions at emergency management, response, public health, and disability conferences have generated debate over the value and use of registries. Although a list of people who may need assistance certainly provides crucially needed information, problems with registries have also been identified. For example, no single agency appears to be the sole entity responsible for development of a registry. Across the nation, it appears that registry lists develop from a number of sources, including emergency management offices, 9-1-1 call centers, public health agencies, private

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contractors, and specific agencies (e.g., client lists from home health agencies, disability organizations, and hospitals). And people may not be at their home address when an emergency occurs; people with disabilities may be at work, school, day care, doctors' appointments, or out doing errands or visiting friends.

A second potential problem with registries concerns the willingness of individuals to selfidentify as having a disability. Some individuals may not see themselves as having a disability, whereas their family members do. Concerns over sharing private information or appearing dependent seem to deter some people from registering. Because a standard for managing confidential information does not exist for registries, and because HIPAA regulations may prevent disclosures, the sharing of information among responding agencies is problematic. Certainly, some issues with this type of information system occur in a large-scale disaster, when emergency responders are needed in many areas simultaneously.

Development of lists can be an issue as well. To reach the potential registrants, significant measures may need to be taken that can require considerable staff time and funding. In an Alabama location with a potential for a chemical release, efforts to develop a special needs registry involved the state and local emergency management agencies, a privately contracted mailing firm, and a variety of social service and health agencies. Reaching those potentially in need of assistance took a great deal of time and money, involving scientifically based random sampling, saturation mailing, self-registration, targeted distribution, agency lists, and referrals (Metz et al. 2002). Argonne National Laboratory organized the initiative, which occurred over several years and revealed a number of challenges:

Accuracy as to names, addresses, telephone numbers, and impairments is essential to being able to provide the assistance needed by each individual of the special needs population. The data... are perishable, requiring constant aggressive maintenance, because a large percentage do not readily respond to update requests. (Metz et al. 2002, p. 278) Indeed, maintenance of a list may be the single most challenging task once a list is compiled. Just as people routinely forget to notify friends, subscription companies, and others when they move, so do people on registered lists. Maintaining a current list of those with needs for assistance during times of emergency is likely to take considerable staff time, funding, and outreach efforts.

Finally, as demonstrated in the California State Independent Living Council report on the 2003 wildfires, access to the registry is an issue. Emergency responders in the wildfires were unable to access the lists to determine who might need evacuation assistance.

Alternatives to Registries

In a post on the American Foundation for the Blind website, individuals discussed emergency preparedness and included items that transition into response. One individual, screen name ocbbound (2007), stated that her local fire department used a system with an outdoor lockbox containing a key to a person's home. Emergency responders could access a person's home during times of disaster if they had made previous arrangements for this system. This would allow responders to come into a home to warn and assist an individual who may otherwise remain unaware of the emergency.

Another suggestion is window placards that identify people at home who may be at risk. An argument against this kind of signaling device is that it might reveal the locations of people who are unable to defend themselves against an intruder, thereby increasing personal jeopardy. Individual alarm systems can also be used to connect an individual who is unable to evacuate to rescue services. However, such systems typically cost more than an individual surviving on Social Security, Supplemental Security Income, or low wages can reasonably afford. Such a system also may not be available universally, particularly in rural areas.

Transportation Assets

When evacuation is necessary, additional attention must be directed toward the availability of adequate transportation for individuals with disabilities and the technology or mobility devices they rely on (e.g., wheelchairs). When assessing lessons learned from Hurricanes Katrina and Rita, Litman (2006) stated that many people did not evacuate during Hurricane Katrina because they lacked a vehicle and money. According to the *Survey of Hurricane Katrina Evacuees*, the most common reason provided by respondents for not evacuating was "I did not have a car or a way to leave" (Kaiser Family Foundation, 2005, p. 6). Furthermore, in the realm of transportation, Litman (2006) asserts that planners met the needs of people who had resources "relatively well," while those who were "poor, disabled or ill were not served well, apparently because decision-makers were unfamiliar with or insensitive to their needs" (p. 12).

In studying the aftermath of Hurricane Katrina among New Orleans residents, the Government Accountability Office (GAO) found that state and local governments did not "integrate transportation-disadvantaged populations" into their evacuation plans (GAO 2006a). GAO also found that most state officials did not believe that many of their residents needed transportation assistance, despite U.S. Census data to the contrary. GAO recommended that federal agencies, such as the Department of Health and Human Services and the Department of Transportation, become involved by "clarifying federal agencies' roles and responsibilities for providing evacuation assistance" and "[encouraging] grant recipients to share information to assist in evacuation preparedness for these [transportation-disadvantaged] populations" (GAO 2006a).

When addressing people with disabilities who lack transportation and money, emergency planners must plan for the evacuation of assistive devices in addition to the person. These assistive devices are often custom fit for the individual and should be evacuated with him or her to ensure maximum independence, to lower reliance on emergency assets, and to speed postevent recovery. Service animals are also vitally important to their owners' ability to maintain independence and should be evacuated with the person. Litman notesVarious strategies could have been used to increase evacuation rates [during Hurricane Katrina], including more information on the risks facing people who stay, subsidized transportation, more comfortable and secure shelters, and better protection of homes. Had residents been offered free transportation out of and back to the city, and the assurance of a relatively comfortable and safe refuge, perhaps half of those who stayed would have left. This would have greatly reduced crowding at emergency shelters and subsequent rescue problems. Assuming that 200,000 residents had accepted free evacuation transportation at a cost of \$100 each, it would have required \$20 million in subsidy. This may seem costly for a single city (it represents about 20% of the regional transit agency annual budget), but it is tiny compared with the costs it would have avoided. (p. 11)

The SNAKE report calls for assurance that "locations selected are serviced by accessible transportation [and that] public transit agencies...ensure that all transportation between shelters, housing and disaster relief centers is accessible" (NOD 2005, p. 13). After Hurricane Katrina, FEMA contracted with American Medical Response (AMR) to provide paratransit evacuation services during the hurricane season of 2006. FEMA subsequently awarded a contract to serve 21 states, including triage, treatment, transportation, hazard recognition, symptom surveillance and reporting, on-scene medical standby, transport of hospital patients, immunizations, shelter staffing, staffing of hospital emergency departments, and setup of mobile medical clinics. FEMA activated the AMR contract for Hurricane Dean in August 2007. AMR provided 300 ground ambulances, 25 air ambulances, and enough vehicles to provide transportation for 3,500 passengers.

Guidance from the Federal Highway Administration is currently in draft form and subject to future release. The guidance describes a protocol for evacuation of people with disabilities and those in congregate locations from residence to reception center or shelter.

Nursing Home Residents

Transportation and long-term living arrangements are major factors in the evacuation of nursing homes. In addition to these issues, nursing homes are routinely caring for "more medically complex patients" (Saliba et al. 2004, p. 1436) and many people with mobility or cognitive impairments. Before Hurricane Katrina, an entire U.S. city had never been evacuated because of a disaster (Klein and Nagel 2007). Such an evacuation gravely impacted nursing home facilities, as most nursing home administrators had difficulty securing transportation (GAO 2006a). Deaths among nursing home residents in New Orleans following Hurricane Katrina highlighted the need to better plan and respond to the special needs in this population (Hyer et al. 2006).

While the National Disaster Medical System (NDMS) assists in the evacuation of hospital patients during natural disasters, it is not designed to aid in nursing home evacuations (Bascetta 2006; GAO 2006a). Issues of transportation for a large number of people (some with mobility disabilities), in addition to the need to secure long-term living arrangements for patients who are evacuated, create major barriers in nursing home evacuations. Evacuation and transportation for facilities of this nature must be multitiered, as residents, their personal items, staff, and long-term medical needs must all be addressed. Personnel must also account for trauma issues. Again, longer warning times can assist facility managers in making arrangements for large numbers of residents when evacuations. Administrators typically make the decision to evacuate; thus, convincing them of the importance of evacuation is key. Facilities that are part of a larger corporation are more likely to be able to evacuate, because beds can more easily be found elsewhere to accommodate residents. (Long-term living arrangements are discussed at greater length in Chapter 4).

Because evacuations are not common among nursing home facilities, preventable problems occur in the evacuation process. For instance, some residents become "lost" temporarily when identifying information is not sent with them. Hyer and colleagues (2006) recommend "development of a universal patient identification system, which would catalogue patient and facility information..." (p. 410). The authors also call for the development of plans among long-term care facilities for responding to hurricanes. They note that nursing homes and emergency management teams seldom work together and that "explicit guidelines for decision making on LTC [long-term care facilities] residents' evacuation must be developed, including systematic pre- and post-event assessments of evacuations" (Hyer et al. 2006, p. w409). The GAO has requested that DHS "clearly delineate...how to address the needs of nursing home residents during evacuations" (GAO 2006a, p. 6).

Developing and providing a transportation system that is effective for all who use it is an ongoing process. The Department of Transportation (DOT) leads the Evacuation Liaison Team (ELT), whose primary role is summed up as providing—

Federal, State, and local emergency management, highway patrol and law enforcement, public safety, and transportation officials with timely and accurate traffic and evacuation-related information during multi-State hurricane threats. The ELT supports regional hurricane response efforts by compiling, analyzing, and disseminating trafficrelated information that can be used to facilitate the rapid, efficient, and safe evacuation of threatened populations. (DOT 2006, H-6)

For additional information on broad recommendations to encourage a resilient transportation system that can better address emergency response for all populations, see Evaluating Transportation Resilience by the Victoria Transport Policy Institute (VTPI, <u>www.vtpi.org/tdm/tdm88.htm</u>).

Buddy Systems

Little has been written on buddy systems during the response phase. Litman (2006) notes that the New Orleans' city website encourages people with disabilities to develop a "support system" for assistance during emergencies, but it "provides no directions for people who lack neighbors, friends or relatives who have extra capacity in their

evacuation vehicles, which is likely to be common in areas where poverty is concentrated" (p. 12). The traditional buddy system often leaves vulnerable populations at even greater risk.

In its post-9/11 report, DHHCAN (2004) notes:

Using the buddy system to notify a coworker or neighbor who is deaf or hard of hearing can be very difficult. The individual must first be located and be aware that someone wants to give them information. Many do not hear their name called or the sound of a doorbell or a knock on the door. (p. 33)

Furthermore, buddies often forget to communicate issues to the people who depend on them or are themselves away or in danger (DHHCAN 2004). The District of Columbia Fire and Emergency Medical Services website (<u>http://fems.dc.gov/fems/site/default.asp</u>) documents the following potential problems with employee buddy systems:

- The buddy is in the building but is absent from the customary work area.
- The buddy cannot locate the employee with a disability because the employee is off from work that day.
- The employee with a disability is working late, when the buddy is unavailable.
- The buddy has not been trained in what to do or how to provide assistance.
- The buddy is inappropriate, not strong enough, or unacceptable to the employee with a disability.
- The buddy forgets or is frightened and abandons the employee with a disability. (para. 3)

The Department of Labor (DOL) (2008) states that "it is important to recognize that alternative plans may be necessary if a coworker is not available. The idea of a personal support network, where several people may be available to assist, is seen as a

better approach" (para.13). For information on assessing the need for a buddy as well as creating and using a buddy system, visit the Prepare Now website at www.preparenow.org.

Search and Rescue

There is a dearth of literature on the topic of search and rescue in general, much less as it relates to people with disabilities. Search and rescue, by its very nature, does not lend itself well to being studied. Unlike the other components of the response phase (e.g., evacuation), rescuing disaster victims always occurs in an unpredictable and hazardous environment. Add to these environmental dangers a sense of urgency and it is easy to understand why researching this topic is difficult. Although evacuation activities can occur under these same conditions, in principle, they are designed to remove people from harm's way long before the disaster strikes. The mechanics of an evacuation make excellent research targets. From designing egress routes to predicting an individual's behavior, research is continually being undertaken to improve this component of response. However, the same is not true of search and rescue.

Planning for search and rescue operations also differs greatly from other response components. Owing to the unpredictability of each disaster, first responders generally do not preplan rescue operations. Rather, they focus on practicing various rescue techniques during training exercises. This is similar to an athletic team preparing for a contest. The team members may have a general game plan in place before the event, but they usually practice the fundamentals and for special situations so they are prepared to adapt to the unpredictable nature of the game. In similar fashion, first responders work on the fundamentals so they are prepared for the unexpected aspects of disasters. It is during the practice of these fundamentals that guidance in lifting, moving, and communicating with people who have disabilities should be incorporated.

Because of our decentralized society, responsibility for the initial response to any disaster rests on the shoulders of the local government (Drabek 1985, p. 85). Thus, the incorporation of special training in rescuing people with disabilities must be initiated at the

local level. Most first responders approach all search and rescue assignments with the same mindset—get the victims out as quickly as possible. While speed may be of the utmost importance in these situations, first responders must also be careful not to exacerbate the situation. This is especially true in rescuing people with disabilities. First responders need to understand the unique abilities and limitations associated with different disabilities. This knowledge must then be transferred into rescue training and actual rescue situations. For example, first responders are cautioned not to use the over-the-shoulder carry when rescuing a person who uses a wheelchair (FEMA 2002, p. 13). This carry can cause additional life-threatening injuries because of the health issues associated with the person's disability. Therefore, rescuers must practice multiple carrying techniques during training to be proficient in applying them during a rescue operation. The old adage "You will play the way you practice" holds true for rescue situations that do not allow the rescuer sufficient time to plan each step of the process.

The U.S. Fire Administration has developed a detailed guide, *Orientation Manual for First Responders on the Evacuation of People with Disabilities*, that should be incorporated into the standard operating procedures of local first responders. Although this guide is primarily aimed at evacuating people with disabilities, many of the concepts could be adapted for use in search and rescue operations. In addition, first responders should attempt to rescue the victim's assistive technology, if at all possible. These assistive devices are often essential to the person's survival and will speed his or her recovery. Although rescuing these assistive devices should not take precedence over a human life, they should receive consideration when time and resources allow.

Incorporating special training in rescue techniques involving people with disabilities will not be easy. The Fire Service in particular is extremely resistant to changes suggested by "outsiders." However, the situation is not hopeless. A publication such as Oklahoma State University's *Social Etiquette—Tips for Firefighters* may be accepted because it was developed by a fire-related entity. It may be beneficial for organizations developing such guides to partner with a well-known fire department, such as NYFD or Phoenix, to

add credibility to the finished product. It may also help if a respected member of the disability community approaches the subject matter with first responders.

Areas of refuge can be problematic during rescue operations. These areas are designed to protect the occupants until first responders arrive to assist with their evacuation. While these areas may work when adequate time and staffing are available, they may not achieve their goal in rescue situations. A number of stories surfaced following the terrorist attacks on September 11, 2001, that described how people with disabilities lost their lives while waiting for rescuers in an area of refuge (CID-NY 2004, pp. 31-32). Owing to the urgency of the situation on that day, time and limited resources prevented the successful rescue of these individuals as well as many others. Local governments may need to rethink the use of areas of refuge, especially in high-rise buildings.

Shelter

Scant research has been conducted on disaster shelters (for exceptions, see Bolin and Stanford 1990; Nigg, Barnshaw, and Torres 2006; Pike, Phillips, and Reeves 2006; Quarantelli 1982; Yelvington 1997). Even less attention has been paid to issues and conditions affecting people with disabilities in shelters, although anecdotal evidence and postdisaster reports suggest significant problems. To understand the shelter experience and shelter operations, this section describes various kinds of shelters and points out areas of concern.

Two types of shelters—emergency and temporary—develop before and after disasters (Quarantelli 1982). Emergency shelters can be defined as those that lack basic amenities and are often developed by individuals or small groups of people. After the Loma Prieta earthquake in 1989, people chose to sleep overnight in tents, cars, and on lawns to avoid the potential effects of aftershocks. People trapped by Hurricane Katrina and the levee failures sought refuge on rooftops, overpasses, and newly created islands. Temporary shelter differs from emergency shelter in that a facility (or, in the case of Hurricane Andrew, a tent city) is typically used. Historically, the American Red Cross operates under a congressional mandate to provide shelter (a role that is being

assessed, with increasing responsibility being switched to FEMA under the National Response Framework), supported often with food, beds, first aid, and mental health and other services as available. The American Red Cross trains shelter managers and volunteers through a preestablished curriculum. In all disasters, though, it is not uncommon for places of worship, community groups, and city officials to open a temporary shelter, depending on local need. These more emergent types of shelters are less likely to offer structured environments with necessary elements to support people with disabilities.

Two types of general temporary shelters often develop: general population shelters and special needs or medical shelters. The latter type can vary significantly depending on local capacity and assets. A special needs or medical shelter may not be possible at all, and in areas where it is, it may be staffed by emergent volunteers who lack predisaster training for such a location. In other areas, special needs or medical shelters can serve affected populations quite well, with tremendous capacity to support chronic conditions. However, a clear-cut definition and cutoff for how shelter staff and volunteers should define special needs or medical needs shelters does not exist across the United States (NOD 2005). Thus, a general population shelter may accommodate a wide variety of individuals or send people with any kind of disability or medical condition to a special needs or medical shelter. Or a general population shelter may accommodate people with disabilities or medical conditions competently or, in some cases, poorly.

The Americans with Disabilities Act mandates that accommodations, which include shelters, must be accessible. Shelters must also accommodate service animals and should provide multiple means for communication. Ideally, shelter staff should be trained to accommodate a wide variety of disabilities and medical needs. However, it appears that such training is not conducted routinely and that people with disabilities and those with medical conditions, as well as service animals, may be turned away from a general population shelter or sent to a special needs or medical shelter.

The type and magnitude of an event, as well as the geographic location of the shelter, may dictate the types of sheltering available to people with disabilities. Some urban

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locations in Florida, for example, have considerable experience in providing appropriate general population and medical needs shelters along with trained staff. Experience in sheltering people with disabilities, due to the repetitive hurricane threat, has generated trained staff and established procedures.

Hurricane Katrina, a catastrophic event, overwhelmed shelter providers and created a wide variety of new shelter providers who opened the doors of community centers, worship locations, private homes, schools, and similar locations to evacuees. At least 1,000 shelters opened across multiple states. In Texas, "mega-shelters" accommodated more than 10,000 people in a single location. Other states saw emergent groups, many new to shelter provision, serve anywhere from a few evacuees to hundreds fleeing the storm. Research on the Katrina shelters indicates that both traditional and emergent shelters experienced considerable problems and challenges in accommodating people with disabilities and individuals with medical needs (NOD 2005).

In an online posting on Audiology Online (<u>www.audiologyonline.com</u>), Bill Prickett, superintendent of the Louisiana School for the Deaf (LSD), shared updates about the use of LSD for sheltering those displaced by Hurricane Katrina (Prickett 2005). LSD housed members of the deaf community and family members of students who returned after the evacuation, as well as staff left homeless or without electricity. Deaf community members included brothers who were deaf-blind and brought to LSD from a shelter near Baton Rouge. LSD's accessibility to members of the deaf community highlights the important role that schools can play as shelter options for people with disabilities after a disaster. Furthermore, the expertise of students and staff in schools for the deaf and blind can be used in existing shelters for education and support of staff who may be serving people with disabilities and have little or no training regarding their needs.

The National Organization on Disability (NOD) conducted a rapid survey of 18 shelters after Hurricane Katrina, supplemented with information from officials involved in response and sheltering efforts. Although two thirds of the shelters included questions regarding disability on their intake or registration paperwork, only minimal recognition of the disability occurred. Translating potential needs into available services lagged behind the intake identification. For example, only 30 percent of the shelters provided American Sign Language. Eighty percent did not provide TTY and 60 percent did not offer closedcaptioned television. Although 56 percent posted written versions of oral announcements, people who were deaf or blind reported missing communications. Some shelters set up specific areas for communication, although such locations have been criticized as unnecessarily segregating people with disabilities.

The shelters were rated as "good" to "chaotic" (NOD 2005). Coordination and communication among shelters was lacking, which did not permit effective deployment of medical staff or contact with disability organizations that may have been able to provide assistance. In some areas, such as Louisiana and Texas, local schools for the deaf and blind sent volunteer staff and students to assist in shelters.

Because of the rapid and chaotic evacuation of New Orleans, people with disabilities reported being separated from family members, who ended up in separate shelters. Disability organizations and schools worked to reunite families. One state school, for example, used its email and website capabilities to reunite families and opened the school as a shelter site for students and parents.

State officials reported that rescue efforts failed to include many pieces of durable medical equipment. Louisiana officials worked for six months, for example, to locate and reconnect expensive pieces of durable medical equipment with evacuees. Meanwhile, evacuees sent to shelters lost their independence because of the loss of their equipment; shelters scrambled to find temporary equipment that may not have fit the specific need; and shelters had to add staff to support individuals who had lost their equipment.

King County in Washington State opened both general population and special needs shelters after a major windstorm triggered significant power outages, including at a nursing home. Shelters, including traditional and faith-based, were able to accommodate individuals with disabilities (and service animals) with minimal assistance. One shelter opened in a sports facility, with programming for people with disabilities. The state after-action report indicated that some evacuees needed assistance during meal times and with personal care; and it noted the importance of encouraging evacuees to take required medications when they left their homes (Washington State Military Department 2007).

Even if shelters are ready to accommodate and support people with disabilities or medical needs, such individuals may not go to the shelter locations. Their reasons may include the typical reasons people do not evacuate, including the belief that the event does not require evacuation or because they prefer to stay near familiar surroundings and support services. In addition, people with disabilities may not be able to evacuate because of a lack of transportation (Kaiser Family Foundation 2005), failure of a buddy system, or the belief that the shelter is not ready to accommodate specific needs (van Willigen et al. 2002). The Department of Homeland Security's Lessons Learned Information Sharing website (www.llis.gov) recommends including medications for individuals with medical illnesses in general population shelters.

The implementation of the functional needs shelter is a new trend toward inclusion of people with disabilities in shelter planning. According to the *ADA Best Practices Toolkit for State and Local Governments* (DOJ 2008), although shelters are often managed by third party providers, such as the American Red Cross, the ADA "generally requires shelters to provide equal access to the many benefits that shelters provide" (para. 1). The *ADA Best Practices Toolkit* recommendations for functional needs shelters follow (DOJ 2008):

- Advanced planning is required to meet the needs of people with disabilities accessing shelter. Such planning requires early identification of the individuals most likely to access shelter, their disabilities and specific needs. A diverse population of people with disabilities must be a part of the planning process for functional needs shelter to voice the needs and efficient means of addressing those needs during shelter.
- The shelter must be accessible to people with disabilities. This includes addressing accessible restrooms, entrances, sleeping arrangements, meal times,

etc. The Department of Justice provides a checklist for shelter accessibility at www.ada.gov/pcatoolkit/chap7shelterchk.htm.

- Shelter managers should carefully consider eligibility criteria and not automatically direct people with disabilities to special needs or medical shelters. People with disabilities should have the choice of staying in a mass care shelter, as having a disability does not, in itself, necessitate a need for a medical shelter. Arrangements should be made early for housing people with disabilities, and families should be able to remain together.
- Shelters should make reasonable modifications to existing policies to better serve those with disabilities. For instance, policies that do not allow pets in a shelter should be modified so that people with service animals are welcome.
 Policies that limit access to food to mealtimes may need to be modified for people with diabetes or other health issues. Sleeping arrangements may need to be modified to allow people who use wheelchairs to safely transfer to and from their beds and chairs.
- Communication should include accessible information for people who are deaf, hard of hearing, blind, visually impaired, or deaf-blind. People with cognitive, psychological, or developmental issues may need to have information communicated in different ways as well. teletypewriters (TTYs) should be available for people who are deaf or hard of hearing.
- The shelter environment should be welcoming and familiar, offering assistance for people who are blind or visually impaired to help them understand the floor plan and accessible routes for those who use assistive devices. The tool kit also suggests providing "stress relief zones" where individuals can relax in a quiet setting and seeking input from people with disabilities about where to place their cots for sleeping.
- Shelter supplies should include medical equipment and medications that may be needed by people with disabilities, as well as refrigeration for medications. When available, electric power should be offered to those who need electricity for ventilators and other life-sustaining equipment, as well as those who need to

routinely recharge wheelchair batteries. Food options should take into account restricted dietary needs, and supplies for service animals should also be available.

• Finally, shelters should provide people with disabilities time to find housing that is appropriate for their needs rather than turning too quickly to institutions for a solution.

Implementing all of these recommendations can be difficult. It is imperative that shelter managers plan early, update their plans regularly, and involve a diverse group of people with disabilities in the planning of functional needs sheltering. Partnerships with organizations that serve people with disabilities can also offer assistance and guidance.

Conclusion

People with disabilities are often forgotten during the response phase of a disaster. Historically, our society has approached people with disabilities by implying they need to take on "extra" personal responsibility to avoid the consequences of disaster rather than by addressing the built environment and social responsibility in an effort to create a safer setting for everyone. When people with disabilities are remembered, they are often grouped into one homogeneous population and provided with instructions that are not appropriately communicated or that are impossible for everyone to follow. The ADA has opened doors for people with disabilities, resulting in more people with mobility, cognitive, sensory, or other limitations being out in the workplace and in public facilities. Legal settlements, such as the one for *Katie Savage v. Marshalls*, mandate that people with disabilities be aided in safely evacuating from public facilities, when necessary. Considerations for the special needs of residents in nursing homes, transportation for those who lack personal vehicles, search and rescue procedures that aid people with disabilities, and shelters that can accommodate this population segment are all issues that must continue to be addressed with the help of the disability community and solutions put into practice by emergency management professionals.

Research Recommendations

- Identify built environment solutions that positively impact people of all ability levels.
- Investigate warning messages that are effective for the deaf and deaf-blind communities.
- Research delivery systems that are effective for the safe evacuation of people who are deaf, hard of hearing, blind, or visually impaired.
- Develop evacuation plans that include nursing home guidelines.
- Typologize and identify the range of registries currently in use.
- Identify the operational and logistical challenges associated with registries and develop strategies to overcome these problems.
- Understand the reasons why registrants may not self-identify.
- Identify various means for developing registries given limitations of staff, time, and funding.
- Assess the needs of various users of registries.
- Understand how registries have been used.
- Specify the challenges associated with buddy systems.
- Identify the conditions that facilitate or hinder buddy systems.
- Outline the consequences of a failed buddy system.
- Conduct research on sheltering people with disabilities and medical needs after disasters, being sure to include the perspectives of both evacuees and shelter providers as well as the full range of shelters, including general population and special needs/medical shelters as operated by the American Red Cross and emergent entities.
- Develop definitions of special needs and medical shelters, with more clearly defined lines for who is to be served.

Practice Recommendations

- Apply tax dollars toward alternative warning systems, such as those for the deaf or deaf-blind.
- Invest in advanced technological devices for people with disabilities that ensure appropriate warning(s) during emergencies.
- Support evacuation plans for people with disabilities in public facilities and workplaces.
- Involve nursing home administrators in evacuation planning guidelines.
- Consider the use of registries after careful assessment of the known challenges associated with registries.
- Ensure that a strong commitment exists locally to develop and maintain a registry on which people's lives depend.
- Assess the need for buddy systems in the jurisdiction and the places where such an effort is most effective. Involve people with disabilities in the decision-making process.
- Develop "two-deep" buddy systems to increase the odds that a buddy will be present when needed.
- Consider various means to inform, transport, and evacuate those at risk as alternatives or supplements to a buddy system. Redundant systems work more effectively under conditions in which a single system, such as a buddy system, might fail.
- Organizations that are developing technical guides dealing with the evacuation and rescue of people with disabilities should partner with a first responder agency to add credibility to their suggestions.
- Develop more definitive intake procedures to identify people who may require accommodations, and develop procedures to transfer that information from intake specialists to service providers.

- Build strong relationships with area disability organizations, advocates, and others who can provide support to shelters accommodating people with disabilities and medical needs.
- Train staff and volunteers on an annual basis on how to accommodate people with disabilities and medical needs (as appropriate) in general population shelters.
- Train staff and volunteers on an annual basis on how to accommodate people with disabilities and medical needs (as appropriate) in special needs or medical shelters.
- Strengthen ties between traditional and emergent (faith-based, civic) shelter providers to improve future services to evacuees.
- Educate the public about the capacity and capabilities of general population, special needs, and medical shelters to build confidence in the availability of appropriate accommodations.
- Develop detailed lists of and guidance for using recommended supplies, medications, durable medical equipment, and other items that general population and special needs shelters should have on hand. Distribute these lists and guidance materials widely.
- It may not be possible to mandate buddy systems that rely on the efforts of volunteers. Involving civic, faith-based, and other types of organizations may be an alternative.
- Promote increased response among people with disabilities living in HUDsubsidized facilities or receiving home health or day care services; promote action among providers in these environments to strengthen personal emergency plans, along with plans for the groups they serve.

Policy Recommendations

• Support policies on international codes that affect the built environment and create safer settings for everyone, regardless of ability.

- Policymakers should address public funds earmarked for civil defense sirens and use some monies for alternative warning systems.
- Require that all public facilities create evacuation plans for getting people with disabilities out in an efficient, safe, and timely manner.
- Mandate that insurance companies cover nursing homes during evacuation procedures.
- Avoid mandating registries without sufficient resources for staff time to ensure that such lists are regularly updated.
- Fund registry policies adequately for both startup and long-term maintenance.
- Require that registry efforts be linked to a full range of appropriate partners.
- Policymakers should add specialized training for first responders on rescue techniques for people with disabilities as a requirement for certain types of Homeland Security grants.
- Mandate training for both traditional and faith-based shelter providers and volunteers where accommodating people with disabilities and service animals is concerned. Involve people with disabilities and related organizations in the training.

CHAPTER 4: Recovery

Introduction

The recovery time period is the least well researched phase in the emergency management life cycle. Coupled with a noted dearth of studies on people with disabilities, it is not surprising that only minimal efforts have been made to address disaster recovery for this population. A comprehensive research agenda must be generated to stimulate evidence-based practices, programs, and policies that can make a difference.

Troubling evidence suggests that the recovery time is a problematic phase for people with disabilities. After Hurricane Katrina, for example, FEMA failed to provide temporary trailers that were accessible. In *Brou v. FEMA* (the Department of Homeland Security was also named in the suit), successful plaintiffs argued that the federal agency had not provided accessible trailers (e.g., with wheelchair ramps, maneuvering room, or grab bars), resulting in a longer wait for temporary housing (more detail is provided in a later section). As another example, housing advocates have noted in conference presentations that mitigation elevations along the Gulf Coast displace people with mobility disabilities and senior citizens. Some organizations report that some of these people have been forced to choose congregate care over independent living (Cahill 2006; NCD 2008a).

Recovery experts have also noted that disasters and the recovery time following such events tend to reveal deeply embedded social and policy problems (Barton 1969; Quarantelli 1991, 1998). It should not be surprising, therefore, that problems with accessibility, affordability, location, and understanding of disability-specific issues would arise during the recovery period. Experts have also noted a number of general deterrents to recovery that may be exacerbated for people with disabilities; for example, "outside donor programs that exclude local involvement; poorly coordinated and conflicting demands from federal and state agency-assisted programs; staff who are poorly prepared to deal with aid recipients; top-down, inflexible, standardized approaches; and aid that does not meet the needs of the needy" (Mileti 1999, p. 230).

Terms and Controversies

What is meant by recovery? Recovery terminology varies considerably and can cause confusion owing to its various uses and applications (Quarantelli 1998). Recovery may mean reconstruction, rebuilding, or even rehabilitation. Each of these terms has different definitions and connotations. Reconstruction and rebuilding often refer to the structural aspects of recovery (i.e., rebuilding community centers, homes, offices). Rehabilitation suggests an improvement of some type, such as a seismic retrofit, in which buildings are reinforced to withstand earthquakes, or hurricane clamps that help keep roofs in place. While not as commonplace as seismic retrofiting or hurricane clamps, implementing accessibility standards during the recovery phase can and should be emphasized and integrated into recovery efforts. (For more on this topic, see Chapter 5 on mitigation.) Even the term "restitution" is used in a recovery context, which may suggest litigation. As seen with *Brou v. FEMA*, legal recourse was believed to be necessary to ensure that accessible accommodations are made available during recovery.

The term "restoration" may suggest that things should be returned to the way they were before the disaster—restored to what was normal. But a "return to normal," and the political pressure to do so, may not be the best course to take, and it may not be feasible. We must ask ourselves, does returning to normal mean that things are put back to the way that they were before? Doing so presumably returns a location and its residents to their original state, risks included, and does not address accessibility concerns. Ideally, the idea of recovery must incorporate mitigation features that promote equitable disaster resilience, including the rights and needs of people with disabilities.

In the 1990s, a group of more than 100 experts in disaster research and emergency management conducted a "Second Assessment" of disaster research. Their conclusions were summarized in a series of recommendations designed to alter how we manage emergencies and disasters so that communities, households, and individuals

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are more disaster-resilient. One key recommendation endorsed equitable outcomes, defined as "a fair distribution of society's resources and hazards across today's population" (Mileti 1999, p. 34). Recovery time periods can be used to open eyes, reframe policies, and devise new solutions that can be institutionalized into emergency management practices.

Recovery can be thought of as a process that involves a series of stages or steps that people move through (Mileti 1999). It can be divided into two phases: short-term and long-term recovery. FEMA defines short-term recovery as efforts that return "vital life support systems to minimum operating standards," with common activities including restoration of utilities and debris removal, as well as body retrieval (FEMA 2007). Shelters, which are designed to provide safety for the duration of the disaster, open and close, while displaced residents attempt to move into temporary housing locations and reestablish their household routine (Natural Hazards Center 2001; Quarantelli 1982). Long-term recovery may take place over several years as housing, businesses, and infrastructure are repaired or rebuilt. FEMA defines long-term recovery as efforts that "may continue for a number of years after a disaster. Their purpose is to return life to normal or improved levels" (FEMA 2007).

Additional steps and stages can be found within the two broad phases. To return home, for example, people may move through emergency shelter, temporary shelter, temporary housing, and, finally, permanent housing. While it is clear that people move through those phases at different rates, it is not clear how people with disabilities experience those phases. Empirical evidence is scant, although post-Katrina conferences have identified significant areas of concern (e.g., see NCD 2008a).

The remainder of this chapter explains the steps and stages common to recovery from most disasters. Where available, research on people with disabilities is integrated. Because of the lack of such studies, however, the chapter aims to elucidate the recovery process in a way that reveals gaps and issues for research, policies, and best practices. At present, more questions remain about recovery periods than what is known empirically.

Summary of Key Findings

Key findings are scant because of the absence of empirical work in this area. However, firsthand, anecdotal, and impressionistic accounts suggest significant areas of concern. For example, recovery planning is rarely conducted before a disaster in any jurisdiction, yet such planning can have great benefits for identifying postdisaster disability concerns. If disability issues are integrated into recovery planning, tremendous forward progress can be made.

The Second Assessment recommends a holistic approach to planning and recovery, linking, for example, housing, work, infrastructure, and health care (Mileti 1999; Natural Hazards Center 2001, 2005). Planning can have particular benefits for people with disabilities. Recovery assistance must recognize access problems and identify additional means to connect with those in need. Housing concerns, including both temporary and permanent forms, must be addressed through the joint efforts of government officials and disability organizations and advocates. Such entities can be particularly helpful in identifying problems and recommending solutions. The federal government has launched several efforts, including the National Disaster Housing Strategy and Plan, to tackle difficult postdisaster housing problems, including those experienced by people with disabilities. The relatively new disaster case management approach (see the Katrina Aid Today website at www.katrinaaidtoday.org/about.cfm) uses local social workers and established procedures to guide individuals through the recovery process. The case management process is a potentially useful method, particularly for low-income households. However, failures in the process have been noted, suggesting that case management needs to be examined for points of intervention (NCD 2008a; Stough and Sharp 2008). It is clear that each dimension of recovery could benefit from specific research, policy, and practice recommendations. A number of these recommendations are outlined at the end of this chapter.

Review of Scientific Literature and Technical Reports

Recovering, rebuilding, and repairing damaged areas after a disaster requires a comprehensive plan, one that emphasizes a holistic mindset (Natural Hazards Center 2001, 2005). A holistic approach promotes an understanding that—

- All parts of the community are interconnected. Homes connect to transportation
 routes that take people to work and back. Utilities supply power, water, and
 communication lines, the first two of which are critical for powering wheelchairs
 and refrigerating medications. Debris management, particularly how it is
 incinerated, affects breathing quality and may even cause new ailments; for
 example, the "World Trade Center cough," so named because many of the first
 responders were found to have lung problems years after the event (Landrigan et
 al. 2004). Recovery planning requires that all parts of the community, including
 local residents, be considered and reconnected.
- Recovery must be sustainable, which means that recovery efforts should improve and protect local quality of life, economic opportunities, and environmental resources. Sustainable approaches require that social and intergenerational equity be incorporated into recovery. The best approach is a participatory process that brings people at risk into recovery efforts. Sustainable approaches result in a more disaster-resilient environment for all who live in the affected area (Natural Hazards Center 2005, p. 1-1).

A holistic, sustainable recovery results in an improved environment for people with disabilities. Imagine the following possibilities when convening a recovery planning effort:

- Temporary housing is accessible and immediately available so that people with disabilities can reestablish household routines, assist their children with returning to school, go back to work, and begin rebuilding.
- Housing is not just rebuilt, it is rehabilitated communitywide to accessible levels through new codes and standards.

- Transportation routes are redesigned to provide wider pathways, auditory signaling systems at crosswalks, and Braille signage.
- Careful debris management reduces the overall effects of air pollution through proper burning and disposal. All workers are provided with protective equipment and monitored for a number of years thereafter.
- Recovery planning meetings involve people with disabilities as active participants. All public recovery meetings offer American Sign Language (ASL) interpreters, materials in Braille, and opportunities for people with cognitive disabilities to provide input as well.
- The rebuilt area features accessible sidewalks, businesses, recreational opportunities, and communitywide transportation options.
- New economic opportunities are recruited into the area to support people with disabilities. These opportunities may include grants to support new businesses, including social enterprises that support people with some kinds of cognitive or developmental disabilities.
- Geographic locations that have larger populations of people with disabilities (e.g., areas with senior care centers, state schools, assisted living facilities, naturally occurring retirement communities) get high priority for road clearance and utility restoration. Rebuilt utilities in these areas have top priority for underground placement of power lines (an expensive option but one that can save lives in an ice storm or other disaster).
- New mitigation efforts address risks experienced by people with disabilities. Mitigation measures that reduce those risks receive priority, such as bracing items that could fall and block exits from buildings, establishing new partnerships with organizations that support people with disabilities, designing preparedness materials that target those at risk, and providing insurance to those of limited means in high-risk areas.
- Workplaces incorporate features beyond the standard smoke alarm and first aid kit to include text and visual alert devices, evacuation devices, safety training, and buddy systems specifically for people with disabilities.
- The recovered community earns recognition as a place where all residents can return to living meaningful and productive lives at the same pace, regardless of disability.
- The burdens borne by people with disabilities in disaster (delays, lack of access, displacement) are reduced significantly before the next event.

To summarize, a holistic recovery is consistent with the principles listed on the NCD website (<u>www.ncd.gov/newsroom/publications/2006/hurricanes_impact.htm</u>):

"Congress should adopt the principles embodied in Livable Communities to guide the provision of reconstruction funds, promoting a Gulf Coast that includes:

- Affordable, appropriate, accessible housing
- Accessible, affordable, reliable, safe transportation
- Physical environments adjusted for inclusiveness and accessibility
- Work, volunteer, and education opportunities
- Access to key health and support services
- Access to civic, cultural, social, and recreational activities."

Issues with Recovery Assistance

The recovery process starts when the president issues a disaster declaration, made at the request of the affected state's governor. Not every disaster results in a declaration, which releases federal aid. Once a declaration is issued though, FEMA will offer recovery assistance through its teleregistration, Internet, or Disaster Recovery Center access points. In this section, we examine issues with recovery assistance. Each

disaster reveals new problems. In 1994, the Northridge (California) earthquake became one of the most costly disasters in U.S. history. Federal agencies and other organizations opened recovery centers and provided significant amounts of aid. Yet, as one FEMA applicant revealed, efforts lacked an understanding of disability issues:

I was not wearing my hearing aids that morning; of course, it was 4:31 in the morning. When my foot hit the floor, my bare feet felt every piece of glass that had broken. My husband was out of town; I was alone and extremely scared. My husband is profoundly deaf, and no one even told him there had been an earthquake. I went to FEMA; there was no interpreter. Someone later suggested I call my congresswoman. Almost nine months passed before I got my FEMA check. (personal communication to authors)

With every disaster, FEMA and disaster aid organizations have responded and revamped their efforts. After the 1989 Loma Prieta (California) earthquake, for example, FEMA increased the number of materials offered in Spanish. The American Red Cross, in response to criticisms, developed cultural diversity training. FEMA responded to the issue of translation after Northridge by hiring interpreters. For example:

FEMA Lends an Ear to the Deaf on St. Croix in the Aftermath of Hurricane Lenny (December 10, 1999, FEMA Release Number 1309-02):

ST CROIX, V.I. -- Like most Virgin Islanders, J.C. worries about hurricanes and has felt the devastating effects of these powerful storms more than once. Until now, though, worry was all she could do, because, like many of the hundreds of deaf residents of the Virgin Islands, she has had difficulty adequately preparing for and recovering from these disasters. Tonight though, J.C. and a dozen other deaf Cruzans sit in the tiny, donated office space of the Deaf Coalition of St. Croix while FEMA community relations field officers describe disaster recovery programs with the assistance of sign language interpreter Myrelis Aponte.

Aponte, a FEMA disaster reservist from Puerto Rico and graduate student at Gallaudet University in Washington, D.C., was called in after a deaf woman came to the Disaster Recovery Center in Christiansted and could not communicate with the staff. "They tried, but nobody at the Recovery Center could help her," said Aponte. "And it is not just a matter of knowing sign language. It takes years of training to become an interpreter who can work with a group like this, and it takes an understanding of the deaf culture to be effective."

On this night, the focus of the presentation is on Individual Assistance programs and the teleregistration process. Through Aponte, J.C. tells how her TTY telephone was damaged during Hurricane Georges last year. She had no idea that FEMA-sponsored programs could have helped her to replace it. And Martin, also at the meeting, finds out that he may now be eligible for assistance to repair his car that was struck by a falling tree when Hurricane Lenny passed through last month.

"Direct outreach to the deaf community is critical," says Aponte. "TTY phones are important, but not a total solution." Ester Perez-Johnson, the director of the Deaf Coalition, agrees. "Many of the deaf here also have limited reading and writing skills or cannot afford a TTY phone. Teleregistration can be an intimidating process without additional assistance." Aponte adds, "This kind of personal attention is necessary to make FEMA programs accessible to the deaf, and the same approach can be extended to other special needs groups."

Accessing Recovery Assistance

Affected individuals and households hoping for federal aid can apply in several different ways. The FEMA 1-800 teleregistration number is recommended most frequently. Applications can also be made through the FEMA website (www.fema.gov), although the application times out after 30 minutes because of security precautions, which may be problematic for some people with disabilities. The FEMA website also notes that applicants can "call TTY 1-800-462-7585 for people with speech or hearing disabilities." People who are experiencing technical difficulties are advised to contact "1-800-745-0243 (TTY users please contact your TRS [telephone relay service] to connect you)." FEMA also suggests that people might be able to visit their library or, where open, a Disaster Recovery Center (DRC) to apply for aid.

To check the status of an application, individuals may log onto the FEMA Individual Assistance website (www.disasteraid.fema.gov/IAC/displayPage.do?forward=home&), call FEMA, or visit a DRC, which is "a readily accessible facility or mobile office where applicants may go for information about FEMA or other disaster assistance programs, or for questions related to your case." Callers with a speech or hearing disability are advised to call "1-800-462-7585 TTY." No further information regarding application assistance relevant to people with disabilities could be found on the FEMA website under How to Apply. During Hurricane Katrina, call volume and Internet use resulted in high levels of frustration for applicants. People who were unfamiliar with the Internet or unable to use a computer fell behind in starting an application. Shelter providers and support organizations began instructing applicants to try the Internet after midnight. Many shelters brought computers in for applicants to use. Several locations, such as the Louisiana School for the Deaf, provided a computer laboratory for online applications. Students and their families used the facility to apply. To streamline disaster aid, Presidential Executive Order 13411 mandates a disaster benefits portal approach to disaster aid across all agencies, effective December 31, 2008 (www.whitehouse.gov/news/releases/2006/08/20060829-9.html). However, the Executive Order does not contain language specific to people with disabilities.

Types of Federal Aid for Disaster Recovery

Federal aid in a presidentially declared disaster begins with the FEMA application. Applicants must first apply for a loan from the Small Business Administration (SBA), which provides loans for homeowners. Low-income households may be rejected by the SBA and referred to the Individual Assistance program. Maximum grants increase slightly every year; in 2008, they were set at \$28,800. There is anecdotal evidence that the SBA denial is confusing to applicants, who then believe that they will not receive aid. It is not known how many people give up at this point, but case managers in past disasters have suggested that outreach to applicants who were denied SBA loans is critical. Empirical studies suggest that outreach is particularly important for elderly applicants, who tend to underutilize assistance programs (Childers 2008; Huerta and Horton 1978). Because the prevalence of disabilities increases with age, outreach may be particularly valuable.

FEMA can fund repairs and replacement, temporary housing, and permanent housing assistance. In addition, FEMA can provide assistance for other emergency items, such as medical, dental, funeral and burial, fuel, moving, and vehicle costs. The FEMA website does not mention items specifically relevant to people with disabilities, such as assistive devices, technologies, or other equipment. However, FEMA may assist with "other necessary expenses or serious needs as determined by FEMA." FEMA opens a special needs desk and staff when the National Response Framework is in operation, usually at the FEMA Joint Field Office (JFO).

David Paulison, FEMA administrator, spoke to the National Council on Disabilities on April 23, 2008. He discussed the following relevant FEMA initiatives:

- Hired a national disability coordinator (referred to as the federal disability coordinator in many materials) as part of the Post-Katrina Management Reform Act.
- Brought in an experienced emergency manager as a point of contact and advocate for special needs.

- Engaged in outreach and provided specialized expertise to tribal, local, and state units to incorporate disability issues into plans and exercises.
- Included disability organizations and involved people with disabilities in the TOP-OFF 4 exercise. Mandated by Congress, TOP-OFF (Top Officials) is a large-scale terrorist drill conducted at the federal level that involves thousands of officials at every level of government, as well as private industry and nongovernment organizations. According to DHS, "The exercise addresses policy and strategic issues that mobilize prevention and response systems; requires participants to make difficult decisions and carry out essential functions; and challenges their ability to maintain a common operating picture during an incident of national significance." TOP-OFF began in 2000 and is conducted every few years (www.dhs.gov/xprepresp/training/gc_1179350946764.shtm).
 FEMA intends to continue including the disability community in future exercises.
- Involved the national disability coordinator in the 2008 California wildfires and Mississippi floods to look at issues in shelters and housing.
- Established a Special Needs Work Group to review the National Response Framework and recommend specific language for these annexes: transportation, mass care, emergency assistance, housing and human needs, public affairs, mass evacuation.
- Involved the disability community in developing a template, checklist, and database of disability resources and training for FEMA regional offices and states. This includes a list of durable medical equipment for shelters and Disaster Recovery Centers. Materials will be available in alternative formats and interpreters will be in the shelters and the DRC (for details, go to www.fema.gov/about/paulison/speeches/2008/042308.shtm).

It is clear that FEMA has recognized some of the problems in aiding and assisting people with disabilities, and that changes are under way. It is equally clear that considerable effort will be required to improve the recovery period for people with disabilities.

Unmet Needs

The term used most frequently when people fail to access aid or do not qualify for programs is "unmet needs." Case managers and voluntary organizations describe the experience as "falling through the cracks" of available disaster assistance programs and policies. Because of the prevalence of unmet needs, an aid process has emerged over the past several decades. The process usually emanates from a coalition of voluntary, faith-based, and government agencies. When the National Response Framework is activated, Emergency Support Function #6 (ESF6) on mass care supports such a coalition. Emergency Support Functions provide a framework for federal agencies to coordinate during disaster, and many states and local jurisdictions follow the ESF framework to ensure continuity of planning, response, and recovery.

The key person in ESF6 is the voluntary agency liaison (VAL). This person connects federal efforts with voluntary and faith-based organizations and, during the 2008 Midwest floods, with the national disability coordinator. The VAL may convene meetings in the FEMA JFO; after Katrina, those meetings sometimes included special needs staff, thereby connecting federal officials to aid organizations that specifically target those with unmet needs. The VAL may also lead or cohost meetings in the community. Usually, such links and meetings are facilitated by the involvement of organizations connected through the National or State Voluntary Organizations Active in Disaster (NVOAD or VOAD, see <u>www.nvoad.org</u>). NVOAD maintains a membership list that includes the American Red Cross, the Mennonite Disaster Service, Catholic Charities, and similar organizations. Currently, no disability organizations are listed on the NVOAD national membership list, a pattern that is repeated at state and local levels.

After a disaster, NVOAD indicates that one of three types of committees typically evolves in the local community. The Long-Term Recovery Committee (LTRC) brings in representatives from a wide set of agencies and organizations. The LTRC focuses on unmet needs and tries to streamline services to households and families. The second type of committee is the Interfaith Committee, which usually emanates from local faithbased groups. This committee historically has built houses, offered stress management programs, raised funds, and/or managed donations. A third committee type is the Unmet Needs Committee, which may also emerge as a stand-alone or subset of another committee. This committee concentrates on those who fall through the cracks. A community may have none, one, or all of these committee structures operating at one time. These committees link critical recovery resources to local case managers who can help those with unmet needs.

It is also possible that emergent groups will appear, if needs remain unrecognized. The 1989 Loma Prieta earthquake resulted in the creation of the *Comité de Diecisiete de Octubre*, which supported Latino families living in FEMA trailers. After Hurricane Andrew in 1992, Women Will Rebuild formed to advocate for the interests of women and children (Enarson and Morrow 1997). Post-Katrina, a number of organizations made efforts to reach people with disabilities and provide resources (e.g., Katrina Legal Aid Resource Center). Many blogs and websites were devoted to such advocacy efforts as well (e.g., Information on Disability for Empowerment, Advocacy and Support (IDEAS), www.katrinadisability.info).

A number of voluntary and faith-based organizations will come to disaster-stricken areas to assist with unmet needs. Typically, they focus on rebuilding housing and fulfilling related needs. Each organization usually sends a representative to a recovery committee meeting, where the circumstances of individual clients are presented by a case manager. Until recently, the case management process was relatively unstructured. The United Methodist Committee on Relief (UMCOR), however, developed professional case management materials for its Katrina Aid Today website through funds donated by the international community and managed by FEMA (www.katrinaaidtoday.org/about.cfm). Participating organizations may accept an entire case or address a particular unmet need. Some organizations take on particular types of cases. The Mennonite Disaster Service (MDS), for example, tends to concentrate on seniors and people with disabilities. After Katrina, MDS also built ramps to FEMA trailers upon a request from special needs staff in the Baton Rouge JFO—a link that occurred through the VAL. However, it does not appear that many voluntary or faith-

based organizations include specific training, outreach to, or direct partnership with disability organizations. Voluntary organizations also appear to underuse people with disabilities as volunteers.

As reported at the January 2008 NCD quarterly meeting, the Katrina Aid Today (KAT) case management process is crucially important in helping people return home, especially those at low-income levels. As one example of a link between disability organizations, the Mississippi Protection and Advocacy Center participated in Katrina Aid Today. Its case managers have linked to 12 long-term recovery committees...and "served 1,713 individuals with disabilities and their families...out of the 1,713, about 818 cases have been closed...unfortunately, some recovery plans were not met because resources were not available and are still not available to meet recovery needs." The problem of getting people back home is exacerbated by existing housing deficiencies. As the Mississippi Protection and Advocacy Center reported, "There is no accessible affordable housing in Mississippi, so that makes a recovery plan addressing that issue impossible to achieve right now."

Capacities and Strengths of People with Disabilities in a Disaster Context

Far too often, reports and studies adopt a perspective that people with disabilities suffer in disasters and must be supported, taken care of, assisted, or helped in some way. To date, few studies note the capacities and strengths that people with disabilities bring to a disaster situation. After Hurricane Katrina, for example, schools for the deaf and blind involved students, staff, and family members in opening shelters, rescuing those trapped in the floodwaters, reuniting lost family members, providing communications via websites and text messaging, offering ASL interpretation and Braille services, picking up debris, managing donations, and advocating for temporary housing. Disability organizations launched extensive efforts to retrieve lost devices and equipment, advocate for service animals, critique response capacities and recommend solutions, and press for accessible housing. Currently, disability seems to be viewed in the recovery context in the following ways: (1) in an advisory capacity; (2) for case management purposes; (3) for consultation when problems arise; and (4) as selfappointed advocates. Overall, disability organizations and people with disabilities are far underutilized for recovery efforts.

Substantive Areas of Concern

In this section, we review areas of concern in the disaster recovery phase. As noted earlier, there are two basic periods in disaster recovery: short-term and long-term. In the short-term time period, efforts are made to plan, remove debris, clear roads, and restore utilities. Long-term recovery includes efforts to restore business sectors and workplaces, housing, medical care, and infrastructure.

Recovery Planning

Few communities develop predisaster recovery plans (the City of Los Angeles is a notable exception). Most frequently, recovery planning commences in the aftermath of an event, when time is of the essence and people press for a return to their normal lifestyles. Executive Order 13347 emphasizes the participation of people with disabilities in disaster and emergency planning, preparedness, and exercises. Few communities, though, have any experience integrating the perspectives, needs, and capabilities of people with disabilities or related support organizations into their recovery plans.

Most guides call for participatory processes to develop plans that meet the needs of local stakeholders (Natural Hazards Center 2001, 2005; Schwab et al. 1998). Yet few checklists for potential participants suggest that people with disabilities or related organizations be invited to the table. Although some advocates call for accessible meeting locations and interpreters, this is only one step in the right direction. True participatory processes actively solicit and integrate stakeholders into every element of the decision-making process for a recovery plan.

Debris Removal

During short-term recovery, it is necessary to clear roads so fire, police, ambulance, and utility crews can conduct life-saving measures (FEMA 2007; Swan 2002). Though not suggested by most guidance documents, integrating debris removal planning with

geographic information system (GIS) mapping can identify crucial locations (perhaps through a registry or identification of congregate facilities) and expedite road clearance. If recovery crews know where large numbers of people with disabilities are located, debris removal can be prioritized. For example, clearing roads to congregate care facilities or schools can expedite postevent evacuation, restoration of utilities, and transportation to medical facilities, shelters, and temporary locations.

It is not clear how long people with disabilities typically remain in shelters or temporary housing. Returning home may depend on road clearance as well as interior cleanup of homes, apartments, and care facilities. Earthquakes, for example, cause objects to fall or move, blocking access for people with mobility disabilities. Individuals who are blind or visually limited may require assistance in restoring the interior environment in which they are accustomed to navigating. In all cases, interior and exterior debris must be removed, separated, and taken curbside for pickup. However, most debris management plans do not address how people with disabilities can be educated, supported, or assisted in accomplishing this. Consequently, the debris removal process is likely to be burdensome and may result in delays among people with disabilities. As Margaret Nosek (2008) noted after riding out Hurricane Ike on a ventilator, "The 211 registry system [should include] a mechanism...that will contact individuals registered in the aftermath to ask about their extraordinary disaster related needs and to refer them to existing resources. This should include assistance with debris removal and prompt access to repair services."

The debris removal stage is just one of multiple variables that may slow the return of people with disabilities to their homes. Even worse, not removing debris can result in legal condemnation of one's property.

Debris reduction efforts may also be of concern. FEMA and EPA guidance specifies that debris reduction must be done in a way that reduces the impact on people's health and well-being, as well as on the surrounding environment. Incineration is one of the most common strategies to reduce debris, but it is usually limited to clean, woody vegetation (EPA 1995; FEMA 2007). However, smoke from the burning process may affect people

with breathing problems such as asthma or chronic obstructive pulmonary disease and thus must be carefully monitored for compliance with proper protocols.

Smoke from the smoldering pile at the World Trade Center is believed to have caused new pulmonary medical conditions in first responders, relief workers, and others exposed to the toxic air (CDC 2002; Landrigan et al. 2004; Lin et al. 2005; Szema et al. 2004). One study reported an increase in unplanned medical visits and respiratory conditions in contrast to a comparison group (Lin et al. 2005). Problems with asthma and other respiratory conditions have been reported. As mentioned earlier, the "World Trade Center cough" has been reported among first responders, tower employees, area office workers, and cleanup crews (Nemery 2003; Trout et al. 2002).

Evidence that debris is problematic comes also from conversations with emergency managers and social service providers. For example, after 9/11, debris (particularly dust) affected residences and workplaces for blocks. In one affected building, FEMA inspectors required access to verify the damage and qualify residents for assistance. Residents had to be present to allow access for inspectors. However, public transportation had not yet been reestablished, particularly for people using motorized vehicles. In order to receive FEMA benefits, people with disabilities had to legally authorize another individual to allow access for the inspectors. In at least one building, 20 percent of the units were Section 504 housing, which included seniors and people with disabilities. Thus, an additional burden was placed on people with disabilities as a result of the debris situation; such circumstances should be anticipated and planned for in future events.

Another example, with a positive outcome, happened during the 2009 flooding in Grand Forks, North Dakota. Mud covered the first floor in the home of an individual with a disability who was working outside his home before the flood. The only accessible postdisaster housing in the area was 250 miles away from his job, family, physician, and support network. Disaster service providers and voluntary organizations prioritized his needs, removing the muck and sediment, and treating for mold (which took only a few days in this situation). This man was able to return home, go back to work, and regain

his independence. Addressing the situation required communication and collaboration among multiple organizations.

Infrastructure

Sufficient research has not been conducted on infrastructure repair and its relevance to people with disabilities. The impact of a disaster can be considerable: "During the recovery phase, if proper transportation infrastructure does not come back quickly, it can cause many ongoing issues. A local advocate from the Advocacy Center reported that transportation has been horrendous for people with disabilities post-Katrina and is a big issue despite efforts by several agencies. After housing, the second most important service severely impacted in the storm's aftermath is public transportation" (NCD 2008a).

In 2005, the American Society of Civil Engineers (ASCE) published its *Report Card for America's Infrastructure*. Infrastructure includes roads, solid waste, transit facilities, wastewater, aviation, bridges, dams, water, energy, waterways, railways, and ports. The nation merited an overall grade of "D," a mark that did not improve in the society's 2009 report. ASCE reported that 27.1 percent of the nation's 590,750 bridges could be considered structurally deficient or functionally obsolete. The cost to eliminate those deficiencies is estimated at \$9.4 billion per year for 20 years. Further, the Federal Highway Administration indicates that one third of our roads are "poor, mediocre, or fair" (ASCE 2005, 2009). Public transit earned a "D+" from ASCE. Rural areas fared worse than urban areas.

Infrastructure matters greatly to people with disabilities, to enable them to move to and from work, school, grocery stores, and health care facilities, as well as for social activities. Infrastructure also needs to include recreational facilities, such as parks. Under the ADA, postdisaster facilities must take accessibility into consideration. In Mississippi, for example, the Biloxi-area Lions Clubs provided funds to create the Lions Sea and Sun Camp, the first park for children who are blind and visually impaired. Because infrastructure in general earns a failing grade and dated infrastructure projects require ADA adaptations, infrastructure offers a potential point of intervention during

recovery efforts. Any disaster can seriously disrupt and detour infrastructure resources for people with disabilities, increasing risks to life, safety, rescue, and long-term recovery. Infrastructure recovery repairs offer opportunities to improve these situations for people with disabilities.

For example, speakers at the 2008 NCD quarterly meeting in New Orleans indicated that "FEMA funds are being used to rebuild streets, schools, civic centers, and privately owned buildings. As rebuilding progresses, attention must be made to increasing accessibility to the community, to the system of this city, and other communities rebuilding after the storm. The entire community benefits as access to public works and structures will increase access to employment, health care, and independence for people with disabilities" (NCD 2008a). A study is needed to examine the impact of disasters on infrastructure for people with disabilities. Such a study could be a positive point of intervention and influence to move forward on providing accessibility in many areas of a community.

Margaret Nosek, the wheelchair and ventilator user who survived Hurricane Ike, said, "Although I was quite well prepared for the storm itself, I really had no concept of what the aftermath would be like. After attending several citywide emergency management meetings...I came up with the following recommendations:

- Provide advance information about conditions that will affect electrical equipment.
- Give priority consideration to people with extraordinary health care needs and life-sustaining dependence on electrical equipment. Establish systems to register with electricity providers.
- Use neighborhood centers for charging batteries and use refrigerators to store medications." (Nosek 2008)

Lex Frieden of the University of Texas-Houston notes that Nosek's circumstances are not unique: "In Houston, we have approximately 40,000 people whose lives depend on

power. Those are people who are on ventilators, people who are on chemo and need pumps to keep the chemo running, people who are on dialysis, people who are on powered feeding tubes; there are several other categories of people who are powerdependent—people who use power wheelchairs and need the chair in order to get to the bathroom or the kitchen." (personal interview)

Financial Recovery and Related Impacts

The financial impact on people with disabilities who endure disasters is unknown, but it seems axiomatic that for low-income households, which are more prevalent among people with disabilities, the impact is considerable. Hurricane Katrina, though not the typical disaster, illustrates a number of problems. Because people with disabilities were displaced and relocated throughout the country, accessing specific services—such as Medicare and Medicare Part D prescription coverage, veterans' benefits, Social Security checks, and Supplemental Security Income (SSI)—was difficult, if not impossible in some instances. In addition, people experienced disruption of work and personal life, often the types of activities that help disaster victims recover more quickly and give a sense of stability during stressful periods. People also lost access to their bank accounts to which monthly checks were being sent. The widespread displacement across the country meant that local, familiar social service and health care providers were not available. Case managers could not find their clients. The impact and extent of the disruption is not known, but it is clear that the effects were profound.

For example, one survey found that among those with one or more chronic conditions, 21 percent cut back or terminated their health care (Kessler 2007). Affected persons were usually elderly, uninsured, and/or isolated. Reasons for cutting back included the following: 41 percent lacked access to a physician; 33 percent could not afford or obtain medications; 29 percent had financial problems; and 23 percent lacked transportation to health care. The finding that these conditions affected seniors (disability prevalence increases dramatically with age) coincides with reports from caseworkers. After the Loma Prieta earthquake in 1989, local social workers reported a higher death rate, a pattern also observed by geriatric specialists in Mississippi after Katrina. Although it

remains very difficult to pinpoint disaster as the exact cause, caseworkers reported going to a lot more funerals after the storm than before. These impressionistic accounts appear to be consistent with one post-Katrina report of higher death rates among the elderly due to a lack of economic resources (Bourque et al. 2006).

Kathy Kliebert, assistant secretary for the State of Louisiana Office for Citizens with Developmental Disabilities, reported at the 2008 NCD quarterly meeting in New Orleans that "several entities, such as the Department of Health and Hospitals, have been focusing intensely on recruitment. A study conducted by the Louisiana Public Health Institute indicated that, for the most part, major health care professionals have returned in sufficient numbers to the area. However, there seems to still be a lack of specific specialties. There are still waiting lists of people in need of specialists." Further, some health care providers do not accept Medicare or new patients, a problem that appears to lengthen the waiting time. Some clients report waiting months to see a neurologist, for example (NCD 2008a). Voluntary and civic organizations have stepped up in some circumstances. For example, Lions Clubs in Mississippi have provided eye screenings and funds for glasses; there is a waiting list for this as well. Other organizations have set medical and dental support vans into affected Katrina areas, though these are short-term solutions.

Families with new disabilities generated by the disaster may find themselves in a confusing set of circumstances as they seek assistance, learn new terminology and procedures, connect to new agencies and organizations, learn how to cope with and manage the new disability, and deal with what could be a major financial blow. One study found that households with above-median income levels fared better psychologically with the onset of a new disability (Smith et al. 2005). Research needs to be conducted in this area, as it represents a particular point of concern. Veterans' organizations may be able to offer insight, given their recent experiences with newly disabled veterans.

The financial impact of a disaster on low-income households can be profound. Families with insurance may find that they have to tap into savings to rebuild. Families that lack

insurance or are underinsured may rely on a FEMA loan or grant. The maximum FEMA grant for rebuilding purposes is currently \$28,800. For families without insurance and those unable to secure a loan, this amount is insufficient to rebuild, and they must enter the local case management system for assistance (if the system and a long-term recovery committee exist). The economic impact is expected to be considerable and can last for an extensive period (Dash et al. 2007). Because a number of people with disabilities report lower incomes, the rebuilding process is likely to be financially burdensome, if not impossible. In disasters in which a presidential disaster declaration is not issued, the problem may be even more serious.

Employment and Business Recovery

Specifics are not available on how disasters affect businesses owned by people with disabilities; in fact, limited research exists on how disasters affect the business sector as a whole (Tierney 1996; Tierney, Nigg, and Dahlhamer 1996; Webb, Tierney, and Dahlhamer 2000). It does appear, though, that small businesses suffer disproportionately in comparison with larger businesses and those with corporate resources. Small businesses owned by women and by minorities have more difficulties and suffer higher failure rates. Thus, it seems plausible that small businesses owned by people with disabilities may also experience considerable disruption and displacement, and higher failure rates. Research needs to be conducted in this area, including investigation into how disasters affect workplaces that employ or serve groups of people with disabilities.

Several types of postdisaster employment issues can be determined. The first concerns the impacts on health care workers and personal attendants who assist or support people with disabilities. The second concerns the impact on employees with disabilities. The catastrophic impact of Katrina has meant that a number of work sectors have been affected. The health care sector, for example, is still struggling to return to the Gulf Coast in its full prestorm capacity (Brookings Institution 2008). Evidence suggests that "the workforce has suffered as well, both in terms of health care workers and direct support and personal care attendants for people with disabilities. Part of the issue has been funding to adequately pay trained staff, an ongoing issue. While some progress

regarding salary increases have been made through legislation, competition is high in the area, making recruitment and retaining personnel challenging. In addition, it has been reported that health care providers have left the area" (NCD 2008a). The implications for people with disabilities who rely on both routine and specialized health care have been profound.

The Burton Blatt Institute of Syracuse University and the Law, Health Policy, and Disability Center at the University of Iowa College of Law examined the roles of 50 disability navigators from 14 states who went to the Gulf Coast region (Morris and Blanck 2006). These disability navigators assisted 3,407 people with disabilities. Unmet needs that emerged included an increase in mental health problems, and a lack of access to affordable housing (including FEMA trailers), transportation, and health care. Failure to secure these basic resources meant that employment was affected. Recommendations included adopting universal design standards for housing and vehicles, and increasing paratransit options to expedite recovery. Economic development incentives could be offered to employers who hire people who receive SSI benefits. Morris and Blanck (2006) also recommended waiving SSI asset limits and permitting permanent Medicaid benefits "regardless of income level." Research needs to determine how many people with disabilities may lose jobs either temporarily or permanently as a result of disasters, what conditions lie behind those job losses, and whether discrimination (the presumption of inability in a postdisaster recovery context) is a component.

Medical and Health Impacts

Falling victim to disaster can affect health outcomes and medical needs of individuals and their families. Surviving large-scale disasters can create a host of health and medical issues. And when disasters also affect the health care infrastructure (i.e., hospitals, clinics, health care agencies, computer systems, etc.), a population's health can be permanently affected.

Disruptions to Medical Care and Service

In a study conducted by an ambulatory pediatric clinic in North Carolina following Hurricane Andrew, researchers found that being a hurricane victim created barriers to receiving medical care, even though the clinic was not in the wake of the storm and remained fully open and functioning (Curry, Larsen, Mansfield, and Leonardo 2001, p. 572). Barriers to receiving health care and health problems reported by flood victims who accessed services were—

- Loss of medication or medical devices
- Finding time to come to the clinic
- Paying for medical care
- A new health problem
- A worsening health problem.

Such issues were present in a population that had access to medical care, as the clinic was unaffected by the damage created by Hurricane Andrew. When the health care infrastructure is itself affected, barriers and poor health outcomes escalate.

Following Hurricane Katrina, the Medical Center of Louisiana at New Orleans was forced to close. The MCLNO includes Charity and University Hospitals, which serve primarily low-income and indigent patients. MCLNO facilities also included the area's only Level 1 trauma center. According to the GAO, the closures caused a significant loss of medical care capacity at a time when other medical safety nets in the city were closed as well (GAO, 2006, p. 2). The damages caused critical care losses, including the loss of approximately 80 percent of hospital beds (GAO 2006a). Staff who lost homes were forced to leave their employment. Patients who stayed or returned struggled to find health care, from critical care to cancer treatment (NCD 2008a). According to FEMA estimates, it would take \$12.4 million to repair University Hospital and \$23.89 million for Charity Hospital (GAO 2006a). "By permanently shuttering historic 'Big Charity' Hospital, by closing University Hospital for 18 months and by forcing half of the doctors and nurses to relocate outside the city, the storm blew as big a gap in the city's medical system as it did in the Mississippi levees" (Sternberg 2007, p. D1). Sternberg reported the following health concerns among adults in New Orleans two years after the storm:

- More than 4 in 10 adults reported worse access to health care.
- In Orleans Parish, one in four adults reported being uninsured.
- Seventy percent of the uninsured were black.
- More than 1 in 10 adults ranked their health as fair or poor.
- Four in 10 said they had been diagnosed with a chronic disease.

USA Today reported the problems faced by New Orleans residents who were undergoing chemotherapy for cancer (Szabo 2006). Many were without their medical records, which had been lost in the storm, a dilemma that could be addressed through the adoption of personal health record (PHR) systems (Tang et al. 2006). Donna Williams, director of the Louisiana Cancer Control Program, reported, "Nearly nine months after the storm, many New Orleans cancer patients still struggle to get care" (Szabo 2006, p. D9). Roy Weiner, director of the Tulane Cancer Center, worried that "some cancer patients may neglect their health because they face so many other crises" (p. D9).

Subsequent empirical studies revealed serious disruptions to health care after Katrina. "Common themes at all facilities included complications in patients with untreated chronic diseases" (such as diabetes) (Berggen and Curiel 2006, p. 1549). One third of health care providers were laid off at Tulane and Louisiana State University (LSU) lost one fourth of its medical school facilities. The closing of Charity Hospital led to the loss of nearly half the pediatric specialists in New Orleans.

Health Care Infrastructure Recovery

In response to the dire circumstances, health care professionals, foundations, and numerous agencies have stepped up to address the needs among the people of New Orleans. To better meet the needs of those living with cancer, Donna Williams and her staff have called doctors, asking for the names of their patients with cancer and then attempting to locate them. They have also walked through neighborhoods, going door-to-door to find individuals in need of chemotherapy (Szabo 2006). Tulane has established cancer treatment facilities outside the city and can provide care at the Tulane New Orleans campus for those unable to travel to other sites. The Department of Veterans Affairs (VA) offered services "in a clinic atop the parking garage of its former building" (Szabo 2006, p. D9). The American Cancer Society established Hope Lodge, a free hostel for individuals with cancer and their families.

An article in *People* focused on Karen DeSalvo, a New Orleans physician serving those in need of medical care (Schindehette 2007). Along with others—such as Donald Erwin, St. Thomas president and CEO, and Ann Beal of the Commonwealth Fund (Sternberg 2007)—DeSalvo sees recovery as an opportunity to improve the health care system in New Orleans (Schindehette 2007). "I figured I'd never again get another chance," she said, "to rebuild a whole health care system from the ground up" (p. 105). Foundation funds and grants have been critical to support local health care after Katrina, although few appear to target disabilities. The Baxter International Foundation provided a grant to the Foundation for the Mid South to assist with disaster recovery efforts (*Philanthropy*, 2006, para. 2):

The Baxter International Foundation Health Recovery Fund will provide grants to community-based health care clinics, nonprofits, and other community-based health services that are delivered by other organizations, including hospices, nursing homes, home health or visiting nurse agencies, domestic violence and child abuse organizations, mental health clinics, dental clinics, senior citizen organizations, youth service organizations, substance abuse treatment

organizations, disability services, physical/occupational therapy clinics, and family centers.

Such grants will assist in the long-term recovery and rebuilding of the New Orleans health care system.

Mental Health

In a study of disability needs at the Houston Astrodome after Katrina, Bloodworth and colleagues (2007) reported that "in a large-scale emergency or disaster, the needs of disabled have not been fully investigated or described." Yet, it is clear, as reported by the National Council on Disability, that "people with mental health needs, whose access to treatment and medications may have been disrupted, are in critical need of treatment and/or medication. In addition, mental illness symptoms are often exacerbated in times of crisis, and many individuals, even those not directly affected by the hurricane, may need assistance in identifying and accessing available resources."

A fair amount of research has been generated on mental health needs after disasters. Unfortunately, most studies do not distinguish disability as a demographic variable that deserves independent analysis. Most of the time, people respond fairly well to disaster events. Severe trauma does not usually result, including high levels of posttraumatic stress disorder (PTSD). In a massive literature review of 160 studies that included 60,000 disaster victims, Norris, Friedman, and Watson (2002a) and Norris and colleagues (2002b) identified depression as the most common symptom to appear after disaster, followed by anxiety, which includes PTSD. The most commonly reported issue was trouble sleeping. Use of alcohol, drugs, or cigarettes did not increase for most people unless those behaviors existed before the disaster. In those circumstances, use of these substances may escalate. Most of the 160 studies reported relatively shortlived symptoms. In most cases, symptoms went away within a year after an event. It is believed, however, that exceptions may arise from some circumstances. Disasters alone do not usually cause mental health problems. Rather, studies have found that a number of conditions interact to potentially increase such problems. First, the severity of the event may make a difference. Events that involve significant exposure to trauma, particularly to violence, appear to increase trauma. Disasters that have been associated with higher levels of trauma have included Hurricane Andrew, the Exxon Valdez accident, and the Oklahoma City bombing. It is likely, therefore, that events like Hurricane Katrina would generate higher rates. Second, those with preexisting mental health conditions may find that symptoms worsen.

Age may or may not make a difference. Among seniors, for example, age may actually provide some buffering because of the wisdom that accrues from years of experience handling difficult events. For children, how their parents respond may make a difference. Parental distress tends to be associated with children's distress. Parents model behavior for their children, who respond similarly. And if parents seek counseling, it is more likely that children will seek counseling (Fairbrother et al. 2004). Middle-aged survivors may be at particular risk, as they often are responsible for both children and aging parents (Norris et al. 2002a).

Social networks and relationships matter. For people with strong social connections, trauma appears to be lessened. Being embedded in a set of relationships means that people are more likely to look out for and take care of each other. People in isolated circumstances are presumed to be more at risk (Cleary and Houts 1984). Some studies suggest that race and ethnicity may increase symptoms, but it appears that other variables are the cause. As a result of years of segregation and other discriminatory patterns, including underemployment and racism, some minorities may bear higher risk. Specifically, segregation means that people may be located in areas of higher risk for floods. Segregation results in disproportionate risk for disaster losses, injuries, and deaths. This type of exposure increases trauma symptoms (Cutter 2005; Perilla, Norris, and Lavizzo 2002). Occupations may also be tied to mental health issues. Professionals who are trained to deal with traumatic circumstances tend to fare better than employees, volunteers, and others who lack such training and may experience more

symptoms (Dyregrov, Kristoffersen, and Gjestad 1996). Finally, collective loss appears to heighten trauma. Loss of an entire community, with its important social networks, means that the people who lived there will have fewer sources of support. In instances such as the 1972 Buffalo Creek, West Virginia, dam failure and flood (see Erikson 1976) and Hurricane Katrina, those losses were catastrophic.

Initial reports suggest that the number of cases of trauma and stress are higher for those who were displaced from New Orleans (Coker et al. 2006). Mental illness rates have increased, as have reports of suicide and domestic violence (Jenkins and Phillips 2008). Across the Gulf Coast, social workers assisting the elderly are reporting higher death rates, which they attribute to the loss of important neighborhood resources and support systems. When people are exposed to dead bodies, trauma is also increased (Taylor and Frazer 1981; Ursano and McCarroll 1990). Again, anecdotal reports for Katrina suggest that "many believe that mortality has increased substantially" (Berggen and Curiel 2006, p. 1550), supported indirectly by observation that death notices in the *Times Picayune* increased 25 percent from January 2005 to January 2006.

What this means for people with disabilities is that any disaster event, whether catastrophic or not, can compromise a person's mental health. Because of the important connections that exist among many people with disabilities, the geographic context in which they live and work, and their relationships with significant others, disasters may be extremely disruptive. The aftermath of Hurricane Katrina could cause potentially severe mental health consequences because of the massive dispersal of people across the United States—away from social networks, social service and health care providers, navigable transportation routes, and workplaces. The higher death rates among the elderly, exposure of people with disabilities to life and death circumstances, an uncoordinated and inaccessible evacuation process, unprepared shelters, unavailable temporary housing, and aid systems that were not prepared to meet special needs all increased the risk of mental health problems. In short, the catastrophic scope and magnitude of Katrina are likely to have exacerbated preexisting conditions or caused new symptoms to appear.

Most studies of mental health issues resulting from disaster do not separate out or focus on disability. However, it seems important to do so, as "mental health distress and disability are pervasive issues among the U.S. Gulf Coast adults and children who experienced long-term displacement or other serious effects as a result of Hurricanes Katrina and Rita. As time progresses postdisaster, social and psychological factors may play greater roles in accelerating or impeding recovery among affected populations. Efforts to expand disaster recovery and preparedness policies to include long-term social reengagement efforts postdisaster should be considered as a means to reducing mental health sequelae" (Abramson et al. 2008). In short, mental health issues postdisaster are significantly underaddressed for people with disabilities in research, policy, and practice.

Two years after Hurricane Katrina, reports of "sleeplessness, depression, and full-blown posttraumatic stress disorder are a part of life for many." Such symptoms are "present in about a third of New Orleanians ... [and] are about twice as common as they were before Katrina." Local clinics are "overworked and understaffed," as are "the extended network of hospitals and clinics in Houma or Baton Rouge, 60 to 75 miles away" (Springgate 2007, pp. 1426–1428).

Considerable disruption to medications and mental health services occurred as a result of Katrina as well as in other disasters. After Hurricanes Ike and Gustav, for example, people remained away from their homes, providers, and pharmacies, and missed out on medications for weeks at a time. Under these circumstances, significant health problems can manifest from withdrawal symptoms or disrupted medication routines (Berggen and Curiel 2006). Special needs shelters and other locations are increasingly addressing these concerns, but challenges remain at many shelter locations. Long-term studies of the consequences of these circumstances should be generated to better inform both policy and practice. Long-term and mobile outreach to affected, displaced populations needs to be further investigated.

Situational Concerns

With any disaster, situational concerns arise that are specific to that disaster or need. After forest fires, smoke inhalation becomes a health concern for the public. The American Lung Association warns individuals that air pollution from wildfires "poses lethal health hazards to people living and working in the surrounding areas" (American Lung Association 2008, para. 1). Because the particles are small, ordinary dust masks are ineffective. Everyone, especially those with respiratory illnesses, is advised to stay inside and keep car windows and vents closed while driving. Household fans are not recommended, and air conditioning units should be set on "recirculate" (para. 3).

FEMA (2005b) warns against mold and mildew exposure following flooding. Mold exposure may cause "wheezing, difficulty breathing, nasal and sinus congestion, burning and watering eyes, dry cough, sore throat, shortness of breath, or skin irritation" (para. 3). The agency's press release provides information on the EPA's cleanup procedures.

Housing

As noted in the response chapter (Chapter 3), four kinds of sheltering and housing exist after disasters. Perhaps surprisingly, housing is one of the least examined areas of recovery research, despite its importance. Residential units typically occupy 60 to70 percent of the local building stock (Comerio 1998). This chapter addresses temporary housing, where people can reestablish a household routine (Quarantelli 1982), as well as permanent housing, which requires no further moves. Lower income housing tends to take a disproportionate hit because it is likely to be older and less likely to be up to code; located in a floodplain or other hazardous area; and less structurally able to withstand an event (such as manufactured housing). Thus, seniors and people with disabilities at lower incomes presumably bear a higher risk of displacement from their homes.

Temporary Housing

Temporary housing may include rental units (homes and apartments), mobile homes or travel trailers provide by FEMA, congregate locations, or staying with host families or friends. FEMA prefers to use available housing in the area; however, tight rental markets exist in some areas. Affordability is an additional concern, particularly in areas of low availability or where a significant loss of residential stock has occurred.

Public housing can be problematic when it has been affected, particularly locations that are approved through the Section 8 Housing Choice Voucher Program. Although HUD maintains lists of available units across the nation, those units may not be located nearby. In past disasters, HUD and local housing authorities have identified and verified appropriate locations for replacement rentals. After the California wildfires in 2007, HUD established a new National Housing Locator System. The system invited prospective landlords and property owners to list units. Approximately 26,000 units were identified within a 300-mile radius of San Diego County. The list included the ability to search for accessible units, although additional concerns remained, including proximity to work, family, health care, banking, pharmacies, and other routinely accessed sources of support.

In New Orleans, public housing units remain unavailable while they are being rebuilt by HUD and area housing authorities. Concern has been expressed by local residents that the new units, which will be in mixed-income ranges, will displace or deter lower income residents. Finding housing near vital support systems needed by people with disabilities, the elderly, and people with medical conditions is also of concern. For example, relocation 100 miles away from a familiar senior center or dialysis center will be problematic.

FEMA may offer travel trailers or mobile homes after a disaster, although the agency is historically reluctant to do so. Placement of such units is difficult in urban areas that lack yard space or trailer pads. Even in areas with more space, it may be necessary to establish a trailer park. This means that FEMA and local government must put in utilities, roads, and other amenities. The park must be located near public transportation that is accessible and within reasonable commuting distance from work, grocery stores, social support networks, and health care facilities.

FEMA experienced several problems with trailers after Hurricane Katrina. First, the overwhelming need for temporary housing meant the establishment of multiple parks in numerous states and placing individual units in urban, suburban, and rural areas. Second, trailers lacked accessibility, including ramps and enough interior space to accommodate assistive devices, durable medical equipment, and general movement. Third, some of the newest trailers were found to have dangerous levels of formaldehyde. A similar problem occurred after the 2008 floods in Iowa, when FEMA discovered mold on external water heaters and offered alternative accommodations. Finally, almost everyone considers trailer living to be unpleasant. Residents often refer to themselves as "Spam in a can" and report family stress and neighborhood conflict.

After Hurricane Katrina, 11 people in Mississippi filed a class action discrimination lawsuit (Brou v. FEMA) against FEMA over the lack of accessible trailers. Necessary trailer features included ramps, room for maneuverability, and accessible bathrooms and kitchens. In the lawsuit, the Louisiana Advocacy Center cited a need for "grab bars around the toilet, raised toilet seats, roll-in showers or accessible bathtubs, and accessible kitchen sinks and cabinets." The Advocacy Center said that some people with disabilities who were seeking accessible trailers "were offered inaccessible units and told to 'make do.'" Some were told that accessibility features or accessible units would come later, while others were simply told that the inaccessible units they were given were "the only ones they were going to get." According to the Advocacy Center, "FEMA's published reports indicate that as of February 3, 2006, five months after the disaster, of the 34,808 trailers FEMA has provided to Mississippi, only 417 units, or just over 1 percent of all trailers, comply with access guidelines." The lawsuit settlement resulted in FEMA provision of additional units by May 2007. The settlement involved establishing a call-in process to request accessible trailers: "Of the 2,553 people with disabilities who called the special toll-free numbers set up by the settlement to receive accessible trailers or modifications to their trailers, 1,400 were determined to need new accessible trailers and 256 were determined to need modifications. 1,260 new accessible trailers had been provided as of the date of the report, leaving 140 with unmet needs for new trailers. 243 modifications had been done." Brou v. FEMA was

one of several efforts by the disability community that have resulted in changes at FEMA when it comes to disaster response and recovery. In another example, FEMA is incorporating disability-specific ideas and language into its National Disaster Housing Strategy and Plan (see the next section).

Congregate facilities—which may include nursing homes, assisted living centers, state schools, and low-income hotels—also pose a temporary housing problem. Evacuating units creates a challenge regarding where to place residents. Facilities that are part of chains or franchises tend to fare best, as they can move residents to other facilities. Independent facilities tend to have more trouble with evacuating and placing residents in alternative locations. A similar situation exists with single room occupancy (SRO) hotels, which tend to house low-income and elderly residents. After the 1989 Loma Prieta earthquake, three out of four downtown, low-income, and senior-friendly SRO units became unavailable. Local social workers secured funding from FEMA and opened a formerly closed nursing home and named it The Garden. A social worker with experience in cognitive disabilities worked with adult protective services to staff the new location. Displaced SRO residents went to nursing homes, assisted living care homes, or The Garden. The first SRO reopened about two years after the earthquake. SROs are a significant part of urban environments—they are often the only form of affordable housing for people with fixed or low incomes. Some people with disabilities fall into this category and live in SROs. In addition, SROs can help prevent people from becoming homeless. While not necessarily safe and arguably not the best kind of housing in some locations, SROs are still an option for some people with mental illness, poor people, and people with drug and alcohol addictions.

Permanent Housing

Permanent housing means that no more moves are required and that a household routine has been reestablished (Quarantelli 1982). Acquiring permanent housing can take place through several avenues. First, displaced residents can secure new rentals or public housing and move from either a shelter or temporary housing straight into a permanent situation. The situation for renters may be more problematic in some circumstances than in others. For example, the 1994 Northridge earthquake had a disproportionate impact on multifamily units. Los Angeles placed red condemnation tags on 7,000 single-family homes and 27,000 multifamily units. Multifamily apartment buildings represented 84 percent of the lost housing stock (Comerio 1998). In such a circumstance, renters are dependent on landlords to rebuild quickly. Unfortunately, an economic recession undermined that ability. Many apartment buildings also had multiple owners with limited cash flow, which meant that rebuilding occurred even more slowly. The state and federal governments established economic assistance programs and encouraged lenders to forgive debts in order to jump-start rental rebuilding—an effort that took years.

Second, people can sell their homes and purchase new ones. But people whose homes are severely damaged may be unable to do this without adequate insurance. In windstorm or flooding events, insurance policies may not be sufficient.

Third, homeowners can rebuild. The rebuilding option depends on having sufficient insurance, qualifying for a loan or a grant, and possibly working with voluntary organizations to rebuild. Homeowners whose property is severely damaged can qualify for federal assistance through FEMA. The first step is to apply to the SBA for a loan. If the applicant is rejected on the basis of income, he or she may apply for a grant. The maximum grant amount is currently \$28,800.

Going home is difficult for many displaced residents, and people with disabilities may have additional problems. Kathy Kliebert, assistant secretary for the State of Louisiana Office for Citizens with Developmental Disabilities, said in January 2008, that "for some people with specific disabilities, housing needs may include retrofitting homes and accessibility issues as well as access to certain social and medical support systems (e.g., dialysis centers, physicians, senior centers). In addition, some people with disabilities may need housing that comes with some sort of voucher system or subsidy" (NCD 2008a).

It is highly desirable that permanent housing also include mitigation features that increase safety and foster disaster-resiliency. Mitigation measures have not been examined well for their potential impact (beneficial or detrimental) on people with disabilities. Elevation (which involves raising houses above the anticipated flood level) has been criticized for preventing access to homes that were previously occupied by seniors and people with disabilities. Mileti (1999) argues that each community must determine the line between acceptable and unacceptable risk. A discussion is needed of where that line falls for people with disabilities vis-à-vis various mitigation measures.

New Efforts Since Katrina

FEMA Disability Coordinator

Hurricane Katrina revealed gaps and weaknesses across many areas. FEMA and other federal agencies have responded in a number of ways. For example, FEMA has hired a disability coordinator. After the Mississippi floods of 2008, FEMA tasked the disability coordinator and staff with responding. The initial report identified specific issues that illustrate the importance of connecting organizations and efforts mentioned so far in this chapter:

> FEMA Disability Coordinator Report 6/20/08 Midwest Severe Weather and Flooding

- Activities for people with disabilities in Iowa
 - Met with Senator Harkins regarding accessible housing
 - Working with local disability groups to provide DRCs with
 - 1. interpreters
 - 2. alternative formats
 - 3. durable medical equipment (DME)
 - 4. signage

- Crisis counselors are available at all 16 DRCs and are set to be available for two other DRCs opening Sunday 6/22/08
- Wisconsin, Missouri, Indiana, and Illinois
 - Discussions with disability and special needs groups regarding alternative formats
- Maintain contact with all JFO IA and VAL (Joint Field Office for FEMA's Individual Assistance program and the voluntary agency liaison working in the National Response Framework ESF #6 mass care).

The FEMA disability coordinator represents an important step forward in pursuing immediate postdisaster concerns around disabilities. The sample report above shows links being made among disability groups, the relevant federal assistance programs, and the voluntary agency liaison. These are steps in the right direction and can be expanded in terms of links and across the time span of both short- and long-term recovery.

National Disaster Housing Plan and Strategy

FEMA published its National Disaster Housing Plan and Strategy in January 2009 (FEMA 2009). The National Disaster Housing Strategy offers a more comprehensive and expedited approach to interim housing. FEMA expects to follow four priority areas indicated on the agency's website (www.fema.gov/emergency/disasterhousing):

The four priority actions of the plan are listed below, and their use will depend on the availability of resources, the cooperation of state and local governments, and individual applicants.

- Maximize available housing resources (e.g., apartments, hotels and motels):
 - o Implement and provide immediate repair and replacement assistance
 - Implement financial rental assistance
 - Catalogue vacant rental properties

- Use transitional shelters
- Use traditional forms of interim housing (e.g., manufactured housing)
- Provide manufactured housing assistance
- Conduct pre-placement interviews for housing
- Catalogue vacant commercial manufactured housing pads
- Identify prospective group site locations
- Employ innovative forms of interim housing
- Search for opportunities to field test alternative forms of direct housing
- Accelerate production and delivery of manufactured housing
- Authorize permanent construction

A key recommendation for the Disaster Housing Strategy is to establish a National Housing Solutions Joint Task Force made up of federal employees. The National Advisory Council is directed to provide recommendations "from a broad range of disaster housing stakeholders" to FEMA and the task force. Each state is also expected to establish a state-led housing solutions task force of government, nongovernment, and private sector partners. As indicated in the strategy (FEMA 2009, pp. 87–88):

To obtain stakeholder input, the Joint Task Force will request the National Advisory Council (NAC) to create a new subcommittee or expand an existing subcommittee, which will assess government efforts to improve disaster housing across the Nation and provide advice and stakeholder input as the strategy is being implemented. FEMA may also seek individual advice from organizations as needed to obtain information on specific disaster housing issues, such as housing needs for special populations. Following are the types of organizations that may be involved:

- Private sector organizations, such as the Manufactured Housing Institute, the building and construction industry, real estate professionals, urban planners, and architects.
- Nongovernment organizations, such as the American Red Cross, National Emergency Management Association, National Association of Home Builders, National Association of Housing and Redevelopment Officials, disability support organizations, the Manufactured Housing Institute, and National Voluntary Organizations Active in Disaster.
- 3. *National or international experts* in sheltering, interim housing, and permanent housing.
- 4. Organizations, such as the National Council on Disability, with expertise in specific important housing-related areas, such as case management, and special needs populations.

The strategy addresses different levels of responsibility (individual, local, state, government, organizational, and nongovernment) that should operate to address sheltering and interim and permanent housing through partnerships. Local partnerships are emphasized under the assumption that "local officials are sensitive to their citizens' needs, including accessible housing for persons with disabilities, low-income housing, and cultural considerations in developing long-term housing" (p. 12). However, the strategy also acknowledges that organizations at "all levels must develop a deeper understanding of and be responsive to the complex needs of disaster victims....for example, individuals with special needs, including those with medical needs and persons with disabilities" (p. 4).

The strategy also advises that disaster housing assistance must "better integrate...with related community support services and long-term recovery efforts...[and] must...focus on improving case management services and increasing the level of awareness of support services for special needs populations, such as persons with disabilities, the elderly, the homeless, or persons living with HIV/AIDS..." (p. 5). Service animals are

addressed in the context of a shelter "when it must meet the full range of individual and household needs, including individuals with special needs, such as people with disabilities and their assistive technology and durable medical equipment, and/or service animals" (p. 30).

The strategy recognizes that a range of needs will exist and that planners must address the fact that "individuals with special needs, including the elderly and persons with disabilities, or persons living with HIV/AIDS, may need physically accessible options" (p. 26). Interim housing, in particular, must be "safe, secure and accessible…available to all eligible persons, including those with special needs. Accommodations that meet the Uniform Federal Accessibility Standards, for example, must be available to those with disabilities" (p. 54).

Regarding permanent housing, wording in the document indicates that "local governments should consider how to provide or encourage provision of adequate, hazard-resistant housing for all income groups and special needs populations, such as the elderly and persons with disabilities, who lived in the disaster-impacted areas" (p. 75). The strategy includes several points of intervention. Most important, the draft suggests that a National Disaster Housing Joint Task Force should be convened. The original draft of the strategy suggested that the task force might include the National Council on Disability.

A National Disaster Housing Resource Center is listed in the strategy but does not appear to be operational as of February 2009. The website is given as www.fema.gov/emergency/disasterhousing (see page 9 of the strategy).

Recommendations regarding the strategy:

- Include federal agencies serving people with disabilities on the National Disaster Housing Joint Task Force.
- The case management process provides an excellent point of intervention for working with and connecting individuals, disability organizations, and disaster

relief. The United Methodist Committee on Relief (UMCOR) has established materials for disaster case management at its Katrina Aid Today website (<u>www.katrinaaidtoday.org</u>). These materials should be incorporated into initiatives for the National Disaster Housing Strategy and revised to address disability issues.

- The National Voluntary Organizations Active in Disaster (NVOAD, <u>www.nvoad.org</u>) is a potentially strong partner and link into disaster organizations that often support permanent housing reconstruction for people with disabilities, seniors, and others. NVOAD should be encouraged to contribute to the National Disaster Housing Joint Task Force and to develop educational and training materials on disabilities for its many local, state, and national partners. State VOADs should seek to participate on state-led housing task forces. These partners represent a wide range of organizations that can be leveraged further to assist people with disabilities in postdisaster contexts.
- Research must be conducted on the experiences of individuals and organizations in working with postdisaster shelters and interim and permanent housing. At present, only anecdotal evidence exists, which is insufficient to support a particular approach as a best practice.
- Local officials and organizations know their communities best but may lack expertise or understanding of disability issues. Consequently, education and training may be necessary, particularly on housing issues.
- Service animals need to be integrated into every section of housing efforts, including shelters and interim and permanent housing.

Conclusion

The recovery period is underexamined in terms of research. Technical reports, testimony, and other materials clearly suggest, however, that people with disabilities experience significant problems in returning home. Dedicated attention must be paid to every element of the recovery process, from damage assessment through temporary
and permanent housing, to assist and support people with disabilities in their efforts to regain a sense of normalcy.

Research Recommendations

Research on the recovery period is scant. Research on people with disabilities and the recovery period is minimal as well. A comprehensive set of research recommendations (in addition to the recommendations made earlier in this report) should include the following:

- A comprehensive body of research needs to be accumulated over every major dimension of short- and long-term recovery. Research could develop as a standalone, specific disability topic or it could be incorporated into other research as a required element. For example, the National Science Foundation (NSF) expects societal impacts, including disability-related matters, to be addressed in every proposal. However, few proposals do so. A partnership between NSF (and other federal funders of research) and NCD could further those efforts.
- Recovery planning is rarely done before disaster strikes, yet, this is when issues on disabilities can be pre-identified and planned for. Both pre- and postrecovery planning efforts should be assessed for their inclusion of disability-related issues, people with disabilities, and disability organizations.
- Debris removal presents both positive and negative consequences for those with disabilities. The debris management process has not yet been fully examined for its impact on people with disabilities, although some research was launched after 9/11 regarding respiratory conditions and other potentially debilitating chronic illnesses. These efforts should be monitored, particularly for people with preexisting or newly developed disabilities. Other dimensions of the debris management process should be examined, from debris removal to incineration to public education/outreach to people with disabilities. The ways in which debris removal is prioritized and the consequences for people with disabilities should be examined as well.

- Various dimensions of the financial side of recovery should be examined, including the displacement and disruption of businesses that employ or are owned by people with disabilities. Financial recovery research should also include the presumably differential impacts on people with disabilities, particularly those at low income levels, and their ability to recover health care, housing, and household items, and to safeguard savings.
- Health care is problematic in the aftermath of major disasters. Access issues
 include finding providers that accept Medicare or other means by which lowincome individuals afford health care. The role of voluntary organizations
 appears relevant, but the extent to which they can address the problem seems
 both minimal and temporary. Studies are needed that examine death rates linked
 to financial problems and health care. Health care research should address
 disruption of service, provider responsibilities to low-income households, ethical
 obligations to provide aid throughout the recovery period, and the impact on
 chronic and episodic health care situations.
- People with disabilities should be included in recovery research that addresses mental health needs. Particular attention is needed regarding risk factors that may increase as a result of the impact of the disaster on the lives and living situations of people with disabilities.
- Anecdotal accounts suggest that infrastructure damage is of considerable importance to people with disabilities. The impact of disasters on transportation systems, highways, roads, sidewalks, bridges, ports, parks, and other public facilities and arteries should be examined. These infrastructure elements connect people to work, home, recreation, health care, merchants, and support networks. Prospective partners on this research include the American Society of Civil Engineers and the U.S. Army Corps of Engineers.
- Housing is an understudied area that must be investigated further.
 - Temporary/interim housing appears to be especially problematic. Accessibility problems erupted with FEMA trailers after Katrina, and little is known about how people with disabilities locate accessible temporary housing, relocate

into these units, reestablish a household routine, and access critical services. The role of case managers appears to be of importance to some clients, but it is clear that recovery planning does not fully address needs. Thus, the case management process itself needs to be examined to identify points of intervention.

- Permanent housing is another of the great unknowns. Again, the case management process appears crucial to getting people back home, but presumably only for a portion of those affected. Relocations may take people away from important economic, social, religious, and medical resources. Mitigation measures may simultaneously reduce risk and displace residents. By conducting research on permanent housing after disaster, it may be possible to identify the path that people move through, the disruption points that cause problems, and the ways in which changes can be effected.
- An important opportunity exists to launch an immediate study of the FEMA National Disaster Housing Strategy and Plan.
- Another important opportunity exists to—
 - Launch an immediate study of the efforts of the FEMA disability coordinator.
 - Study the roles of disability navigators and disability organizations.
 - Investigate how case management works or fails to work.
 - Identify the failure points of case management for people with disabilities (e.g., lack of resources to meet needs).

Practice Recommendations

 Convene case managers funded by Katrina Aid Today who worked with disabled clients to glean their best recommendations. Develop guidelines and materials for training case managers for future disasters; these individuals can range from professional social workers to new hires without experience. Offer these materials to social work programs across the nation.

- Work with NVOAD to build new bridges among voluntary organizations; conduct education and training for their national and state members; and encourage disability organizations to become NVOAD members.
- Strengthen the relationship between the FEMA VAL, disability organizations, and disability case managers. ESF #6 should seek out and involve disability providers and key advocates.
- Develop training for the local partners that FEMA expects to fulfill obligations under the National Disaster Housing Strategy and Plan. These partners (including emergency managers, social workers, organizations, and agencies) may lack the familiarity that is presumed necessary for working with people with disabilities and disability organizations.
- Incorporate disability organizations into all recovery planning efforts and all recovery committee types. Integrate efforts into housing, economic and workplace issues, health care, and infrastructure.
- Monitor websites and blogs after a disaster to identify emerging issues and topics of concern.
- Develop contingency plans for long-term health care of all kinds, particularly for low-income individuals and those with chronic medical needs. Monitor the continuing impact of a hazard, such as lingering smoke or the long-term effects of debris, on those with existing and new disabilities.
- Conduct disaster recovery awareness training for those likely to be tapped in such a context, including disability navigators; faculty and staff associated with schools for the deaf, blind, and visually impaired; advocacy organizations; senior centers and aging agencies; rehabilitation offices; and other relevant organizations.
- Encourage emergency managers to develop recovery plans before an event and to address issues relevant to disabilities in advance.

• Provide funding for mental health treatment programs for those at risk. Pay particular attention to risk factors that may be heightened for people with disabilities because of the disaster context.

Policy Recommendations

- Executive Order 12311 on the Disaster Portal requires language specific to disability issues.
- The FEMA registration/intake process for Individual Assistance should include questions about disability needs. A disability specialist should be assigned immediately to each identifiable case.
- Denials of FEMA aid should be referred to the disability specialist or other relevant case manager for follow-up. This is particularly crucial for senior citizens, who are less likely to qualify for loans and tend to underutilize or not understand the aid system.
- The Individual Assistance program needs to specify that assistive devices and durable medical equipment can be included as qualified items. Specific examples of items that qualify should be included.
- Encourage further development of the HUD National Locator System for accessible rental units. Encourage the expediting of new vouchers in disaster areas for people with disabilities.
- Encourage the development of a national health care disaster strategy to provide long-term care (i.e., multiple years that span recovery) for individuals at low income levels.
- Establish policies that require providers to ensure continuity of care for people with cognitive disabilities and those in need of psychiatric or psychological treatment.

CHAPTER 5: Mitigation

Introduction

Mitigation, according to McLoughlin (1985), means those activities designed to "reduce the degree of long-term risk to human life and property" from disasters (p. 166). Petak (1985) suggests that mitigation is "deciding what to do [when] a risk...has been determined to exist; and implementing a risk reduction program" (p. 3). Although many emergency activities strive to "mitigate" the effects of a particular disaster, true mitigation focuses on long-term solutions that have a positive impact on future events. Godschalk and Brower (1985) say, "Mitigation deals primarily with longer term, more general hazard reduction issues" (p. 64). Additionally, effective mitigation must include an all-hazards approach in designing long-term solutions. Ideally, mitigation reduces the potential for injury, loss of life, or property damage. Mitigation also helps a community to become more disaster-resistant and to rebuild more quickly after an event. Mitigation may be the most powerful tool to reduce risks to people with disabilities. As this chapter indicates, however, mitigation efforts often fail to consider the needs of people with disabilities.

The goals of mitigation are easily defined but difficult to implement. Although most mitigation activities appear minor at first glance, McLoughlin (1985) suggests that these small changes can have a significant "cumulative effect" when the focus is on the long term (pp. 170–171; see also Godschalk and Brower 1985, p. 65). Generally speaking, mitigation—

- 1. Seeks to change the nature of the threat by eliminating or reducing the frequency and intensity of a disaster.
- 2. Works to decrease vulnerability to damage by changing the way a disaster affects people and their support systems.
- 3. Strives to reduce the exposure of people to the threat by modifying the way they live and the systems they create.

The purpose of mitigation is to reduce risk, create a more disaster-resilient built environment through structural measures, and enhance individual resilience through nonstructural measures. Mitigation often overlaps with preparedness, particularly with regard to nonstructural measures, such as public information campaigns. Mitigation has not always been a focus among emergency managers; however, in the 1990s, FEMA director James Lee Witt did emphasize mitigation measures (Gerber 2007; Holdeman 2005). In addition to an emphasis on strengthening the built environment, such as through structural mitigation measures, Witt supported the idea that mitigation needs to have a human element by developing nonstructural mitigation techniques. Individual resilience can be increased through a variety of means. Mitigation can be implemented on two distinct fronts: nonstructural and structural.

Nonstructural Mitigation

Nonstructural mitigation encompasses a host of activities, some of which were introduced in the preparedness chapter (Chapter 2). Blanck (1995) argues that "information is often the most valuable resource for effective mitigation" (para. 2). As individuals implement the actions suggested in the preparedness literature, they are mitigating the impact of future disasters. The simple task of developing an emergency preparedness bag can mitigate the effects of loss of medications, assistive devices, communications, and related resources.

Insurance is another nonstructural mitigation measure that can be used (with limits, depending on provider coverage) to replace lost items, from assistive devices to critical medical equipment to accessible housing. In addition, public education programs reduce risk by informing and motivating individual as well as collective preparedness. The Alabama Chemical Stockpile Emergency Preparedness Program (CSEPP) was developed to mitigate the potential impact of a hazardous chemical release on the people living near the facility, where well over 1,000 individuals participated in a special needs registry (including people with medical and transportation needs as well as those who required specialized equipment). Although evacuation of the area was the first line of defense against human exposure, a second option—sheltering in place—became the

focus of this program. Residents in the immediate response zone (those closest to the facility) were given the following:

- 1. Respiratory protection equipment that would provide limited protection while evacuating or sheltering in place.
- 2. Portable room air cleaners that used charcoal filters to remove the chemical weapons agent from the safe room.
- 3. Tone-alert radios designed to provide hazard notification and protective measures advice.
- 4. Shelter-in-place kits to reduce the infiltration of potentially contaminated air into the safe room. (Metz, Tanzman, Nieves, and Holt 2005, p. 36)

The unique thing about the CSEPP is that planners considered the needs of people with disabilities. They realized that some people might encounter difficulties setting up the portable room air cleaner or establishing their safe room. Consequently, adjustments were made that enhanced the effectiveness of these mitigation activities for people with disabilities. One of these adjustments was the substitution of painters tape instead of the duct tape normally included in the shelter-in-place kit, after Argonne National Laboratory concluded that "painters tape...[was] more user friendly and provided a level of in-leakage protection at least equal to conventional duct tape and plastic" (Metz et al. 2005, p. 42). Furthermore, trainers went to the homes of those at risk to set up protective devices and provide in-home training for both individuals and support persons. An extensive effort was put forth to establish a registry of persons who would require assistance in the event of an accident.

Structural Mitigation

Structural mitigation can be seen in our built environment. From automatic sprinklers that counteract the effects of fire to the tornado protection afforded by a safe room, these built-in features structurally protect people from the effects of a disaster. Other examples include elevations and levees in floodplain areas, blast-resistant exteriors for terrorism threats, seismic retrofits for buildings in earthquake-prone areas, and

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hurricane clamps for roofs in high-wind areas. Godschalk and Brower (1985) suggest that codes requiring the development of hazard-resistant utility systems, such as underground electric lines, are also structural mitigation techniques.

Implications for People with Disabilities

The primary goal of mitigation is to reduce risk. The United Nations designated the 1990s as the "International Decade for Natural Disaster Reduction," noting that, through planning and mitigation, "many of the harmful effects of disaster are avoidable" (Blanck 1995, para. 2). According to Blanck, the ADA has similar goals, including avoiding the "impact of societal and altitudinal barriers" for people with disabilities, given proper preparation and mitigation (para. 2). Mitigation allows people with disabilities to "remain at home during or after a disaster, or to return more quickly" (FEMA 2003, p. 3.2).

According to Mileti and Peek-Gottschlich (2001), between 1975 and 1994, 100,000 individuals in the United States and its territories were injured as a result of a natural hazard. Without sufficient mitigation, individuals with disabilities face an even greater risk of becoming injured or dying during a disaster. And when people are exposed to disaster, they face the risk of developing a new disability. During the 1999 tornado outbreak in Oklahoma, for example, several individuals sustained injuries that created permanent mobility disabilities, including paraplegia. The terrorist attacks of 9/11 also caused numerous new disabilities, including injuries that caused damage to sight, mobility, and respiratory abilities. In short, mitigation reduces the risk that new disabilities will be created and enhances the survivability of those with disabilities. Mitigation is the single best step that can be taken to safeguard human well-being.

Any person may be vulnerable to disaster at one time or another. Like everyone else, people with disabilities practice nonstructural mitigation when they acquire and follow checklists and ensure that they have prepared for disaster to the best of their ability. Insurance is a commonly recommended nonstructural mitigation measure. In some hazardous contexts though (such as earthquakes), insurance is not affordable for many people. Given the lower income level of many seniors and some people with disabilities,

buying enough insurance to cover all losses may not be possible. Further, insurance providers may require additional premiums for replacement of specific items, including specialized wheelchairs, TTYs, or other necessary equipment.

In the workplace, individuals are protected from the effects of hazards, such as fire, by alarm systems. Although audible alarms suffice for most individuals, people with hearing disabilities may be unaware that an emergency is occurring and thus exposed to additional risk. To mitigate this problem, employers with alarm systems are required to have visual and audible alarms to ensure that everyone is alerted to the emergency (see the DOL website, <u>www.osha.gov/dts/shib/shib072205.html</u>). For an extensive list of work-related mitigation measures specifically for people with disabilities, see the Job Accommodation Network website (<u>www.jan.wvu.edu</u>).

When the built environment is compromised in a disaster, it can block exits. Furniture may become an obstacle to negotiate or walls may shift, leaving exit doors difficult to open. The cables, insulation, and air-handling ducts normally hidden above the ceiling tiles may fall to the floor or remain partially suspended. These unanticipated obstacles greatly affect the ability of people with disabilities to safely exit the structure. Simple measures to secure freestanding furniture, cupboards, bookcases, and similar items can reduce the potential for injury and increase the potential for escape. Alternate escape plans must be developed and practiced to mitigate the effect of hurdles created when items fall and block egress.

To truly address mitigation in the long term, structural mitigation must be a priority. Structural mitigation features, such as elevations, have been criticized as a structural barrier to seniors and people with disabilities. Although the mitigation feature affords safety, it may decrease accessibility. In a unique example of accessible mitigation, a few homes along the Louisiana coast put in elevators for homes that were elevated to U.S. Army Corps of Engineer standards. Some of these units were installed with assistance from faith-based organizations after Hurricane Andrew in 1992. As another example, a congregate shelter has been created at the Des Moines, Iowa, Fairgrounds that is above ground and accessible. However, congregate rooms (and accessible safe

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rooms in general) are relatively rare. Mitigation measures should be specifically identified that can be adapted for or by people with disabilities.

Mitigation measures offer increased levels of protection, but many currently recommended practices fail to address the needs of people with disabilities. Consider, for example, that the most effective safe rooms are underground. Plans for accessible underground safe rooms have not been developed. For example, the FEMA FAQ page on safe rooms offers only the following information (www.fema.gov/plan/prevent/saferoom/index.shtm):

Q: Besides FEMA guidance, what other codes and standards are there for safe rooms and community shelters?

A: Currently, the International Code Council (ICC) is developing a consensus standard for the design and construction of hurricane and tornado shelters. This new standard should be available for adoption in the summer of 2006. Currently, design and guidance exists in FEMA 320, Taking Shelter from the Storm, Building a Safe Room Inside Your House; FEMA 361, Design and Construction Guidance for Community Shelters; and the National Storm Shelter Association (NSSA) shelter standard.

The ICC published its American National Standard for the design and construction of storm shelters in June 2008 (ICC 2008). Section 101 on page 101.4 on special needs says "provisions that are necessary for persons with special needs, including any special electrical or mechanical equipment, sanitary facilities, or other special features, are outside the scope of this standard." Section 501 does specify occupant density, including people using wheelchairs or those who are bedridden (p. 21).

Summary of Key Findings

Mitigation measures require time, funding, expertise, and both the economic and political will to implement. A recent article in *Fire Chief* stated, "Due to the population and overall low economic status of the city [Petersburg, Virginia], there is an increased need for more of an emergency response than emergency mitigation and preparation" (Enos 2008, para. 4). The article goes on to discuss the "political battle" (para. 7) surrounding disaster mitigation and notes that mitigation activities should not pull funding from other stages of disaster management. Gerber (2007) notes, "Hazard mitigation is in many ways not a question of scientific understanding but of political will, a will that is found to be lacking in many instances" (p. 237). However, as Hurricane Katrina demonstrated through the levee failures, mitigation of major catastrophes "is beyond the capabilities of state and local government to deal with [alone]. It requires a national response" (Holdeman 2005, para. 1). To effectively mitigate, a partnership among local, state, and federal partners is usually necessary to fuel and fund appropriate initiatives.

Burby (2006) found that the effects of Hurricane Katrina and other disasters were exacerbated by policies and actions carried out by federal and local governments. Burby notes—

The *safe development paradox* occurs when federal efforts to make inherently hazardous areas safe for development in fact make them highly susceptible to disasters of catastrophic proportions. In New Orleans, these federal efforts consisted primarily of funding hurricane protection levees and other flood control works to promote urban development in the "protected" areas and the provision of flood insurance at subsidized rates. The *local government paradox* occurs when local governments, whose citizens bear the brunt of human suffering and financial loss when disasters occur, give insufficient attention to threats posed by hazards when they allow the intensive development of hazardous areas. In New Orleans, this paradox is illustrated by the city's facilitation of development in eastern New Orleans and by the Orleans Parish Levee Board's unwillingness to help underwrite the costs of higher levels of flood and hurricane protection. (p. 184)

Presidential administrations have emphasized different phases in the life cycle of emergency management, with mitigation generally falling into last place. An exception occurred during the Clinton years, when James Lee Witt emphasized mitigation. However, it seems fair to say that few government partners at any level have considered mitigation specific to people with disabilities an important issue, and researchers and policymakers have neglected the topic. Reviews of typical mitigation measures identified for local planners seem limited to recommending the implementation of registries and the prioritization of utility service for congregate facilities.

Recently, a broad shift toward mitigation has occurred as a result of catastrophic events such as Hurricane Katrina. Public opinion tends to swing toward the source of the problem, and thus mitigation efforts have resurfaced. Edwards (2007) noted—

As a result of the failure of the levees shortly after Hurricane Katrina hit New Orleans, the Department of Homeland Security (DHS) has acknowledged the importance of mitigation against disasters. This failure forced the recognition that prevention and mitigation are not the same when dealing with natural hazards and that focusing national emergency preparedness solely on terrorism is no longer appropriate. (p. 67)

Mitigation efforts in New Orleans since Hurricane Katrina have included new flood insurance rate maps by FEMA, Levee Board restructuring, evacuation planning, and a long-term "comprehensive flood protection system" (Edwards 2007, p. 68). Edwards notes that while "levees need to be rebuilt and strengthened…restoration of natural barriers such as wetlands may also provide cost-beneficial flood protection" (p. 68). At

the same time, insurance (a form of nonstructural mitigation) has either risen in price or been denied to area homeowners.

According to Mileti and Peek-Gottschlich (2001), many losses following a disaster are predictable and result from the interactions of "three major systems" (p. 62). Effective mitigation must address the systems and their interactions with one another. According to the authors, the three interdependent systems are—

[T]he physical environment, which includes hazardous events; the social and demographic characteristics of the communities that experience them; and the buildings, roads, bridges, and other components of the constructed environment. Growing losses in the United States result partly from the fact that the nation's capital stock is expanding, but they also stem from the fact that all these systems and their interactions are becoming more complex with each passing year. (p. 62)

Add to the social and demographic characteristics mentioned here the specific inclusion of people with disabilities and the environments that are inaccessible to them, and the complexity of the issue expands. It is clear that research has failed to address the question of mitigation for people with disabilities in any meaningful manner. Scant evidence exists in practitioner materials either.

Quarantelli (1987) addresses the need to recognize the potential for new disasters such as disease outbreaks, cyberterrorism, pandemics, and public health dilemmas (e.g., unsafe food supplies, air pollution, and environmental hazards). When the term is used in this broader sense, mitigating disaster is both a duty and a possibility in many areas. In today's society, growing populations place an increased demand on food supplies, solid waste disposal, and environmental resources, while increasing globalization allows diseases to spread quickly across regions and continents. The import and export of goods and materials in a global market, as well as accessible world travel, exacerbate these problems. Strong mitigation actions are needed to reduce morbidity and mortality

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among communities. Mitigation at this level of disaster focuses on the need for a public health infrastructure that can put policies and environmental supports in place to deal with emergencies. Such activities include broadly immunizing populations against emerging disease as well as communicating the need for such immunizations. Having policies in place to protect the food supply as well as the environment also address this level of disaster.

For each type of hazard—whether familiar, emerging, or yet to be identified—people with disabilities need to participate in mitigation planning and implementation activities. It is not enough to mention people with disabilities in these activities; mitigation programs must include people with disabilities as partners.

Transforming Mitigation for People with Disabilities

There is some disagreement regarding the best course of action for improving mitigation in general. In addition, there is practically nothing that specifies direction for mitigation measures for people with disabilities.

In the Congressional Research Service (CRS) Report for Congress (CRS 2005), which examines insurance losses and financial risks incurred following Hurricane Katrina, Rawle O. King discusses the two historical options individuals and businesses have used to protect themselves financially from a disaster. First, predisaster mitigation that reduces physical/environmental vulnerabilities must be incorporated. This chapter addresses mitigation planning as a starting point, then discusses environmental mitigation for people with disabilities. Second, the CRS recommends risk financing designed to reduce financial vulnerabilities (p. CRS-2). King suggests that Congress consider a "federal disaster insurance system to ameliorate the potential damages to homes and commercial buildings stemming from natural disasters" (p. CRS-11). King says—

Supporters of a federal disaster insurance program argue that it would be justified by the national scope of the Hurricane Katrina disaster and by the inability of the private insurance industry to handle future high payouts from a mega-catastrophe event without federal involvement. (p. CRS-12)

But insurance is often unaffordable for many Americans, especially senior citizens living on Social Security and individuals at lower income levels. People with disabilities are disproportionately found in these two groups; thus, accessing insurance as a mitigation action can prove quite difficult for them. Perhaps the answer lies in insurance programs that specifically address mitigation activities for seniors and those in lower income brackets.

Mileti (1999) outlines six guidelines for improving mitigation; these guidelines require a transformation in how we approach hazards in general.

- Adopt a global systems perspective. The built environment, as affected by the physical environment, has consequences for human systems. Lack of a built environment that is adequate to support and protect people with disabilities results in a higher loss of life, personal injuries, and property damage.
- Accept responsibility for hazards and disasters. Disasters occur because we place people in harm's way. Mitigation offers a means to alter that reality and requires acceptance of this responsibility at personal and government levels.
- Anticipate ambiguity and change. Disasters can and will vary. New disasters will appear and challenge the measures that are in place. New technologies and structural engineering breakthroughs will benefit people with disabilities and those interested in mitigation. By anticipating these transformative elements and incorporating them into a built environment (or related area), it is possible to take advantage of what they offer.
- **Reject short-term thinking.** Mitigation may have a payoff today or in 100 years. The cost, and the wait, are worth the benefit.
- Account for social forces. In recent years, people with disabilities and disability organizations have become more involved in personal and community

preparedness. By introducing mitigation measures to these groups, it may be possible to leverage that interest.

Embrace sustainable development principles. We cannot continue to develop
areas that fail to reduce risks, which include environmental threats along coastal
areas, the effects of pollution, and the impact of overdevelopment.
Environmentally friendly efforts in particular offer additional protection to people
with respiratory conditions and environmental sensitivities.

To implement these guidelines, Burby (2006) calls for local government policies that ensure hazard mitigation. He concludes that losses are lower when local governments are required to incur a larger fiscal burden of disaster when developing in areas known to be hazardous (rather than relying on the state to be responsible for such matters).

Burby (2006) also calls for the federal government to amend the Disaster Mitigation Act of 2000 "to require that regular mitigation plan updates mandated by the legislation be integrated into local comprehensive plans, where they exist" (p. 184). Finally, he suggests amending the Flood Insurance Act to require "the preparation of local comprehensive plans with hazard mitigation as a condition for continued partnership in the program" (p. 185). Finally, Burby states, "The major change in approach I have...would shift the program from insuring individuals and businesses for flood losses to insuring communities" (p. 185).

Edwards (2007) warns that a narrow focus on terrorism mitigation to the exclusion of natural disaster mitigation creates an environment that allowed the devastating effects of Hurricane Katrina. In her research following the 2005 hurricane season, Edwards says—

Inadequate training of federal staff members in the new plans, inadequate knowledge of the new plans and structures among local officials, and a Washington-centered approach to response (rather than the traditional reliance on FEMA regional employees) caused errors in the 2005 storm season response. As a result, a new NRP [National Response Plan] revision process is under way, which includes more local agency representatives. (p. 69)

According to Edwards, the inclusion of partners at the local and state levels, as well as the participation of "professional emergency managers" in disaster planning, are steps in the right direction for effective mitigation (p. 70). To improve on this model, people with disabilities should also be invited to the table to provide insight into the distinct needs of the disability community and to better address mitigation activities that are universally accessible.

Mitigation Planning

Section 322 of the Disaster Mitigation Act of 2000 requires mitigation planning at the local level before receipt of Hazard Mitigation Grant Program (HMGP) funds. To assist locals with mitigation planning, FEMA has introduced a series of mitigation planning guides over the past few years (FEMA 2002). In FEMA 386-1 *Getting Started: Building Support for Mitigation Planning*, FEMA outlined three steps to launch the mitigation planning process. Step 1 recommends that local planners assess community support to see if the community is ready to initiate mitigation planning. Step 2 creates the planning team and obtains official support and recognition for the effort. In Step 3, the public is engaged and a public education campaign is created. Throughout the mitigation planning series, FEMA recommends that the team, outreach efforts, and educational campaigns be inclusive.

There are several possible points of intervention in the FEMA mitigation planning series that would heighten involvement of people with disabilities. Doing so would raise issues of concern, increase awareness, and build useful partnerships. Currently, the mitigation planning guides do not offer specific ideas for including or reaching out to people with disabilities. For example—

• Task B of Step 1 determines whether the community is ready to begin the planning process. That effort taps into how much citizens know about hazards in

their community. Surveys and other tools could be used to assess the knowledge of specific groups, including people with disabilities, workplaces that employ people with disabilities, and organizations that provide support to this population. This task also identifies available resources that can be tapped, particularly employers and organizations.

- Task C of Step 1 addresses barriers to knowledge, support, and resources, including interest levels and funding. By surveying community members and those who link to people with disabilities, it is possible to identify barriers to mitigation planning within the disability community.
- The final part of Step 1 encourages the identification of a mitigation "champion." This person could be recruited from within the disability community, providing a conduit and an advocate for information, insights, and communication both to and from people with disabilities.
- In Step 2, a planning team is assembled. Stakeholders are generally identified (pages 2-4 to 2-5), but the disability community is not specifically mentioned here. A checklist (Worksheet #1) does not include any representatives from disability agencies or organizations.
- In Step 3, the public is engaged and a community education effort is launched. Step 3 is thus the next most important dimension of mitigation planning that must be influenced. Broad-based engagement that is open and accessible to all must be made possible. This section should require that locations for meetings be accessible and offer, for example, sign language interpretation and Braille materials. The guide recommends the use of instruments to gather information, such as questionnaires, but does not acknowledge a need for alternative formats. The public education campaign relies on news media, written materials, outreach activities, and the Internet. This section of the plan does not include suggestions about making outreach materials accessible. A simple checklist could be inserted to assist planners.

 In Step 2, mission and vision statements are developed. This effort provides an opportunity to introduce a broadly inclusive consideration of all affected, including low-income, senior, and disability sectors of the community.

Additional guides elaborate on other elements of the mitigation planning effort, such as loss estimation, historical preservation, implementation, and assessment. Two strategies might be considered in future revisions of these documents: (1) integration of the suggestions listed above, and (2) creation of a stand-alone guide that provides specific means for including and reaching out to the disability community. Additional recommendations can be found later in this chapter.

Mitigation Funding

A variety of mitigation programs are in place for individuals and communities. Most focus on structural mitigation and provide competitive grants, small loans, or resource information. While only one of the following programs is specific to people with disabilities, all of them aid in addressing mitigation. To improve mitigation activities, programs should include people with disabilities in the development of guidelines and the type of assistance provided.

FEMA's Predisaster Mitigation (PDM) program "provides funds to states, territories, Indian tribal governments, communities, and universities for hazard mitigation planning and the implementation of mitigation projects prior to a disaster event" (<u>www.fema.gov/government/grant/hmgp</u>, para. 1). This program allows entities to competitively apply for funding to address mitigation and reduce the amount of financial need postdisaster. According to Representative Sam Graves (R-Missouri)—

In 2005, the National Institute of Building Sciences issued a study that conclusively demonstrated federal mitigation programs save the federal government money. Specifically, the study found that for every dollar spent on mitigation, the American taxpayer saves over \$3 in federal disaster payments (Federal News Service 2008b, para. 8). According to another article on FEMA's PDM program-

Seattle Mayor Paul Schell and other public officials cited predisaster mitigation grants that had fortified buildings as one of the primary reasons that lives and property were saved during the [Nisqually] earthquake (Federal News Service 2008c, para. 4).

The Small Business Administration provides loans to repair homes after a disaster but can also award funds for mitigation purposes (Federal News Service 2008c), although "proposals [for mitigation] will be reviewed on a case-by-case basis" (para. 4).

According to its website (<u>www.flash.org</u>), the Federal Alliance for Safe Homes (FLASH) is a nonprofit organization that focuses on disaster mitigation through property protection. FLASH provides home mitigation plans for earthquakes, tornadoes, flooding, wildfires, and other natural disasters. An article published in *Business & Finance Week* stated, "New codes can impact approximately 2 percent of the built environment in any nondisaster year, but that percentage can increase dramatically in a poststorm rebuilding period, according to FLASH, Inc" (Chapman-Henderson 2008).

FEMA may also be able to provide additional funding. For example, the State of North Carolina received funding to supply weather radios to people who are deaf or hard of hearing (Quillin 2008). The radios use a strobe light and pillow vibrator to wake the person in the event of an emergency. For residents in rural and mountainous areas, an extra antenna is provided so that they can receive reception from the National Weather Service (whose signal triggers the alarm). According to one user, "the only quibble with the unit is that it's fully electric, with no battery backup" (para. 18).

In 2008, FEMA provided funds for the first congregate safe room to mitigate high wind and tornado risk for some people with cognitive disabilities. Through its Hazard Mitigation Grant Program, FEMA funded the Association for Retarded Citizens of Baldwin County (Georgia) with \$3.2 million to construct a shelter for 430 people. The structure will meet FEMA 361 safe room standards and provide wind resistance up to 200 mph. Funds will also retrofit the laundry and the Life Skills Training Center to withstand a wind load of 120 to 200 mph.

Peter David Blanck, Annenberg Senior Fellow and a commissioner on the American Bar Association Commission on Mental and Physical Disability Law, notes that "information is often the most valuable resource for effective mitigation" (Blanck 1995, para. 2). Unfortunately, "mitigation efforts of both the disaster and disability communities have all too often failed to intersect" (para. 3).

Blanck (1995, paras. 7–13) notes seven principles that involve or support people with disabilities to reduce the effects of disasters:

- Accessible disaster facilities and services: Access to appropriate facilities—housing, beds, toilets, and other necessities—must be monitored and made available to individuals with disabilities before, during, and after a disaster.
- 2. Accessible communications and assistance: It is crucial that people with disabilities help develop accessible communications and reliable assistance technologies.
- 3. Accessible and reliable rescue communications: Communications technologies can assist field personnel in rescue coordination and tracking and can be combined with databases that house information on optimal treatment for particular disabilities or that track the allocation of postdisaster resources.
- Partnerships with the media: The media—in partnership with disability and government organizations—should incorporate advisories into emergency broadcasts in formats accessible to people with disabilities.
- 5. Partnerships with the disability community: A nationwide awareness effort should be devised and implemented to inform people with disabilities about necessary precautions for imminent disaster. ... In addition, more young people with disabilities should be encouraged to study technology, medicine, science, and

engineering as a way of gaining power over future technological advances in disaster relief and mitigation.

- 6. Disaster preparation, education, and training: Relief and rescue operations must have the appropriate medical equipment, supplies, and training to address the immediate needs of people with disabilities.
- 7. Universal design and implementation strategies: Designing universal access into disaster relief plans, far from being a costly proposition, can pay off handsomely. ... In addition, a universal design approach to meeting the needs of people with disabilities before and after a disaster will benefit many people without disabilities, such as the very young or the aged.

Environmental Mitigation

As the principles developed by Mileti (1999) indicate, it is imperative that society accepts responsibility for hazards and engages in practices that are sustainable. Mileti and Peek-Gottschlich (2001) point to environmental conditions that can mitigate disaster. As people move into more hazardous areas, "local ecosystems that could have provided protection from natural perils" are destroyed (p. 62). Such events include the "draining of swamps in Florida and the bulldozing of steep hillsides for homes in California" (p. 62). Sometimes, they point out, even mitigation activities can heighten the risk of disaster by diminishing the natural effects of the environment (e.g., levees that increase flooding downstream).

In 2005, levees and canal walls in New Orleans were discussed on the National Public Radio (NPR) program *All Things Considered*. The interview provided the following information:

After Hurricane Katrina, one of the greatest challenges was how to make New Orleans and the surrounding areas more resilient in the face of flooding and hurricanes. Melissa Block talks with coastal oceanographer Robert Twilley of Louisiana State University about how the wetlands should be rebuilt. They provide a buffer for storms but have been seriously eroded. Robert Siegel talks with engineer Hassan Mashriqui, also of LSU, about strengthening protections around New Orleans, such as levees and canals. The city was flooded partly because of breaks in the levees and canal walls. (Block and Siegal 2005, para. 1)

Edwards (2007) notes the importance of natural barriers (such as the wetlands in New Orleans) to help mitigate disasters. She focuses on the need to address the natural environment:

New Orleans lost its natural protection from storm surge when the wetlands were filled in or removed for development without regard for the loss of a crucial flood mitigation mechanism. Future development needs to have more regard for the interrelationships of the natural and built environments. (p. 68)

Such development exacerbated the effects of the storm surge that flooded New Orleans following Hurricane Katrina. The majority of people who died were over the age of 60, and many had disabilities or were unable to leave owing to lack of transportation. Some of those who perished were living in nursing homes. Without proper mitigation, risks increase for everyone, but this is especially true for people with disabilities (NCD 2006). As described in earlier chapters, many of those who remained behind during Hurricane Katrina lacked transportation, were elderly, had disabilities, or were serving as caregivers for those who could not evacuate. The destruction of coastal wetlands (the result in part of levee construction) as well as the estimated billion-dollar cost to begin addressing the situation, combined to produce a storm surge higher than what existing mitigation measures could handle. It also prompted concern about future events. Because of the challenges associated with evacuating people with disabilities, as well as individuals living in nursing homes and others in similar situations (see the response chapter, Chapter 3), the destruction of natural safeguards, such as coastal wetlands, is even more problematic. Coalitions between disability and environmental advocacy organizations may forge an important partnership to address this continuing threat.

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The Gulf Coast is not the only area that demonstrates the links among environmental devastation, people with disabilities, and the need to mitigate the effects of disasters. Tsunamis—waves created by underwater earthquakes or volcanic activity—can cause considerable damage to life, property, and the environment (Arya, Mandal, and Muley 2006). As reported by the Indian news agency New Kerala

(www.abilityinfo.com/ticker/arch/archtsunami.html): "Disabled people in the Andaman and Nicobar Islands were the worst hit in the December 26 tsunami, as they could not escape to high ground to evade the sea's onslaught,' a leading rights group said Monday. A statement from the National Centre for Promotion of Employment for Disabled People (NCPEDP) said none of the 700 polio victims on Car Nicobar island could be located three days after the tsunami, which also disabled many people." A summary of tsunami mitigation and concern for people with disabilities notes that "planners of reconstruction often miss the opportunities to improve access by failing to adapt the designs of built environments" (Australian Council for International Development 2006). The article concludes that developing accessible environments helps prevent future disabilities and minimizes existing impairment. By helping people mitigate disaster, we can save lives and limit additional disability.

The talent, insight, and abilities of people with disabilities should be included in environmental planning and mitigation activities that seek to protect and improve natural mitigation areas, such as wetlands and swamps. Supporting and promoting education among people with disabilities in the fields of environmental science, urban planning, ecology, and related areas will help guide environmental mitigation that accounts for the diverse needs and environmental interests of all people.

According to Edwards (2007), "ensuring environmental justice for the community" is as important as focusing on the built environment. By opening up the mitigation planning table to people with disabilities, mitigation through the use of natural barriers and environmental justice can reach even loftier goals. As mentioned earlier, universal planning for people with disabilities can serve all people, even those without disabilities.

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Building Disaster Resilience

In addressing mitigation, Rose (2006) asserts that resilient communities are better able to reduce the effects of hazards and thus mitigate disaster. Rose states, "Perhaps the most important feature of the modeling of resilience is the identification of policy strategies to reduce the losses from infrastructure failure" (p. 10). Communities with capacity are better able to address the negative effects of disaster. A number of programs that ensure the participation of people with disabilities and disability organizations offer models for such efforts.

One much-heralded FEMA program is Project Impact (FEMA n.d.; FEMA 1999a; Holdeman 2005). The project began in October 1997, in an effort to help communities mitigate the devastating effects of disaster. By 1999, close to 200 communities and more than 1,000 businesses were involved (FEMA 1999a). The State of Washington credited Project Impact with saving lives and property during the Nisqually earthquake in 2001 (Holdeman 2005); however, the program lost funding just as it was being publicly lauded for its successes.

Project Impact was initially piloted in seven communities throughout the nation (FEMA n.d.). All seven were coastal regions and had been affected by numerous storms and hurricanes throughout the years. Because the project seeks to mitigate disaster, both public education and structural mitigation initiatives are carried out in these communities. Project activities have included hiring an emergency manager, raising streets in flood-prone areas, and sharing knowledge with other communities (FEMA n.d.). The program promoted grassroots efforts and building capacity among communities, supporting such activities with federal funding. The effort laid a good foundation for potentially involving people with disabilities. Project Impact set the following objectives:

- Identify and recruit partners in the community, such as local government leaders, civic and volunteer groups, businesses, and individual citizens.
- Determine the community's risk for natural disasters.

- Set priorities and target resources to reduce the impact of future disasters.
- Keep the entire community informed and focused on Project Impact's ability to reduce the damages and costs of future disasters.

Another program that developed under Project Impact entailed a series of videos that addressed mitigation measures for key facilities. In the *Stormworthy*! video, FEMA and the Florida Department of Community Affairs addressed concerns about medical buildings and nursing homes at risk during hurricanes. The purpose of the video was to motivate facility administrators to involve engineers and architects in structurally safeguarding the facility. During Hurricane Andrew, one hospital lost the use of its facility because of storm damage through vulnerable windows. The facility closed, patients were transferred, and a key resource for the community was lost for quite some time. Mitigation measures included strengthening roofs, glazing windows, shuttering, establishing generator operation plans (to avoid overheating; also recommended was moving generators to a higher floor), and securing potential projectiles (light poles, signs, etc.). Although costs to complete these mitigation measures were higher than originally budgeted, facility administrators pointed out that the facility must be safeguarded to maintain critical community services. The video emphasized the importance of local building and land-use codes. According to the video, Florida facilities must be located outside the 100-year floodplain and inland from predicted Category 3 storm surges.

Another model is the Oregon Partnership for Disaster Resilience, "a coalition of public, private, and professional organizations working collectively toward the mission of creating a disaster-resilient and sustainable state" (Oregon Partnership n.d.). The partnership's focus on community capacity is evident in its promotion of public education and inclusion of the state's citizens as partners. Mitigation plans are developed for local communities, and predisaster mitigation training is offered. In another model, Canada's National Disaster Mitigation Strategy seeks to partner with stakeholders to mitigate disaster (Canada's National Disaster Mitigation Strategy n.d.). This program is heavily focused on capacity building. According to the strategy's

website (<u>www.publicsafety.gc.ca/prg/em/ndms/index-eng.aspx</u>), "Disaster mitigation is most effective when activities engage the community. Therefore, public awareness and education initiatives should be a priority" (2.2). The following are the strategy's primary goals with regard to capacity-building:

- Promote a culture of mitigation in Canada. Federal/provincial/territorial emergency management officials will work collaboratively to promote and facilitate disaster mitigation initiatives within their own jurisdictions and in cooperation with other stakeholders, to affirm disaster risk reduction as a way of life for all Canadians.
- Work with nongovernment organizations and other stakeholders (including the private sector) to create public engagement, education, and outreach activities focused on disaster mitigation. (2.2)

Conclusion

In *Facing the Unexpected* (Tierney et al. 2001), several research-based principles were generated to further the general goal of risk reduction. First, "build a consensus that avoiding disasters is preferable to responding to or recovering from them" (p. 256). Although this principle seems obvious, a significant amount of attention and funding is currently directed toward response and recovery. However, mitigation measures can be arguably cost-effective, particularly over the long term. If the goal is to enable people with disabilities to remain in their homes or to return home quickly after disaster (FEMA 2003), then mitigation must be emphasized. Another research-based principle is to "integrate hazard management into the activities of grassroots community organizations" (p. 258). This principle supports the idea that mitigation efforts must be broadly inclusive, including key organizations that work in the disability community and connecting them to people at risk. A third relevant principle is to "tailor preparedness and response efforts to the needs and capabilities of those being served" (p. 260). Although this principle ties into other phases in the life cycle of emergency management, it serves the goal of mitigation as well. As Tierney and colleagues (2001,

p. 260) point out, "Households, organizations and communities vary markedly both in their hazard vulnerability and in their capacity to mitigate, prepare, respond, and recover from disasters." These authors recommend that policies and programs should connect to "specific groups and community settings rather than being uniformly applied." To accomplish this, they recommend the involvement of community residents, including people with disabilities. FEMA's mitigation planning series (see www.fema.gov/plan/mitplanning/resources) emphasizes that mitigation needs a "champion" to take it on as a cause. Who or what organization will become the champion of mitigation for people with disabilities?

Mitigation is the long-term solution to reducing the effects of disasters. Its potential is real and the range of solutions is wide. Mitigation can be carried out in small, inexpensive steps as individuals make their homes and businesses safer. It includes community planning and networking to improve common areas and individuals to advocate for change at the city and state levels. Mitigation is the responsibility of the government, the community, and the individual. It includes all populations and should be especially inclusive of those living in poverty, the elderly, and people with disabilities. It highlights advances, such as universal design, and promotes the interruption of the effects of hazards. Mitigation is an appropriate stage to focus research, funding, and attention as the larger society seeks to minimize the effects of disaster. Mitigation that centers on providing a safer and better built environment for people with disabilities serves the entire population. For examples of hazard-specific mitigation measures, see the table at the end of this chapter.

Research Recommendations

- Identify universal standards in the built environment and analyze the long-term cost savings of such activities.
- Conduct research on accessibility needs in the built environment, including strategies that improve disaster mitigation among people with disabilities.
- Assess the economic impact of mitigation activities and develop cost analyses for individuals, municipalities, states, and the federal government.

- Investigate affordable insurance practices that include mitigation planning for the working poor and those living in poverty.
- Identify best practices for capacity-building and assess programs such as FEMA's Project Impact.
- Test mitigation measures for people with disabilities, such as measures to prevent injury during various kinds of terrorist attacks.
- Conduct research specific to community capacity for people with disabilities.
- Investigate sustainable practices and long-term mitigation solutions.
- Understand the connection between the physical and social environments, including the increased risks associated with environmental degradation and natural resource depletion.
- Identify environmental justice issues that affect disaster mitigation and develop a plan of action to address these over the long term.

Practice Recommendations

- Promote burying underground utility lines to decrease damage from hazards such as ice storms and high winds. With a consistently available source of power, those who require power for medical needs and motorized equipment, and those in congregate settings, can be supported through a crisis, often remaining in a stable, fixed location for the duration of the event.
- Locate generators and other power backup sources in areas where they will be resistant to known hazards. Hospitals in New Orleans lost power when flooding destroyed underground generators.
- Give priority in mitigation planning to key facilities that require protection, such as dialysis centers, nursing homes, assisted living centers, state schools, and similar locations.
- Establish accessible structural mitigation measures in key congregate locations. Safe rooms, for example, should be a required element of mobile home parks,

schools, nursing homes, assisted living centers, retirement centers, and similar locations.

- Establish building codes that require accessible safe rooms in all new buildings, including private homes, public facilities, trailer parks, and public housing.
- Increase and expand accessible public services for a wide range of locations (e.g., mass transportation, public buildings, restrooms).

Policy Recommendations

- Revise the FEMA mitigation planning series to incorporate involvement and issues relevant to people with disabilities.
- Request that FEMA develop a mitigation planning guide that addresses issues of relevance to people with disabilities.
- Task the state hazard mitigation officer with building partnerships among state and local agencies and organizations that link to people with disabilities, and ensure that these partners are incorporated into mitigation planning initiatives.
- Encourage organizations, such as floodplain associations, to put mitigation of risk for people with disabilities on their conference agendas.
- Encourage FEMA review of local mitigation plans to assess them for the involvement of and impact on people with disabilities.
- Revise mitigation manuals to include information that is relevant to people with disabilities, and develop additional manuals specific to people with disabilities and mitigation strategies.
- Provide tax incentives for businesses that provide accessible points of egress and for individuals who implement mitigation strategies in their homes.
- Support communities and states by providing funding for mitigation projects.
- Require mitigation planning in all major metropolitan areas that is inclusive of people with disabilities.

- Adequately fund capacity-building programs with a history of success and beneficial grassroots initiatives (such as FEMA's Project Impact).
- Promote a broad range of preparedness and mitigation activities under FEMA to address both manmade and natural disasters.
- Support and fund long-term mitigation planning.
- Upgrade the FEMA mitigation video series to current technologies and formats, such as downloadable videos. Expand the coverage beyond medical facilities to include congregate care facilities, schools, retirement communities, public housing, and individual housing. Specifically address the value of mitigation activities and measures with and for people with disabilities.

FEMA Recommendations

According to FEMA's Mitigation Directorate website

(www.fema.gov/about/divisions/mitigation.shtm), the directorate manages "a range of programs designed to reduce future losses to homes, businesses, schools, public buildings, and critical facilities from floods, earthquakes, tornadoes and other natural disasters" (www.fema.gov/about/divisions/mitigation.shtm, para. 1). Mitigation activities include (recommendations in italics):

- Complying with or exceeding National Flood Insurance Program (NFIP) floodplain management regulations. *Develop a means for low-income households to secure insurance for assistive devices, durable medical equipment, and other necessary resources.*
- ii. Enforcing stringent building codes, flood-proofing requirements, seismic design standards, and wind-bracing requirements for new construction or for repairing existing buildings. *Develop recommendations consistent with ADA standards for measures such as safe rooms and other mitigation initiatives.*
- iii. Adopting zoning ordinances that steer development away from areas that are subject to flooding, storm surge, or coastal erosion. *Require new construction or*

poststorm rebuilding to be ADA-compliant, including a means for access to elevated structures.

- iv. Retrofitting public buildings to withstand hurricane-strength winds or groundshaking. *Require bracketing and other measures to secure cupboards, appliances, and other large items that can injure people or block egress.*
- v. Acquiring damaged homes or businesses in flood-prone areas, relocating the structures, and returning the property to open space, wetlands, or recreational uses. *Develop a policy that ensures that people with disabilities who relocate can regain access to work, transportation, health care, and other needed resources.*
- vi. Building community shelters and tornado safe rooms to help protect people in their homes, in public buildings, and in schools in hurricane- and tornado-prone areas (para. 3). *Provide new funding to ensure that these facilities are accessible for a variety of disabilities.*

Three divisions fall under FEMA's Mitigation Directorate: Risk Analysis, Risk Reduction, and Risk Insurance. The Risk Analysis Division identifies potential hazards and manages risks through "engineering and planning practices" (para. 9). The Risk Reduction Division "works to reduce risk to life and property through the use of land use controls, building practices and other tools" (para. 9). This division focuses on both preand postdisaster mitigation. Finally, the Risk Insurance Division provides flood insurance and promotes "floodplain management regulations that mitigate the effects of flooding on new and improved structures" (para. 9). The NFIP falls under this division. *Mitigation information on the website does not specifically address people with disabilities; this omission should be corrected*.

The following table adapts material from the FEMA IS-1 Emergency Program Manager tool kit to identify mitigation activities that support people with disabilities.

LONG-TERM MITIGATION Long-term mitigation includes any activities that eliminate or reduce the occurrence of a disaster. Also includes long-term activities that reduce the	MITIGATION AS IT PERTAINS TO PEOPLE WITH DISABILITIES (adapted for this report) Mitigation activities that take into account the special needs of people with disabilities should include all activities in the left column, as outlined by the IS-1
effects of unavoidable disasters.	tool kit, plus additional activities listed here. Please note that this is not a comprehensive list.
GENERAL MANAGER	
 Building codes Vulnerability analyses updates Tax incentives/disincentives Zoning and land use management Building use regulation/safety codes Compliance and enforcement Resource allocations/interstate sharing Public education 	 Universal design Analysis of accessibility needs Tax incentives/disincentives for providing accessible points of egress Zoning and land use that recognizes slope, grade, and other factors Training and drills for serving all populations during an emergency Resource gathering from the disability community and specialists
HAZARD-SPECIFIC MEASURES	
Flood	
 Dam construction/inspection Stream channelization Construct/protect retention barriers Reforest/prevent deforestation Contour farming Flood-proof buildings 	 Accessible shelter and public buildings Resource gathering from the disability community and specialists
Epidemic	
 School inoculations Rodent/insect eradication Water purification Sanitary waste disposal Health codes/laws/inspections Public health education 	 Accessible, sanitary restrooms Resource gathering from the disability community and specialists Assurance that points of distribution (PODS) are accessible

Continued next page

LONG-TERM MITIGATION	PEOPLE WITH DISABILITIES (adapted for this report)
HAZARD-SPECIFIC MEASURES	
Fire	
 Fire codes No-smoking laws Fire zoning Fire safety information Hazardous Materials Spill	 Accessible shelter and public buildings Resource gathering from the disability community and specialists
 Transport speed limits Container structure codes Corporate licensing Restricted routing Materials identification codes 	 Environmental justice focus to ensure equal burden and benefit of hazardous waste facilities by residents with disabilities (especially those who are low-income or elderly) Resource gathering from the disability community and specialists
Landslide	
 Forest management Preserve ground cover Maintain natural runoff Stabilize slopes Real estate disclosure laws 	 Accessible egress from homes and buildings Resource gathering from the disability community and specialists
Wind	
 Roof anchors Window size and thickness codes Windbreaks 	 Accessible shelter and public buildings Resource gathering from the disability community and specialists
Hurricane Storm Surge	
 Barrier islands Coastal wetlands protection Replace coastal sand dunes Construct breakwaters/levees Coastal zone management Public information program 	 Accessible transportation Accessible shelter and public buildings Resource gathering from the disability community and specialists

MITIGATION AS IT PERTAINS TO

Continued next page
LONG-TERM MITIGATION	MITIGATION AS IT PERTAINS TO PEOPLE WITH DISABILITIES (adapted for this report)
HAZARD-SPECIFIC MEASURES	
Gasoline Shortage	-
 Alternative research Allocation/international sharing Mass transit systems/car pooling Design emergency efficient engines Reduce speed limits Energy conservation program 	 Accessible mass transit systems/car pooling Design emergency efficient engines in vans Prioritize paratransit for distribution Resource gathering from the disability community and specialists
Nuclear Plant Accident	
 Site zoning Waste management/containment research Plant safety codes/inspections Plant operator training Environmental impact research/statements 	 Environmental justice focus to ensure equal burden and benefit of facilities by residents with disabilities (especially those who are low-income or elderly) Evacuation planning for people with disabilities in the area Resource gathering from the disability community and specialists

CHAPTER 6: Working with Emergency Managers

Introduction

In 2004, Harris Interactive conducted a survey of emergency managers in large, midsized, and small cities across the United States. The results indicated that the needs of people with disabilities had been incorporated into 69 percent of emergency plans, with an additional 22 percent of plans still under development. However, during a congressional briefing in 2005, Hilary Styron, director of the National Organization on Disability's Emergency Preparedness Initiative, stated that nearly 86 percent of the community-based organizations serving people with disabilities in the Gulf Coast region did not know the name of their local emergency manager. Clearly, a disconnect exists between emergency managers and the people with disabilities they are trying to protect.

Disability issues are receiving more attention than ever before in the field of emergency management. For example, the newest version of the National Response Framework incorporates the needs of people with disabilities into its activities. The 2009 National Disaster Strategy (www.fema.gov/emergency/disasterhousing) acknowledges the need to connect with the disability community and knowledgeable advocates to plan for and manage postdisaster temporary and permanent housing needs. Courses are available within FEMA and are offered at emergency management conferences on disability concerns and special needs topics. The door is open for additional progress to be made.

Particular attention must be placed on the local level. The local emergency management office "plays the most active role in emergency operations" (Labadie, 1984, p. 489). Thus, disability leaders and local emergency managers must work to create a pipeline that both enables and encourages the transfer of information in both directions. Accomplishing this task is a two-way street. Emergency managers must connect with people with disabilities and advocacy organizations to ensure that their concerns are heard and information is disseminated. On the other hand, people with disabilities and advocacy seek out opportunities to make

their concerns known, and they must make an effort to understand the content of current emergency operations and recovery plans.

This chapter identifies several avenues that can lead to the creation of an information pipeline and an effective partnership between emergency managers and the disability community. The first step in developing such a system is to understand the field of emergency management and emergency managers themselves. It is important to understand that any effort to interact with or influence emergency management personnel must be made well in advance of a disaster, as it is likely to be more difficult to enter the picture and have an impact during the response period.

Development of the Emergency Management Field

The federal government first entered the disaster relief arena in response to a disastrous fire in Portsmouth, New Hampshire, in 1802. The resulting special assistance legislation was the first of 128 disaster-specific acts passed by Congress between 1803 and 1950 (Platt 1999). During this period, Congress realized the need for a more organized method of responding to disasters. In 1905, Congress officially recognized the American Red Cross (ARC) as a vital disaster relief organization and tasked ARC with providing "mass care," which includes shelter, food, and first aid (Rubin 2007). The Federal Disaster Act of 1950 formalized the involvement of the federal government in emergency management (Rubin 2007). State and local governments were given primary responsibility for managing disasters, and the federal government's role was viewed as strictly supplemental. This same year marked the passage of the Civil Defense Act. In similar fashion, state and local governments were given primary responsibility in the area of civil defense.

Over the next 29 years, the face of disaster-related agencies changed almost as often as the presidency. Shifts in national policies concerning civil defense and natural disasters, along with numerous reorganizations of federal agencies, resulted in a weakened emergency management system. In response to public and political pressure to create a more effective emergency response system, President Jimmy Carter created the Federal Emergency Management Agency (FEMA) in 1979. This independent agency consolidated several federal civil defense and disaster-related agencies and programs (Rubin, 2007).

Although the creation of FEMA was an attempt to improve the effectiveness of federal disaster response, poor performance continued to plague the federal emergency management machine, which resulted in congressional inquiries during the 1980s (Rubin 2007). A number of major disasters affected FEMA, none more so than the events of 1989. In the fall of that year, a series of events and circumstances pushed FEMA to its maximum capabilities. A typhoon in Guam, Hurricane Hugo in the Carolinas, and the Loma Prieta earthquake in California caused both FEMA and the ARC to expand and send personnel to numerous areas. Issues involving the geographic spread and considerable racial and ethnic diversity revealed inadequacies in FEMA procedures, materials, and abilities. One subsequent change involved the development of the Federal Response Plan (FRP), which laid the foundation for today's National Response Framework. Other changes involved

- increasing the number of Spanish-speaking staff and materials (not to mention other languages);
- the creation of new building codes (for roofs in Florida, for example) and retrofit strategies (for older buildings in California); and
- the institution of community outreach teams (which were subsequently used for Hurricane Andrew).

These events also made emergency managers and the general public aware of the needs of vulnerable populations.

In 1992, FEMA informally used the FRP as the backbone of an effort to assist with Hurricane Andrew in Florida. This massive effort revealed that FEMA still needed considerable restructuring and, some believe, even affected the presidential election. In 1993, President Bill Clinton appointed James Lee Witt as FEMA director and charged him with improving emergency management at all levels. The focus of FEMA shifted toward mitigation and preparedness, and the agency emphasized an all-hazards approach to emergency management. In addition, disaster funding increased, relief eligibility expanded, and "the FEMA director was invited to attend cabinet meetings" (Rubin 2007, p. 34). Excited about the potential benefits of a comprehensive approach to emergency management, many state and local governments reorganized their own emergency management offices to reflect FEMA's emphasis (Rubin 2007; Wilson and Oyola-Yemaiel 2001).

Major events typically initiate or accelerate changes in the field of emergency management. One recent example is the way the 9/11 terrorist attacks transformed emergency management. In response to this event, President George Bush created the Department of Homeland Security (DHS). The DHS was given responsibility for oversight and coordination of 22 different agencies, including FEMA (which lost its cabinet position). This initiative marked a shift in emergency management policy back toward national security (Rubin 2007).

The implications for disability organizations seeking to work with emergency management include these:

- Each presidential administration seems to put its stamp on emergency management at the federal level. It is wise to stay abreast of such changes.
- Major disasters result in changes and can be used as opportunities to transform policy, practice, and programs. Disasters can provide an opportunity to alter the way emergency managers understand and meet the needs of people with disabilities.
- FEMA directors are appointed by the president. Historically, political appointees have not had expertise in the field of emergency management. Long-term FEMA employees do have such expertise and are often a good point of contact.
- FEMA has created the position of national disability coordinator, who can serve as a key resource.

- FEMA has been the target of complaints and criticisms for failures in numerous disasters. However, historically, FEMA's funds tend to focus on long-term recovery and restoration rather than response. After 9/11, the focus switched to response, although FEMA was severely criticized for its handling of the response to Hurricane Katrina. Federal inquiries pointed to a disconnect among federal, state, and local emergency management and elected officials. It is important to understand that emergency management offices are not uniform across the various levels of government. The most significant structural differences occur at the local level of emergency management, which is where community-based disability organizations can have the greatest impact.
- The U.S. political system demands that each level of government hold individual responsibility, although they must work in a cooperative, interactive fashion to deal with major events and disasters. Different layers of government have different roles and responsibilities, as well as different kinds of resources and expertise.

Understanding Local Emergency Management

A 1982 survey of 6,000 local and county emergency management agencies revealed "considerable structural variation and lack of standardization" (Mileti 1999, p. 217). An understanding of the potential variation among these local offices is vital to developing a working relationship with the emergency manager. Disability organizations and people with disabilities themselves should determine these two things in preparation for interacting with the local emergency manager:

- What type of emergency management office exists in the local community?
- Who is the emergency manager and what is his or her background?

Labadie (1984) suggests three possible organizational structures that might define a local emergency management office:

- The emergency manager functions as a department head reporting directly to the head of the local government. Although this option might provide a stronger voice for emergency management issues, the emergency manager will have to battle other departments for adequate staffing and funding, which might reduce the amount of time he or she can spend on emergency management activities, thereby weakening the effectiveness of the office. This structure tends to mimic that at the national level, with changes in direction accompanying changes in city leadership. Disability issues may not garner the attention they deserve because of limited time and resources.
 - Disability organizations seeking to work within this type of structure should contact the department head and offer appropriate levels of support. It is important to identify any organizational units in the local office in which the disability organization or advocate might participate. Because the office probably lacks information on disability issues, the disability advocate or organization might offer to help establish a task force of relevant agencies. It is important to spend time getting to know the emergency manager, to build trust and credibility, and to establish a working relationship that can make a difference. A disability organization can also connect the local emergency management office with key resources, knowledge, and volunteers on disability issues.
- The emergency manager and emergency management agency function under the auspices of another line agency (e.g., fire or police). In these cases, the emergency manager is often a police officer or firefighter who performs these duties on top of his or her normal job. When operating under the umbrella of a response agency, emergency managers tend to align their activities with those of their boss. Disability issues probably take the biggest hit under this type of organization because of the limited knowledge of those working within this structure.
 - The emergency manager wears several hats in this configuration, which means that local resources are stretched extremely thin. The perspective of

the emergency manager may lend itself to a singular focus on one dimension of disasters, such as a response focus. Disability advocates and organizations can use this as a starting point to establish a working relationship; perhaps by working with or through Citizen Corps or a similar effort that is response-oriented. Efforts to expand the influence of disability organizations into preparedness, mitigation, and recovery initiatives can then be pursued.

- The emergency manager and emergency management agency function as a stand-alone entity serving several communities or counties (e.g., regional emergency management offices). These offices often report to an advisory council composed of representatives from the protected entities. The protected communities contribute funding to the offices according to the size of their population and oversight is provided by the entire advisory council. Thus, the emergency manager has more time to focus on protective activities instead of politics. This structure offers the best chance for disability issues to receive attention. It may be wise for disability organizations to push for representation on the advisory council to ensure that they have a voice in the direction of the emergency management office.
 - Disability organizations may find it easier to make inroads in this structure. It is likely that several areas exist within the main structure through which the disability organization can extend its expertise (VOADs, for example). In addition, it is far more likely that in larger emergency management offices, a staff member(s) will be tasked with disability or "special needs" issues. If this is the case, the disability organization will probably interface with that particular staff member on most matters. However, if applicable, it is also wise to ensure that representatives from the disability community serve on councils, boards, and task forces. Attempting to influence the structure for the good of people with special needs may seem bureaucratic and cumbersome, but the results can be profoundly successful.

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It is difficult to predict or mandate the size of an emergency management office. FEMA tried to establish staffing guidelines for local emergency management offices in the 1980s (Edwards and Goodrich 2007). Their suggestion was to employ one professional for every 100,000 in population, along with a support staff person for every three professionals. However, these guidelines never became firmly entrenched within local emergency management offices. Thus, we face a wide range of staffing levels today. For example, in 2002, the New York City Office of Emergency Management employed only 100 staff members to serve a population of 9 million. Using the FEMA model, 75 of these staff members would have been professionals, creating a citizen-to-professional ratio of 360,000 to 1, which is well below the suggested guideline. In contrast, Oakland, California, population 250,000, maintained an emergency management staff of 12 during the years 1992 to 2002—a 28,000 to 1 citizen-to-professional ratio that exceeded the FEMA ratio.

Another survey of the largest cities in the United States revealed that approximately 87.5 percent of the responding cities had emergency management offices with six or fewer professionals (Parle and Brown 2005). In a number of smaller cities across the country, a single individual staffs the local emergency management office (Edwards and Goodrich 2007). In many instances, this person must also perform other duties for the city, such as the role of fire chief (Parle and Brown 2005). Unfortunately, smaller emergency management offices, especially those staffed by a single person, may not be able to devote sufficient time to disability issues. The following are some options for overcoming this staffing shortage and ensuring that disability issues receive adequate attention:

- Disability organizations could assign a staff person to serve as a liaison.
- Local and state emergency managers could create a Special Needs Advisory Panel (SNAP) or similar committee.
- Funding for additional staffing could be solicited through grants and other sources.

The knowledge and skill set of an emergency manager often determines the success of emergency management activities (Labadie 1984). Although the function and philosophy of emergency management has been around for quite some time, the development of the field of emergency management as a career path is relatively recent. Over half (51.4%) of the respondents to a survey of emergency managers working in larger U.S. cities were over the age of 50 (Parle and Brown 2005). Although this would seem to demonstrate considerable experience in the field, roughly 57 percent stated that they had held their current position for fewer than five years (Parle and Brown 2005).

Historically, emergency managers generally fit into one of three categories (Neal 2008; see also Blanchard n.d.):

- Practical experience but limited formal education. These individuals are often
 retired from the military or public safety field and are working in emergency
 management after retirement. They are familiar with the stress of emergency
 situations but have limited exposure to the research associated with disasters.
 Emergency managers who fall into this category may not be cognizant of the
 needs of people with disabilities owing to a lack of formal or continuing
 education. Disability organizations should identify opportunities to partner with
 this type of emergency manager.
- Formal education but limited practical experience. This group consists of recent college graduates entering the emergency management environment on the ground floor. Their educational experience has exposed them to a number of theories and issues in the field. They may have a basic understanding of disability issues; however, this knowledge is usually based on a limited amount of academic research on disasters and disability issues. They typically have very limited, if any, experience dealing with an actual emergency situation. Disability organizations might want to offer internships to college students or practical, hands-on experience opportunities to new emergency management employees as a way to educate and train the next generation of emergency managers.

Practical experience coupled with a formal education. This group combines
the best of both worlds—education and experience—and represents the
nontraditional student. These people have enjoyed careers in relevant fields and
have earned a degree to complement their experience. They understand the
importance of melding the two worlds into one, and they have the credibility in
both areas to make it happen. These emergency managers are among those
most likely to have been exposed to research and best practices for vulnerable
populations. Disability organizations may find this type of emergency manager
open and enthusiastic about working with the disability community.

As Presidential Executive Order 13347 stated, emergency managers must involve people with disabilities, disability organizations, and knowledgeable advocates in every phase of emergency management practice: preparedness, response, recovery, and mitigation. That process begins with understanding how emergency management works as an organizational structure. The next step involves understanding how emergency managers secure information so disability organizations can disseminate their knowledge base into the emergency management sector.

Creating a Cultural Shift

Often, the unique needs of people with disabilities demand different strategies when it comes to disaster planning for this population (Mileti 1999). The 2004 Harris survey found that just over half of emergency managers had incorporated input from the disability community into their emergency plans. Although this is a step in the right direction, much work remains to be done. Creating a culture of cooperation and collaboration is essential (Kailes 2005b).

Executive Order 13347 calls for a cultural shift in how emergency preparedness is conducted. Emergency managers must develop working partnerships with disability organizations along with other community organizations to ensure the effectiveness of emergency plans. An example of a cooperative culture emerged after the Northridge earthquake in 1994. Norma Vescovo, director of the Independent Living Center of

Southern California in Van Nuys, recognized the fact that relief agencies would not be prepared to address the needs of people with disabilities (Hammitt 1994). Vescovo met with local FEMA officials and the two organizations established a designated service center for people with disabilities. Hammitt commented that people with disabilities and disability organizations "must take the initiative to work with disaster agencies to develop emergency plans" (1994, para. 13).

In several locations, disability task forces, offices, or agencies have fostered positive change. For example, the City of Chicago's Mayor's Office for People with Disabilities pulled together builders, architects, developers, and the disability community to design a new, accessible building code. The effort connected people in a partnership that produced change. A pending effort includes a review of how construction/building plans might be inspected for accessibility, which could positively influence the postdisaster reconstruction period. An earlier effort by the City of Chicago produced an emergency procedure ordinance for high-rise buildings (see the mitigation and response chapters for additional information), demonstrating the power of an ordinance to drive change (NCD 2007).

Cultural shifts occur at the broad societal level and require time to develop. Change mechanisms involve the impact and influence of a number of agents, including powerful local officials or organizations such as the Independent Living Center in Van Nuys. Local governments must support the efforts of emergency managers to think outside the box to address the needs of vulnerable populations, which is the intent of Executive Order 13347. When firefighters in Victoria, Australia, recognized the need to communicate with a growing Turkish population, they decided to learn the language (Mitchell 2003). This unique project would have never gotten off the ground without the support of local officials. Local governments should support emergency managers who are looking to develop communication methods that can reach the disability community.

Groups and organizations can link emergency managers and the disability community and facilitate interaction. In 1998, the Southern California Earthquake Center (SCEC) and the Adams Normandie Neighborhood Association (ANNA) joined hands to launch

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an earthquake awareness campaign (Andrews 2001). Activities of the SCEC-ANNA Earthquake Watch project included after-school programs, training workshops, and safety fairs. Andrews concluded that hazard awareness and personal safety responsibility increased as a result of this program. The project also led to "more frequent communication and ongoing interactions" among the participants (Andrews 2001, p. 10). The story of Jim Davis, EM coordinator in Pittsylvania County, Virginia (introduced in Chapter 2) demonstrates the effectiveness of community links and interaction. His work to increase the safety of people with hearing impairments earned him the 2007 Clive Award from the National Hurricane Conference, and the National Organization on Disability is assessing his efforts as a possible nationwide model.

In short, individual initiatives, group and organizational efforts, and government support are all required to effect the cultural shift necessary to transform emergency management. The mechanisms through which that shift occur include training and education, and building partnerships from the disability community into the emergency management sector.

Transfer of Knowledge for Emergency Managers

Emergency managers prefer to receive information through conferences, meetings, workshops, and personal relationships (Mileti 1999). These avenues facilitate a face-to-face transfer of knowledge that is bolstered by the reputation and practical background of the presenter. Other avenues for obtaining knowledge include academic and trade journals, although these are not the most common sources of information. A void exists in understanding how emergency managers acquire knowledge about disability issues, although we know that information dissemination tends to occur through conferences (including specific sessions), listservs, online courses at FEMA or on-campus courses at the Emergency Management Institute (EMI), state workshops, and professional networks. Links and interactions with emergency managers also appear to be effective ways to disseminate information (Fothergill 2000).

A first step in the transfer of knowledge process for disability organizations should include becoming familiar with the emergency management community. Recommendations for that step include the following:

- Learn the language of emergency management. The field is noted for its use of acronyms. To an outsider, this statement might not make sense: "The NRF has been activated, and they need that intel ASAP at the JFO in ESF6, but be sure to go through ICS, because NIMS is in effect." However, a number of easily accessible acronym lists are available to begin learning EM jargon, such as the glossary for the National Response Framework at www.fema.gov/emergency/nrf/glossary.htm.
- Become familiar with how emergency managers structure their activities. A beginner course is available at the FEMA Independent Study website. IS-100 "Emergency Manager: An Orientation to the Position" offers basic content on this subject matter. The tool kit for the course provides a particularly helpful one-page overview of the four phases of emergency management. It is available at <u>http://training.fema.gov/EMIWeb/IS/is1.asp</u>. Other courses are also available.
- Attend emergency management conferences. State and national conferences are useful forums for acquiring information and taking the initial steps toward identifying professionals who might be interested in developing partnerships with the disability community.
- Arrange meetings with emergency management agencies. Directors and coordinators can meet with disability organizations to discuss issues and points of mutual cooperation. First steps would include assessing the structure of the local agency, its staffing, and the challenges it faces (e.g., budget), and determining the agency's interest in partnering with local organizations on disability issues.
- Join in on the various ways that emergency managers learn or obtain information. Those avenues for learning include the Lessons Learned

Information Sharing system (<u>www.llis.gov</u>), after-action reports (AARs), situation reports, debriefing sessions, and hot washes that review what happened.

• Distribute this report to local, state, regional, and national offices of emergency management and related agencies.

Education and Training on Disability Issues for Emergency Managers

A number of resources exist for emergency managers who need to learn content, procedures, and information relevant to people with disabilities. These sources can be starting points, although some caveats are noted. For more resources, see the appendices.

- FEMA offers a free, interactive Independent Study course—IS 197 "Special Needs Planning Considerations for Service and Support Providers"—at <u>http://training.fema.gov/EMIWeb/IS/is197SP.asp</u>.
- FEMA also offers a course known as G 197 "Emergency Planning and Special Needs Populations" that is available as a conference seminar or through a trainer at various state agencies.
- The FEMA Higher Education Project offers a set of teaching materials on "Social Vulnerability to Disasters," which is available free at www.training.fema.gov/EMIWeb/edu/sovul.asp. The course materials include minimal attention to disabilities. These materials will be published in a book in 2009 by CRC Press; the book will include additional chapters on disabilities and medical needs (Phillips et al. 2009).
- The National Organization on Disability published and disseminated its "red guide"—*EPI Guide for Emergency Managers and Planners*—to all state emergency managers. NOD has also developed disability-specific brochures. All these materials can be downloaded from <u>www.nod.org</u> (select Emergency Preparedness Initiative).

- DHS awarded a grant to Telecommunications for the Deaf and Hard of Hearing, Inc. for the Community Emergency Preparedness Information Network (CEPIN) project. CEPIN developed pilot courses for San Francisco, Tulsa, Boston, and Philadelphia called "Emergency Responders and the Deaf and Hard of Hearing Community: Taking the First Steps to Disaster Preparedness." The website has useful materials that are accessible (www.cepintdi.org).
- Various universities and colleges offer stand-alone courses on the subject of vulnerable populations; these courses usually include content on disabilities. They typically cover a broad spectrum of populations in addition to persons with disabilities.
- Emergency managers glean information from a variety of sources. By connecting to those sources and participating at relevant events, it may be possible to influence or get more consideration for disability issues. Avenues for gaining information include hot washes and debriefings, the LLIS website (www.llis.dhs.gov/index.doc), after-action reports, and traditional information sources in the field of connected practitioners.
- Increasingly, practitioner conferences are offering training and presentations on disability issues. Attendance at such conferences offers the opportunity to gain critical information from familiar peers.
- Federal agencies have increased their contributions to understanding disability issues and disasters. The Office of Civil Rights and Civil Liberties at FEMA posts regular updates on its website

 (www.dhs.gov/xabout/structure/editorial_0375.shtm). Other federal agencies have held online webinars on accessible communications and evacuation. By tapping into listservs for professional organizations, an emergency manager can learn about these easily available opportunities.

In several cases, localities have taken it upon themselves to fill the information gap. Trainings have been developed by community groups, emergency management agencies, private consultants, and interested individuals or advocates that specifically address disability-related emergency management issues and planning. However, a number of concerns exist regarding the availability or format of emergency management education and training opportunities:

- Existing training courses and materials should be assessed for content. Materials likely require updating, especially in light of the significant changes that have occurred since Hurricane Katrina.
- Training courses and materials should also be assessed regarding their usefulness. Is the context of the materials relevant to the trainee or the student? Are the materials actually used after the course is completed?
- Additional training should be developed and offered through multiple venues, including in-person conferences and courses that can be taken on the Internet. Trainers could use distance education delivery technologies that incorporate video, captioning, and other interactive methods to disseminate information. Courses should feature people with disabilities as instructors and highlight the resources that disability organizations can bring to an emergency management partnership.
- Funding should be made available to update or develop courses. Much of the funding for these projects has dried up.

Building a Partnership with Emergency Managers

A number of methods or tools can be used to developing a culture of cooperation and collaboration. In the process, the expertise of emergency managers can be augmented by the knowledge of others (Kailes 2005a). The following list describes some ways to build a partnership between emergency managers and the disability community. Emergency managers and disability leaders are also encouraged not to limit themselves to this list but to explore any means possible to increase their interaction. Social relationships and networks are crucial to create the partnerships necessary to advance inclusion in the emergency management field and in preparedness initiatives.

- Network. The most effective tool for connecting with emergency managers is networking (Drabek 1987). Contact emergency managers and start building a connection to the disability community. Networking can occur through email, inperson meetings, participation in local events, and attendance at conferences. Networks take time to develop, but the payoff occurs in the establishment of trusted relationships across different areas of expertise. Those relationships can form the basis for an advisory committee on disability, modifications in local practices, new policies, and, eventually, a broader cultural shift in the way things are done.
- Interact. Attend and participate in conferences sponsored by each other's professional associations. As noted earlier, this is one of the primary sources of disability-related information for emergency mangers.
- **Communicate.** Write for each other's publications. Printed information can be a useful resource, especially for those in jurisdictions with limited funding to attend conferences. Disability organizations should seek out opportunities to write in publications that are read by emergency managers, such as the *IAEM Bulletin*.
- Access listservs. A number of listservs can be recommended to emergency managers, including those at <u>www.disabilityinfo.gov</u>, which include topical content on emergency preparedness and a wide variety of other issues, such as education, employment, and housing. In addition, professional organizations such as the International Association of Emergency Managers (IAEM) have listservs that are read daily by emergency managers. By participating in these listservs, it is possible to acquire and disseminate useful information.
- Participate in or create methods to reach emergency managers. For example, one resource from which emergency managers and first responders acquire information is the Lessons Learned Information Sharing system (LLIS, at <u>www.llis.gov</u>). Useful practices and ideas can be shared through this system.
- Form advisory committees. Local emergency managers should develop a local Special Needs Advisory Panel (SNAP) or the equivalent with partners from the disability community. Those partners should include organizations that link to a

wide variety and number of people with disabilities and that can generate and offer productive insights and strategies for risk reduction.

- Cross-train. Offer training to emergency management agencies on a wide range of issues, such as disability etiquette, terminology and the importance of language, approaches to disability issues (e.g., special needs versus functional needs, see Kailes 2007), recommendations from various reports (e.g., the NOD SNAKE report, the California SILC wildfire report), transportation, and the like. Disability organizations should seek out and obtain training on emergency management procedures, such as those involving evacuation, sheltering, and recovery assistance. Disability organizations should take FEMA courses either online or through the EMI campus. To see the options, go to www.fema.gov/about/training/emergency.shtm.
- Share information. Bring new or significant information to the attention of emergency managers. It is likely that much information that crosses the desk or lands in the email inbox of a disability organization will not reach an emergency manager unless someone forwards it.
- Offer critiques. Many emergency management agencies have emergency operations plans and checklists for standard operating procedures. Disability task forces, committees, and others can offer to critique the content, steps, and procedures to see if recommendations/improvements can be made.
- **Review situation reports.** During an event, "sit reps" are written that describe a situation. A preexisting task force or committee can review these sit reps, help identify areas of concern, and offer practical suggestions and solutions to problems. Sit reps are read by a number of people and can serve as learning tools and sources of information.
- Join after-action debriefings. Disaster situations are usually followed by a debriefing. By sitting in on the debriefing and contributing to the after-action report (AAR), representatives from the disability community can identify points of intervention and change.

Recommendations for Creating a Culture of Change

- Sponsor a cross-disciplinary, national-level symposium that fosters collaboration between disability organizations and emergency managers at all levels.
- Explore different methods of incorporating disability issues into disaster training and other information aimed at the emergency management community. Content for such training and other materials should be based on practices that are supported by empirical research and experience. It should be created and vetted by people with disabilities and disability organizations that have experience and expertise in disaster situations.
- Establish a National Advisory Committee on Disabilities and Disasters, with the primary mission of addressing the full life cycle of emergency management preparedness, response, recovery, and mitigation—and how each phase relates to special needs populations
- Connect disability organizations with emergency management agencies to build collaborative, sustainable partnerships.
- Direct federal funding toward fostering/strengthening partnerships between disability organizations and emergency management agencies at all levels of government: local, state, and federal. Such funding should specify cross-training, representation of people with disabilities and disability organizations, and specific deliverables relevant to the full life cycle of emergency management.
- Engage people with disabilities in emergency management activities as employees, volunteers, and consultants.
- Preserve and reissue training materials on disabilities. Most training materials have a short life span for delivery, but sponsors do not enjoy having to continually pay for new materials. Many excellent training materials have been developed that can be updated and repurposed. Videos produced in past years (e.g., by FEMA) need to be updated for current distance delivery. For example, videos that demonstrate evacuation protocols for people with disabilities or mitigation measures for medical facilities can be updated and delivered through

Internet video streaming (see the appendices for lists of videos, CDs, DVDs, and related materials).

- Dedicate funding streams for annual conferences on disability and emergency management. At present, such conferences are topical and episodic, or are embedded in broader conferences as a single session. Although such sessions should continue to be included in general conferences, it is difficult to anticipate when and where an emergency management conference with disability-related content (or vice versa) might occur. Consequently, it is difficult for local jurisdictions to plan financially for such opportunities. Annual or biannual conferences that occur at specific times and various locations (and are taped and later archived on the Internet) would enable emergency management agencies to budget for the event and plan to send staff.
- Offer webinars on a regular basis. These webinars would need to be widely advertised as a bridge-building effort between the two communities. A series of webinars should be developed on topics ranging from learning each other's language to approaches toward evacuation, transportation, rescue, recovery, and other issues. Webinars should be archived for easy access.
- Secure and post materials and reports relevant to disabilities and emergency management on a centralized website. Though a number of websites offer various reports and tools, no single website captures the full range of materials or organizes it in a way that is meaningful to emergency managers. The four-phase life cycle approach in emergency management is one possible framework for such organization.

CHAPTER 7: Working with Voluntary Organizations

Introduction

Depending on voluntary organizations to provide specific services as well as volunteers with needed skill sets allows emergency planners to coordinate activities following a disaster in a more efficient manner. In this chapter, we look at how voluntary organizations have provided crucial support during disasters and address their important roles in helping people with disabilities.

Volunteerism in response to emergencies is widespread. As early as the 1950s, studies by the National Opinion Research Center (NORC) began documenting the voluntary response of both individuals and organizations who sought to provide help following a disaster (Fritz and Mathewson 1957 as cited in Drabek and McEntire 2003). Studies show that "individuals and groups typically become more cohesive and unified during situations of collective stress" (Drabek and McEntire 2003, p. 99). Voluntary response is most readily provided by voluntary organizations, including many faith-based groups. Additionally, many people who are not tied to a particular voluntary organization arrive on the scene to offer assistance. These volunteers are referred to as "spontaneous unplanned volunteers" or SUVs. Such help can be difficult to coordinate during ongoing response and recovery efforts. Consequently, any effort between the disability community and voluntary organizations should take place through established, knowledgeable disaster organizations.

As noted at the January 2008 NCD quarterly meeting, advocacy and disability organizations need to connect and collaborate with voluntary organizations in advance of a disaster. By doing so, they will avoid being turned away during the disaster, as people from the Houston Independent Living Center were at the Houston Astrodome during Hurricane Katrina (NCD 2008a). The State of Missouri specifically recommends that disaster and disability organizations connect and interact to avoid just this situation (NCD 2008b).

In the 1960s, after a number of storms and disasters, voluntary organizations realized that they needed to organize volunteer labor. Many opted to coordinate under the umbrella of what became the National Voluntary Organizations Active in Disaster (NVOAD, see <u>www.nvoad.org</u>), the approach recommended by panelists at the January 2008 NCD quarterly meeting. Since then, voluntary organizations have become well established and effective in times of disaster. NVOAD enjoys a consistent membership, with about two-thirds of the organizations from various faith traditions. Many faiths have created faith-based organizations (FBOs), a disaster-specific structure that provides volunteer labor, such as the Presbyterian Disaster Assistance and the Mennonite Disaster Service groups. Volunteers affiliated with these types of organizations typically receive training as well as careful supervision and can help fuel a recovery.

Generally speaking, voluntary organizations can provide thousands of volunteers for weeks, months, or even years. They also focus on helping individuals with unmet needs, preferring to assist those who "fall through the cracks" of assistance programs, a group that often includes people with disabilities. Voluntary organizations are designed to be of considerable aid to people with disabilities and their advocates.

Types of Voluntary Organizations

According to Powell and Steinberg (2006), voluntary organizations include "those that receive substantial contributions of time (volunteering), below-cost goods or services, or money" (p. 3). Generally, voluntary organizations are considered not-for-profits. Not-for profit (or nonprofit) is a legal term indicating that—

- The organization does not make a profit from the work it does and the services it provides.
- The organization seeks to provide services (educational, social, advocacy, etc.) that are for the betterment of the public sector.
- The organization has the IRS status of 501(c)3 or 501(c)4 and does not pay corporate taxes (Powell and Steinberg 2006).

The terms "voluntary organization" and "nonprofit" are sometimes used interchangeably and sometimes distinctly. According to Powell and Steinberg (2006), "Some writers regard the voluntary sector as synonymous with the nonprofit sector, while others restrict the term...causing confusion" (p. 3).

While the National Center for Charitable Statistics and the Internal Revenue Service list 26 classifications for nonprofit organizations, we will discuss four broad and commonly accepted categories: faith-based, community-based, civic, and social service. These categories are not rigid, nor do they have straightforward definitions. For example, a faith-based organization can also be considered a social service organization.

Faith-Based Organizations (FBOs)

As the name indicates, an FBO is a nonprofit organization that is centered on a specific faith but that provides services to anyone in need. The missions of FBOs range from providing services to the needy to responding to disasters domestically and abroad. FBOs play a critical role in disaster preparedness, response, and recovery, and often help devastated communities rebuild so people can return home. Historically, these groups have been of more help to people with disabilities than many other types of disaster relief organizations.

The Department of Housing and Urban Development (HUD) has classified FBOs into three primary types:

- 1. Congregations.
- 2. National networks, which include national denominations, their social service arms (e.g., Catholic Charities, Lutheran Social Services), and networks of related organizations, such as the YMCA and YWCA.
- 3. Freestanding religious organizations, which are incorporated separately from congregations and national networks (HUD 2001).

FBOs have a long history of working with people with disabilities. For example, some home-based care organizations are faith-based and provide basic health services to

people with specific medical conditions. Catholic Charities, for instance, operates homes for the elderly (e.g., assisted living centers), nursing homes, shelters for the homeless, and programs that aid people who are living in poverty. During disasters, Catholic Charities not only helps people in their own communities, they also deploy disaster response teams to areas in need of assistance. The organization has expertise in the areas of medical care, mental health, and disability and elder care, so responders have a better understanding of how to meet the unique needs of people with medical conditions and disabilities during a disaster. Many FBOs, including those in the disability community, offer critical support in times of emergency.

As one example of capacity and support that emanates from within the disability community, the Woodhaven Baptist Deaf Church of Houston provided support to those affected by Hurricane Ike in 2008, demonstrating the power of a faith-based effort to help those affected by disaster. The church served as a food location, at which the American Red Cross served more than 4,000 people. Church members have also helped with debris removal in their community, and they have collected and organized donations (particularly through their food pantry) and assisted people who lacked electricity. The church even gathered those affected by Ike for a free Thanksgiving meal.

Community-Based Organizations (CBOs)

As the name indicates, CBOs are typically organizations that provide an array of services in a community—from disaster recovery to mental health and general health to employment and job training. CBOs tend to focus on addressing community needs and aiding causes that directly help the people in the local community. CBOs may work with community members who are suffering from unemployment, lack of access to health care and mental health services, domestic violence, or a range of other social issues. According to the Johns Hopkins University Center for Civil Society (n.d.), "Much of our nation's ability to improve the lives of children, overcome poverty, clean the environment, promote the arts, and build sound communities depends on the strength and vitality of the nation's private, nonprofit organizations" (p. 1).

Whether they are part of NVOAD or linked with local emergency management, CBOs have direct connections to their clients and can often provide some of the best executed postdisaster services to both the general public and the disability community. Services that CBOs provide include the following (for more on CBOs, see Appendix B):

- Advocacy for clients.
- Education on response and relief agencies.
- Support to people devastated by disaster as they try to rebuild their lives.
 - Mental health. Mental health clinics, for example, can assist with postdisaster counseling. Some clinics are better equipped to help people with mental illness deal with the added stress and trauma of a disaster, because they have expertise other agencies may not.
 - Job placement. After disasters, communities are often affected economically—people may lose their jobs, small businesses might close down, and many survivors may need new sources of income. For some people with disabilities, job training and placement are specific needs that must be tailored to their abilities. Unfortunately, these people often face discrimination and misunderstanding about their abilities; in addition, they may need certain modifications or accommodations on the job.

Civic Organizations

Civic organizations (also referred to as civil society institutions or organizations) are nonprofit groups that can include academic institutions, veterans associations, and youth-focused organizations (Snare Web Guide n.d.). Civic organizations engage in initiatives ranging from supporting local community programs to joining international humanitarian efforts. Most people think of veterans organizations, such as the American Legion, as a prime example of a civic organization (American Legion n.d.). However, civic organizations differ dramatically from one another. Another example of a civic organization is Feeding America (formerly known as America's Second Harvest). Feeding America helps to feed working class and poor individuals and families throughout America who otherwise cannot afford meals on a daily basis. Although Feeding America is a national organization, its chapters throughout the country are community-based. Feeding America is also a member of NVOAD; after a disaster, the organization assists with mass care services and distributes donated food.

Other civic organizations, such as Kiwanis and the Elks Club, are also national in scope but are run at the local level. Civic organizations tend to have active voluntary memberships. Many of them have played an important role in the disability community, linking people with disabilities to services and volunteers. One example is Best Buddies, which is "dedicated to enhancing the lives of people with intellectual disabilities by providing opportunities for one-to-one friendships and integrated employment" through an extensive volunteer program (Best Buddies n.d., para. 1).

In certain areas, civic organizations can help communities during disaster response and recovery. On the national level, some civic organizations provide funds during disasters. The American Legion has a specific fund—the National Emergency Fund—to help Legion members and their families who have been affected by a disaster. It also aims "to compassionately heal the wounds of catastrophe and help save their homes" (American Legion National Emergency Fund n.d., Assistance page, para. 2). The Lions Club International Foundation (LCIF) gave \$5.1 million to Hurricane Katrina relief efforts. The funds supported disability advocacy agencies, people with vision loss, and others. LCIF funds, along with money raised locally by the Biloxi (Mississippi) Lions Club, built the first playground for children with disabilities in the area. The Bayou La Batre (Alabama) Lions Club assisted with vision screenings and replacement eyeglasses for more than 400 persons affected by Hurricane Katrina.

Social Service Organizations

Social service (or human service) organizations deal more directly with clients and often involve or connect with local volunteer resources (Mattaini and Lowery 2007). According to Mattaini and Lowery, social service organizations—

Include such diverse practice settings as hospitals, schools, child welfare agencies, nursing homes, settlement houses, employee assistance programs, domestic violence shelters, and prisons. [Social service organizations] differ from other organizations with similar aims in at least two key ways: (1) their "raw materials" are people, who become clients and are transformed, processed, or assisted in some specified manner; and (2) society mandates that the agencies serve both client and societal interests. (p. 356)

According to Fink and colleagues (2001), social service organizations, while differing in focus and goals, generally work with the poor, disenfranchised, and those in vulnerable positions, who have difficulty advocating for themselves. Fink and colleagues (2001, para.1) state, "Social service organizations address a wide range of low-income families' needs. These agencies are part of a larger system that involves government provision of services and government funding for private institutions." Social service organizations may be faith-based, like Catholic Charities, or community-based, like local Centers for Independent Living. Social service organizations may be international as well, like Care International.

Social service organizations play a critical role during disasters, especially during the recovery period. They are often the lifeline to people in communities, providing services that ultimately help populations get back on their feet. Whether the focus is community, faith-based, civic, or social service, all types of organizations based on or connected to volunteer efforts can play an important role in disaster preparedness, response, and recovery—especially with regard to people with disabilities. Disability organizations often provide knowledge of disability issues as well as direct outreach and relationships with people with disabilities. Understanding the diverse needs of people with disabilities during the recovery process can make the difference between whether people with disabilities during a disaster is building partnerships among these various organizations to leverage their knowledge and resources.

Help can come from other sectors as well, including the educational system. For example, Lamar University of Texas offered special needs support through its nursing program after a 1997 ice storm. The project began with creating a database of elderly and medically dependent individuals. A key element in this effort has been the use of technology, particularly hand-held personal digital assistants (PDAs), which nursing team members used in door-to-door assessments. The data were then imported into a mapping program that identified individuals who might be at risk. Lamar University also distributed survey forms (at the sixth grade reading level to compensate for literacy levels) to capture information through Meals on Wheels, home health organizations, and the area agency on aging. Lamar University nursing faculty members extended their outreach to churches to identify and map special needs members of their congregations. Using the survey results, the team has been identifying key needs, such as requests for evacuation information. The project is a potential foundation for modeling evacuation assistance and demonstrates the power of interorganizational collaboration among volunteer agencies.

Another example is the involvement of the Center for Independence of the Disabled in New York (CIDNY) in the disability community during 9/11. CIDNY worked with other nonprofits to coordinate recovery services in the disability community and to offer educational workshops and training (CIDNY 2004). Most important, CIDNY served the disability community by advocating for inclusion in all recovery programs, educating various agencies (especially FEMA) on the needs of people with disabilities, and making sure all people with disabilities were represented in the recovery process (CIDNY 2004). According to the report—

From the outset, lack of appropriate access and accommodations for people with disabilities seeking response and recovery services in the aftermath of the WTC 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 identified a series of administrative procedures that resulted in inappropriate service denials with a wide range of public and private agencies. CIDNY also observed that agencies lacked disability-related information. (p. 7)

Overall, people with disabilities affected by the attack were unable to access services for many reasons. For instance—

- Those with vision impairments or other disorders could not read signs.
- People with hearing impairments lacked access to ASL translation services.
- TTY systems were not set up for reaching specific hotlines.
- There was a disregard for reimbursement of assistive technology destroyed in the attack.
- There was a lack of effort when it came to making visits to homebound consumers to assist them with disaster relief paperwork.

A more recent example occurred during Hurricane Ike in 2008, when Baptist Child and Family Services (BCFS) of San Antonio, Texas, worked to support those affected. A faith-based social service organization, BCFS oversees residential services and emergency shelters for children who are experiencing abuse or emotional disturbance; the organization also provides assisted living services and vocational training (see <u>www.bcfs.net</u>). BCFS was able to offer support and assume responsibility for shelter operations in Galveston County under the Governor's Division of Emergency Management; the organization also was the main medical special needs shelter provider in Texas. The state contracted with BCFS to provide medical special needs population training throughout Texas.

Roles of Volunteers and Voluntary Organizations in Disaster

Just as the size and scope of these agencies vary, so do their roles in disasters. Some organizations, such as the American Red Cross, have established roles from the federal

level down to the local level and are an integral part of the response system. Others, such as the Salvation Army or Catholic Charities, have a rich history of disaster response participation and have etched out specialties in their services to disaster victims. Still others have less well-defined roles; they typically address service gaps or unmet needs.

The roles of ARC and NVOAD are articulated in the National Response Framework (NRF) under ESF #6 mass care (e.g., shelters). In 2004, FEMA became the lead agency for this ESF (ARC had been in that role for years), with the primary responsibility for coordinating mass care federal assets and implementing them at the local level (GAO 2008b). However, as the largest mass care provider in the United States, ARC still plays a leading role in coordinating mass care efforts and providing mass care to impacted communities. This includes activities such as sheltering, feeding, first aid, emergency assistance, and human services. NVOAD's role under ESF #6 is to facilitate voluntary organization and government coordination. The state and local VOADs take on this role at their respective levels and also coordinate with NVOAD.

The NVOAD website has a Resource Directory that provides information on agencies and their roles during disasters (NVOAD, n.d.). According to the site, NVOAD members work in the following areas:

- Preparedness and/or mitigation
- Mass care
- Emergency assistance and casework
- Emotional or spiritual care
- Recovery and reconstruction
- Case management and advocacy
- Donations management
- Volunteer management

- Outreach and information/referral
- Animal and pet services
- Long-term recovery committees

Often after a disaster, there is an initial rush of volunteers and donated goods. Unfortunately, the spirit of giving tends to lessen as the disaster fades from public memory, even though many people still require assistance (especially those with historically unmet needs, like those with disabilities). It is critical, therefore, to maintain connections to potential volunteers who can help through an extended recovery period.

Disability organizations and agencies need to connect to those efforts. They can do this through several avenues, including the NVOAD or state VOAD. A local community (if it is well organized) may open a volunteer coordination center (VCC) to organize and assign volunteers—disability organizations can send volunteers or request volunteer assistance. Many local and state emergency management agencies (EMAs) have their own, completely separate, volunteer management plans. Contacting the EMA is another avenue to participation. However, volunteer effort is best managed through pre-event contact, meetings, training, and coordination. Therefore, it is imperative that disability organizations work with local emergency managers and volunteer centers before an event so they will be effective during the response period. It is possible that the local EMA may not yet have conducted volunteer management planning. Disability organizations can view this as an opportunity to work with an emergency manager on such an initiative and forge a strong connection at the same time.

After the immediate response period, many significant needs remain, from helping people regain independence to rebuilding homes. For many people with disabilities, federal, state, and local programs fail to address their concerns, causing them to fall through the cracks of assistance programs. To address these needs, communities often create coalitions of voluntary organizations with disaster recovery assistance capabilities. The structure of the coalition is based on the needs of the community. NVOAD offers models called long-term recovery organizations, long-term recovery

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committees, and interfaith committees. In addition, many communities create an unmet needs committee or roundtable. In these models, voluntary agencies come together to act as a single entity and pool resources to address community needs. Some of these groups become formal nonprofit organizations with broad recovery missions (e.g., longterm recovery organizations). Others may collaborate and develop specific missions; for example, case management. Regardless of scope, the primary goal of these organizations is to ensure that services and goods are available to meet the recovery needs of disaster survivors in a coordinated, systematic way.

The NVOAD website offers a guidance document on establishing these types of groups, using models that have worked in communities after disasters (NVOAD 2004). Some of the activities of a long-term recovery committee are:

- Meeting the need for ongoing coordination among agencies providing support for disaster survivors.
- Focusing on identifying and addressing the long-term recovery needs or unmet needs of disaster survivors through a case management system.
- Volunteer management.
- Donations management.
- Spiritual and emotional care.
- Providing advocacy for the people who are most vulnerable to having their needs overlooked in the public recovery planning processes.

These organizations, regardless of structure, are the key point of contact for disability organizations looking to participate in the recovery process. An organization may be facilitated through the National Response Framework under ESF #6 mass care. In this ESF, the primary point of contact is the voluntary agency liaison (VAL), who is a FEMA employee. The VAL may coordinate and convene efforts that facilitate the emergence of local recovery committees.

Post-Katrina Reform

The structure of unmet needs committees and the services offered differ from region to region and from disaster to disaster, but the overall goal tends to be the same. The Post-Katrina Reform Act highlighted the need for work in the area of case management and makes federal funding available to aid in developing this field. After a disaster, it can be very confusing to try to access services because of the extensive paperwork and the array of organizations providing services—a person may not know where to turn. Filling out applications for each agency can be exhausting, especially for those who recently suffered through a disaster and lost family members, friends, or property. Without a coordinating agency, it is likely that a duplication of efforts and services will occur among agencies, which is not an effective way to use resources. As a result of the Katrina Reform Act, the Katrina Aid Today program (a case management model implemented in the Gulf Coast area after the 2005 hurricanes) has been the model for a pilot project led by Catholic Charities USA (Catholic Charities 2008, see also www.katrinaidtoday.org). The Katrina Aid Today program, led by the United Methodist Committee on Relief (UMCOR), streamlines and professionalizes the case management process. After case managers assess the needs of clients, the cases may be presented to a recovery committee, interfaith group, or unmet needs committee. Organizations then offer resources to assist the client. The case management process and local coalitions of voluntary organizations form a centralized, coordinated network to assist those who might otherwise fall through the cracks or experience prolonged recovery, which includes people with disabilities. Disability organizations and agencies should establish connections with such efforts to help their clients and to help the recovery committees or groups identify and address unmet needs.

Connecting and Coordinating with Voluntary Organizations

In reports after the 9/11 attacks and Hurricanes Katrina and Rita, the need for greater coordination and collaboration among voluntary agencies in conjunction with emergency management was identified. Issues included access to aid, coordination among charities and with FEMA, and planning processes for future events (GAO 2008a). NVOAD, while a tremendous resource for voluntary organizations, has limited staff

resources that "constrain its ability to effectively fulfill its role in disaster response situations" (GAO 2008a, p. 5). Few reports indicate any significant degree of integration with disability organizations or advocates. In fact, most reports fail to address the issue of disability at all. Coordination with disability organizations and ensuring that agencies and services are accessible to people with disabilities are problem areas. Unfortunately, people with disabilities tend to be forgotten or overlooked (Women's Commission on Refugee Women and Children 2008), making it ever more critical that they are included in all aspects of the unmet needs recovery process. This is one area in which disability service and advocacy organizations play a pivotal role. Disability organizations not only advocate for the needs of people with disabilities, they are also experts at providing services. Long-term recovery groups, including unmet needs committees, must include disability organizations.

In many communities during times of disaster, the recovery committee format works relatively well in terms of addressing most needs. However, many disability organizations are not connected to this organizational structure. Coordination and collaboration are key to the provision of relief services to those affected by disaster.

The following are some ways disability organizations can get involved in voluntary response and recovery:

- Contact the relevant EMA (state or local) before a disaster and participate in volunteer management planning for the Emergency Operations Plan (EOP).
- Contact and join the volunteer coordination center, if one is set up after a disaster, to participate in volunteer planning efforts or response and recovery efforts.
- Participate in NVOAD or state or local VOADs as a partner, and attend regular meetings, committees, and trainings.
- Contact the assigned regional FEMA VAL before a disaster or when the National Response Framework is implemented at the regional FEMA office.
• Join the local recovery committee, interfaith group, unmet needs committee, or relevant organization that coordinates the volunteer effort.

Disability Organizations with Experience in Disasters

Disability organizations are increasingly becoming involved in disaster response and recovery, as illustrated throughout this report. Identification, recognition, and integration of these volunteers are key for voluntary organization networks, emergency management agencies with voluntary management plans, and local volunteer centers. As of this writing, Katrina Disability Information (http://katrinadisability.info), a website dedicated to people with disabilities, maintains a registry of volunteers with specific skills related to serving people with disabilities. The link can be found on the Katrina Disability Information homepage or by visiting www.network54.com/Forum/436944. The registry also allows vendors and agencies with access to durable medical equipment to sign up if they are willing to donate those items when needed. While this service is currently focused on aiding the recovery of Katrina victims, the site is a model that could be used on a much broader scale.

Disabilityinfo.gov also offers a list of volunteer resources specifically meant for people with disabilities. The following programs are mentioned on the list and may prove helpful for people with disabilities during the response and recovery stages of disaster:

- ABILITY House Program (<u>http://www.abilityawareness.org/House.htm</u>). This
 program works in collaboration with Habitat for Humanity. It organizes volunteers
 to build homes for families in which one or more family members has a disability
 or medical need. Volunteers with disabilities are invited to serve as well.
- American Red Cross Programs for People with Disabilities

 (www.redcross.org/services/volunteer/0,1082,0_72_,00.html). The American Red Cross offers local preparedness and other training programs for people with disabilities.

 National Service Inclusion Project (www.serviceandinclusion.org/index.php). The National Service Inclusion Project (NSIP) provides training and technical assistance to help people with disabilities serve in voluntary programs and offers materials on disaster issues.

Involvement of Disability Organizations and Volunteers with Disabilities

While many of the organizations that are members of NVOAD serve and work with people with disabilities (e.g., Mennonite Disaster Services), no disability-specific organizations are involved at the national level. As far as volunteerism within organizations, it is uncertain how integrated people with disabilities are in existing organizations, although the numbers are probably quite low.

Reports from NCD quarterly meetings indicate that to be the case, though a number of efforts are under way that may make a difference and should be monitored for their results. These efforts tend to stem from advocacy efforts. For example—

- Staff from LIFE of Mississippi, a center for independent living, have advocated for accessibility in FEMA trailers, for emergency kits for clients, and for the availability of various services necessary for people with disabilities to be able to return home after a disaster.
- The Houston ILC has advocated for housing needs and even developed an accessibility checklist based on the Uniform Federal Accessibility Standards regarding basic entry and movement. Although they reported that the effort was helpful, significant problems remained with regard to gaining access to clients in shelters and actually translating those standards into appropriate housing for people with disabilities.
- The Office for Citizens with Disabilities in Louisiana initiated Operation House Call to identify the needs of people affected by Katrina.
- The State of Missouri established a Government, Faith-Based, and Community Partnership through an executive order issued by the governor. A special needs

task force, which includes people with disabilities, was developed to identify gaps and barriers and to find solutions to problems stemming from disaster situations. The state realized early on that mitigation and preparedness would be crucial to building capacity and encouraged appropriate planning efforts. A task force emerged that includes state agencies, state-level collaborative groups, various associations, councils, and NGOs as well as the statewide Independent Living Council. Materials were produced in closed captioning, Braille, and various foreign languages.

Volunteer organizations can take steps to increase the participation of people with disabilities. According to the National Organization on Disability (NOD), 35 percent of Americans with disabilities say they are completely uninvolved in their communities, compared with 21 percent of those without disabilities (NOD as cited in City Cares 2002). Lack of involvement often occurs not because of the person's disability itself but because of physical barriers, assumptions about abilities, or negative attitudes in the community. Organizations that want to attract people with disabilities to serve as volunteers must promote a culture of inclusion and ensure that volunteer programs are accessible and flexible. These organizations must strive to include people with disabilities in meaningful ways.

The following key steps can be taken to promote an inclusive environment (City Cares 2002):

- Include images of members with disabilities in brochures, flyers, application packets, videos, and other recruitment tools.
- Identify local individuals or organizations that will review materials to ensure appropriate use of language and positive portrayals of people with disabilities.
- Make questions related to disability optional on application forms.
- Provide information in alternative formats, including websites.

- Provide opportunities for people to make accommodation requests and make an effort to appropriately accommodate them.
- Include opportunities for people with disabilities to meaningfully participate in leadership roles.
- Offer disability awareness training for staff and volunteers.

A model of an inclusive disaster-specific volunteer program is the Community Emergency Response Team (CERT) in Denver, Colorado. In 2007, Denver's Office of Emergency Management offered CERT fully accessible courses specifically designed to train people with disabilities (Herr 2007). The courses offered—

- Teams of sign language interpreters.
- Two certified deaf interpreters on hand to provide close-up signing for those who were deaf-blind.
- Live captioning through a computer-assisted real-time transcription (CART) provider and projection of the text onto a large screen.
- Trainers who adapted to the communication needs of the participants.

The training offered a unique opportunity to test the accessibility of CERT materials (for example, they realized that videotapes were not captioned) and to identify weaknesses. Furthermore, participants were given the chance to address specific topics, such as search and rescue, from a different perspective, and adaptations of standard CERT training practices were offered to people who did not hear well. This was a successful learning opportunity for all involved. This type of training speaks directly to the feasibility and benefit of including people with disabilities in volunteer programs.

The following are some of the organizations that promote including people with disabilities in volunteer programs:

- The Corporation for National and Community Service, according to its website, is "the nation's largest grantmaker, supporting service and volunteering" (Corporation for National and Community Service, <u>www.nationalservice.org</u>). It provides volunteer opportunities for people of all ages to address critical community needs through its programs: Senior Corps, AmeriCorps, and Learn and Serve America. It promotes the inclusion of people with disabilities in all its programs. For example, Access AmeriCorps provides up-to-date, practical information on how to include people with disabilities in AmeriCorps programs. The website, <u>www.ucp.org/ucp_generalsub.cfm/1/6619/6621</u>, contains information specific to AmeriCorps but also has general tip sheets and information on ways to include people with disabilities in any program.
- As the result of a year-long project, *The Effective Practices Guide to Creating Inclusive and Accessible Days of Service* was created to provide guidance to organizations on how to create inclusive volunteer programs. This document can be accessed at

http://nationalserviceresources.org/files/legacy/filemanager/download/711/InclusiveAccessibleService.pdf.

 The Scope and Leonard Cheshire organizations developed a guide prior to National Volunteers Week in the United Kingdom. The guide, *Can Do Volunteering*, can be accessed at <u>www.worldvolunteerweb.org/fileadmin/externalphotos/guide_vol_disabled.pdf</u>. It

offers guidance on eliminating barriers and making volunteer programs more inclusive of people with disabilities.

Institutionalizing Disability Organization Involvement in Voluntary Efforts

This chapter has discussed the importance of voluntary organizations in disasters for people with disabilities but has noted the absence of disability organizations among those responding to disaster. A number of opportunities exist to develop and strengthen relationships between disability and disaster organizations. The way to start is to learn about each other's areas of expertise. A number of resources are available to facilitate this effort:

- NVOAD is an excellent source to learn more about the disaster roles of voluntary organizations. The website (<u>www.nvoad.org</u>) lists all members and their roles in disaster; it also includes a list of all the state and local VOADs.
- FEMA offers an independent study course, IS-288 "The Role of Voluntary Agencies in Emergency Management," that provides a basic understanding of the history, roles, and services of disaster relief voluntary agencies. The course can be accessed at <u>http://training.fema.gov/EMIWeb/IS/IS288.asp</u>. Unfortunately, the course does not specifically address the inclusion of disability organizations in VOADs. However, FEMA VALs are linked directly to voluntary organizations and can be good resources for facilitating involvement in planning efforts with disability organizations.
- Citizen Corps was a post-9/11 initiative to offer opportunities to all citizens to help make their communities safer, stronger, and better prepared for handling threats of terrorism, crime, and other emergencies and disasters (www.citizencorps.gov). Citizen Corps councils are designed to help communities implement the Citizen Corps programs, which include CERT, Fire Corps, Medical Reserve Corps, USA on Watch, and Volunteering in Police Service. According to the website, "Citizen Corps councils help drive local citizen participation by coordinating Citizen Corps programs, developing community action plans, assessing possible threats, and identifying local resources" (Citizen Corps n.d.). The councils bring together the emergency management community, voluntary organizations, government, and the private sector to carry out these programs.
- The American Red Cross (ARC) is the largest of the nation's mass care service providers (GAO 2008b). During large disasters, ARC activates a national disaster program to support local chapters that are directly impacted. Resources from around the country (volunteers, staff, and supplies), are brought in to support the local response effort. To learn more about ARC, visit <u>www.redcross.org</u>. ARC

also offers a wide range of courses about its disaster services program and many opportunities for volunteering.

Resources are also available to help voluntary organizations become more familiar with disability organizations as they participate in emergency planning and response.

- The Department of Homeland Security (DHS) developed the Disability Preparedness Resource Center, which can be accessed at <u>www.disabilitypreparedness.gov</u>. This site offers emergency preparedness information and resources related to disability and other special needs populations. DHS also provides updates on policies and activities in current disasters.
- Other valuable resources are the State (or Statewide) Independent Living Councils (SILCs), which are required (as a result of the Rehabilitation Act) to assist people with disabilities in each state. Centers for Independent Living (CILs) at the local level carry out services and advocacy initiatives for people with disabilities. The National Council on Independent Living's website offers helpful information, including state and local CIL contacts. It can be accessed at www.ncil.org. Services include teleconferences, webinars, and conferences that, from time to time, address emergency management issues. (These events are listed on the website calendar.)
- The Consortium for Citizens with Disabilities is a coalition of approximately 100 national disability organizations. The group also has an Emergency Preparedness Task Force that looks specifically at how to improve the integration of disability issues into emergency management. The website offers some key contacts and information; it can be accessed at <u>www.c-c-d.org/task_forces/</u> <u>emer_prep/tf-emergency.htm</u>.
- The National Organization on Disability (NOD) created the Emergency Preparedness Initiative in 2001 to address disability-related issues in times of emergency. The website (<u>www.nod.org/emergency</u>) offers an abundance of

information, including articles, brochures, conference reports, and studies specifically related to disability and emergency preparedness.

The National Disability Rights Network (NDRN) is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) systems and Client Assistance Programs (CAPs) for individuals with disabilities. NDRN claims to be the "largest provider of legally based advocacy services to people with disabilities in the United States" (see www.napas.org). Every state has a P&A office, and these agencies are becoming increasingly involved in disaster preparedness, response, and recovery. In 2006, the Department of Health and Human Services and DHS held a "Working Conference on Emergency Management and Individuals with Disabilities and the Elderly"; each state's P&A group was invited and nearly all participated. In Louisiana, the state P&A office, called the Advocacy Center, is involved in the Hurricanes Katrina/Rita recovery effort through advocacy and the development or improvement of existing services. This effort includes accessible and affordable housing, public transportation, accessibility of places of commerce, personal assistance services, and targeted legislative issues (NCD 2008a).

Scheduled disaster conferences, such as the NVOAD Annual Conference, the National Hurricane Conference, and those routinely listed at websites like the University of Colorado at Boulder Natural Hazards Center website (www.colorado.edu/hazards/ resources/conferences.html) also provide an opportunity for needed links among disaster personnel, voluntary agencies, and the disability community. In the past, NVOAD has included the topics of disability and special needs in annual conferences. For example, in 2003, "disability" was a specific break-out session. State and local VOADs also hold conferences that offer opportunities for learning and greater collaboration. For example, the Mississippi VOAD held a two-day disaster conference in February 2008 (FEMA Press Release 1604-624, para. 9). More than 100 professionals attended the conference, the first of its kind for the state VOAD. Sandra Braasch, director of disaster response for Lutheran Episcopal Services in Mississippi, said, "The conference was a great opportunity to share experiences and spark conversation. We were able to interact and find ways to partner together for the future." It is a natural segue to include the disability community and people with disabilities in such events in an effort to foster additional partnership opportunities.

Likewise, disability-related conferences held by various agencies are increasingly including emergency management on their agendas in breakout sessions and keynote addresses. For example, NOD's Emergency Preparedness Initiative in partnership with Government Horizons has put on a series of technical conferences focusing on disability issues in emergency management (<u>www.nod.org/emergency</u>). The events have been attended by disability organizations, other voluntary organizations, and emergency management planners.

As part of its efforts to promote policies and programs that include people with disabilities, NCD holds open quarterly meetings. People with disabilities are encouraged to attend and all sessions include time for public comment. NCD often holds meetings to discuss problems and recommendations concerning existing disaster response and recovery activities. Such meetings offer an opportunity to participate in open dialogue regarding the inclusion of people with disabilities in voluntary organizations that serve during disasters. Connections to experts in the disability community can also be developed at quarterly meetings, leading to improved training among voluntary organizations that wish to better serve people with disabilities after a disaster.

Voluntary organizations must incorporate people with disabilities in their training and outreach efforts, and be willing to cross-train with disability organizations. New Jersey's Citizen Corps, for example, aired a TV commercial with CERT members and people with disabilities. By holding joint training conferences, phone conferences, and video conferences, key leaders of both disaster and disability organizations can learn to approach disaster response and recovery in a more holistic manner and further promote the inclusion of people with disabilities. As these diverse groups form partnerships, identify and solve problems together, and openly share information, the result will be new training techniques, adapted response protocols, and more inclusive response and recovery efforts.

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A particular benefit of linking various organizations is to help disability organizations prepare for disaster. As noted at the January 2008 NCD quarterly meeting (NCD 2008a), many agencies and staff were dramatically affected by Hurricane Katrina. Agency services were disrupted, staff members lost their homes, records were lost or destroyed, and clients were displaced. Given that 200,000 people with disabilities were evacuated, including 13,000 with developmental disabilities, the loss of knowledgeable agency support is devastating. Such services are crucial to restoring normalcy in the lives of people with disabilities. Therefore, efforts must be made to prepare organizations adequately for disaster and to establish a plan for organizational continuity and continuity of operations and services, and restoration procedures for services must be undertaken. The Missouri CILs, for example, have developed a continuity of operations plan (COOP) to ensure that everything runs as smoothly as possible after a disaster (NCD 2008b). Missouri also offers training, including a CIL-based train-the-trainer course and FEMA's G-197 course on special needs.

Conclusion

A wide variety of voluntary organizations make important contributions in disaster situations. Their experience is highly valuable to emergency managers. Yet, many disability organizations and agencies lack disaster training, and many emergency management agencies as well as voluntary organization associations fail to include either people with disabilities or disability organizations. By involving those most at risk and providing cross-training, it is possible to increase disaster resilience and provide a critical set of resources in times of disaster.

Research Recommendations

- Conduct research on existing volunteer agencies to determine how they are meeting the needs of volunteers and the people with disabilities they serve.
- Provide grants and other financial incentives for researchers to explore postdisaster volunteer service that focuses on serving people with disabilities.

- Assess the needs of voluntary organizations that assist after disasters, especially those that pertain to the incorporation of volunteers with disabilities and their service to people with disabilities.
- Identify mechanisms that most effectively integrate disability organizations into all phases of emergency management activities.
- Research issues of coordination and collaboration between disaster organizations and disability organizations.
- Assess the extent to which volunteer training addresses disability issues and the ways organizations strive to include people with disabilities or neglect to do so.
- Research the level of involvement of disability organizations in the VOAD movement at the state and local levels. Identify barriers to membership.
- Research disaster programs run by disability organizations and disaster-related activities that these organizations are involved in.

Practice Recommendations

- Integrate disability organizations into NVOAD, as well as state and local VOADs.
- Integrate disability organizations into predisaster voluntary management planning.
- Integrate disability organizations into the workings of volunteer coordination centers.
- Integrate disability organizations into long-term recovery organizations.
- Include questions on volunteer forms that ask for skill sets related to working with people with disabilities.
- Develop national and regional databases so disability organizations can list adaptive equipment, resources, and knowledge that may be used/needed during disaster response and recovery.
- Provide conferences, meetings, and workshops that encourage disaster-related organizations and disability organizations to form partnerships.

- Develop a model for states on how to incorporate a cabinet-level position that focuses on managing disaster volunteers; encourage people with disabilities to serve in the position.
- Support cross-training among emergency management and disability
 organizations at all levels. Programs, such as those mentioned above, could
 easily expand their current databases and incorporate people with disabilities by
 asking volunteers about their skill sets (e.g., sign language experience,
 knowledge of how to execute proper transfers for people with disabilities,
 experience working with people with cognitive disabilities). Such programs
 should partner with agencies serving people with disabilities and develop
 databases on access to resources (e.g., TTYs, adaptive equipment available via
 loan programs).
- Provide volunteer opportunities and training to people with disabilities who are interested in disaster relief and recovery work.
- Use the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities website (<u>www.dhs.gov/xprepresp/committees/editorial_0591.shtm</u>) as a place for voluntary organizations and disability organizations to find information, contacts, and networking opportunities.

Policy Recommendations

- Request that the federal disability coordinator (under FEMA) encourage and integrate disability organizations into voluntary relief work.
- Ensure that all FEMA voluntary agency liaisons (VALs) integrate disability organizations into the National Response Framework when it is implemented.
- Revise the National Response Framework to integrate relevant disability organizations, particularly in ESF #6.

- Provide funding and support for a national database that connects disability organizations with disaster management personnel and allows volunteers to note disability-specific information with regard to their skills.
- Offer financial incentives to disaster programs that find meaningful ways to partner with disability organizations.
- Provide financial incentives to disability organizations that develop partnerships with disaster-related voluntary organizations.

CHAPTER 8: Implications from the Research

Introduction

The existing empirical research, reports, and guidance documents demonstrate clearly that much remains to be done to ensure that people with disabilities are included in all four phases of emergency management. To date, most of the work has been in the areas of preparedness and response, with minimal efforts made in recovery and even less in mitigation.

It is equally clear that there is a disconnect among policy, practice, and research when it comes to emergency management issues involving people with disabilities. For example, Executive Order 13347 requires the participation and inclusion of people with disabilities in every phase of the emergency management life cycle. However, there is only minimal integration of disability organizations and people with disabilities into emergency management practices, despite the perspectives, networks, resources, and expertise they could offer. Although emergency management agencies at the local, state, and national levels have begun to address disability issues (usually in response to an event and often focused on response issues), much remains to be done. Recently, efforts such as the development of shelter accessibility guidance from the Department of Justice and a Disaster Housing Strategy from FEMA show promising progress. However, such policies and guidance have yet to be implemented (or understood) extensively throughout the nation.

Unfortunately, the scientific evidence required to inform both policy and practice is relatively scarce, uneven by topic, and scattered across the disciplines. The field of disaster research, which should lead in this area, has generally failed to address the topic or integrate disability even as a basic demographic variable. Specific disciplines have begun to conduct some studies, but this work is limited to certain topics when it should be more comprehensive in scope. What emergency management and people with disabilities require is a concerted, comprehensive, interdisciplinary research effort to systematically address the full life cycle of emergency management. That research

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effort must incorporate experts from relevant fields, exceptional practitioners, and prominent disability organizations to push forward a relevant body of evidence that fosters effective policies and informs practice beyond the limited evidence available to date. At present, it is possible only to identify general principles for the assessment of existing practices. This chapter describes general principles using the life cycle of emergency management as a framework. Topics in each phase are discussed, followed by suggestions for implementation in those areas based on the recommendations in previous chapters. The discussion of general principles is followed by an outline of a research agenda to build a fuller, more meaningful body of research to support emergency managers and disability organizations working in a disaster context.

In previous chapters, the life cycle of emergency management has been examined for relevant research, policies, and practices in preparedness, response, recovery, and mitigation efforts. This chapter sets out key principles for practical application in those critical areas.

Preparedness and Response

The essential idea behind preparedness is to develop capacities at the individual, organizational, and interorganizational levels. Individually, everyone is ultimately responsible for his or her own safety. However, some individuals may be incapable of ensuring their own safety. Many emergency management agencies and communities lack understanding or insight into the needs of people with disabilities. Those insights can be gleaned from the participation of people with disabilities and disability organizations in emergency management activities. Thus, the first principle governing preparedness is *inclusion*. The following practical steps can be taken:

- Establish or expand an organizational structure to include people with disabilities and related organizations in all dimensions of preparedness and planning. This means—
 - Identifying and casting a wide net to include the full array of relevant organizations (e.g., social service, health care, advocacy, community-based).

- Ensuring representation of all kinds of disabilities as well as recognition of the variations in each kind of disability (e.g., from independent to dependent, from mild to severe).
- Integrate disability issues into all aspects of preparedness and planning, from educational materials to emergency operations plans.
 - Disability-related matters should be incorporated into all educational materials and should also be developed as separate, disability-specific materials.
 - For planning purposes, the subject of disability should not be isolated in a separate annex; rather, it should be embedded in all functional areas.

Unfortunately, because income levels vary and are often lower among people with disabilities, it may be difficult to secure sufficient resources to prepare adequately when it comes to serving this population. Furthermore, the range of disabilities and the extent of a disability can vary considerably, as can the age at which they occur. People with disabilities can be infants or frail elders, can come from any racial or ethnic group, speak or sign various languages, rely on minimal or extensive technologies, and range from low levels of literacy to postdoctoral scholars. Thus, the second principle of preparedness is to *recognize the variation and diversity of people with disabilities*. The following practical steps should be considered regarding this principle:

- Secure funding to provide resources (e.g., materials, preparedness items, mitigation tools) to individuals at lower income levels.
- Diversify the means for disseminating information (audio, tactile, written, pictorial, language) among target audiences.
- Provide a range of materials designed to reach all ages, literacy levels, and comprehension levels with content specific to disability issues.
- Increase the means through which outreach materials are disseminated. Use technologies, organizations, media, and public locations to distribute a wide variety of materials.

• Ensure the accessibility of materials in Braille as well as for those with low levels of literacy through the use of pictures, video formats, sign language interpretation, and closed captioning.

Disasters are low-salient events in the lives of most people and may rank low among the daily priorities of people with disabilities. Consequently, it is essential that **those at risk be educated and motivated to address disaster planning and personal preparedness**. Disability organizations that serve as trusted and credible resources for many people with disabilities can be a tremendous asset in this endeavor. The social networks provided by friends, family, neighbors, and coworkers can be used to disseminate information, encourage preparedness, and assist in other ways when necessary. In concert with emergency managers, a multilevel effort that uses personal and organizational relationships can play a crucial role in educating and motivating the diverse array of individuals at risk to develop personal plans. Such plans can encourage—

- An understanding of the area hazards and the type of preparedness necessary.
 For example, protective action for a rapid onset event such as a tornado requires different responses than that for a slower onset hurricane or an isolating pandemic.
- Identification and rehearsal of appropriate protective actions. This includes identifying protective locations in one's immediate vicinity (home, work, school, public setting) and away from home (family, hotels, shelters, centers).
- An understanding of the importance of taking immediate protective action when a warning is issued and of the means by which someone can do so.
- Transportation solutions for evacuation from a hazardous location. These solutions may involve personal transportation, public and paratransit resources, or the support of people in one's social network.
- The creation of emergency "go-kits," which include backup medications, prescriptions, medical records, devices, and equipment (see <u>www.ready.gov</u> for an example).

- The creation of disability-specific checklists and guide cards that explain hazardspecific preparedness and response actions.
- The creation, placement, and application of shelter-in-place kits for appropriate hazards.
- The implementation of support systems that can be activated when people are temporarily separated from their homes and health care provider networks (e.g., social services in shelters and temporary housing).
- Advocacy and support as needed for an eventual return to permanent housing.
- Funding for emergency circumstances, warning devices, transportation solutions, and temporary housing situations.

Organizational preparedness is a relatively low priority across all types of organizations, and disability organizations are no exception. Most organizations carry out minimal preparedness efforts, such as providing a first aid kit and basic safety training for employees. Thus, *building disaster resilience* within organizations, especially those that may participate in disaster contexts, is of the utmost importance. Few organizations have disaster or continuity of operations plans in place so they can continue to provide key services after a disaster. Since disasters are a time when disability organizations will likely offer crucial services and support, it is necessary to *conduct disaster planning and mitigate risks*. A well-prepared disability organization will have—

- A well-developed disaster plan that ensures that staff complete preparedness training and are kept apprised of their duties during times of crisis. The plan should provide for organizational continuity, identify areas for relocating and reestablishing services, and ensure that people can manage business disruptions with minimal impact on clients. Specifically, per FEMA recommendations, disaster plans should include the following (www.fema.gov/business/bc.shtm):
 - Designation of employees responsible for specific functions.
 - Functional sections that address response, recovery, and restoration.

- Training and exercise schedules to teach and test the plan, as well as a way to revise the plan in response to exercise results.
- A current contact list of key personnel necessary to implement the plan.
- Identification of resources necessary to recover and function, particularly client records.
- Backup locations for services and records.
- Preplanned messages to disseminate to clients regarding resumption of services.
- Structural mitigation features that protect facilities and resources.
- Sufficient insurance to recover from a disaster.

The planning process offers an important opportunity to generate change in terms that will ensure that people with disabilities are not forgotten or neglected in times of disaster. Historically, disability issues have been excluded or marginalized as annex plans. To embed disability issues into all functional areas, it is necessary to **assess existing plans** at the local, state, and national levels. It is important to—

- Critique existing emergency operations and related plans.
- Involve disability organizations in the assessment.
- Integrate disability issues into functional areas rather than as a separate annex.

Organizational and interorganizational plans are useless unless they are understood and can be properly activated in an event. Thus, the next principle is to **conduct training and exercises** with disability organizations and people with disabilities. In addition, participants who use or rely on the plan should be involved in writing it. Though consultants can guide the process, a boilerplate plan without the engaged input of those likely to use it or rely on it for life safety is not very useful. Training allows plans to be learned and become routine. Training requires that the full range of those likely to be involved in response activities participate in *learning plans, techniques for rescue, and protocol for working with people with disabilities*. Those individuals include—

- Emergency managers
- First responders
- Health care workers
- Transportation personnel
- Shelter managers, staff, and volunteers
- Caregivers
- Home health and long-term care providers

Currently, training and exercises centered on specific plans are haphazard and uneven when it comes to incorporating disability issues. For example, TOP-OFF exercises only recently incorporated disability issues. Remedies for this problem would be to *strengthen and enforce Executive Order 13347*, which mandates the inclusion of disability issues in all federally supported or funded exercises and to *lobby state governors to create similar executive orders or policies*. For example—

- Require that all state and local exercises funded by DHS or FEMA incorporate people with disabilities and disability organizations.
- Conduct training across all first responder units on basic lifting techniques, proper communication, and transportation needs relating to people with disabilities. Require that such training involve people with disabilities and disability organizations to ensure that instruction methods are correct.
- Assess training and exercises by involving people with disabilities and disability organizations in the assessment. Revise training and exercises accordingly.

- Fund communication devices for first responder units as part of Homeland Security grants.
- Test all procedures/activities that would occur during an emergency, including activating warnings, search and rescue, protective action, evacuation, transportation methods, and sheltering.
- Run through a variety of hazards, from rapid onset to those with opportunities to evacuate, when conducting training and exercises.
- Mandate the involvement of people with disabilities and disability organizations in debriefings and plan revisions.

Warning messages are the single most effective way to alert people to an impending risk. However, jurisdictions fail to develop and disseminate warning messages that are adapted to or meet the needs of people with disabilities. A key principle to improve warning messages is to *diversify and offer redundant, affordable, and accessible formats*. Another key principle is to *distribute warning messages through trusted, credible sources*. Strategies that can enhance success in this area include the following:

- Draft warning messages for specific, anticipated events and vet them with disability organizations and people with disabilities to see if they are effective.
- Develop various means for disseminating warning messages, including media, texting, email, sirens of various kinds, pagers, highway signage, closed captioning, live sign language interpretation, and social networking sites. Ensure that audio, tactile, and written warnings are issued to maximize distribution.
 Increase the number and type of accessible formats. Ensure that warning messages are available in several formats for those with various levels of comprehension.
- Require that any federal funding that supports the purchase of warning systems include diverse means to alert the entire public, particularly those with disabilities.

- Work with the local disability community to identify and test preferred and evolving message information systems and technologies that meet the specific needs of the community.
- Disseminate warning messages through trusted individuals and organizations, which can include families, friends, guardians/caregivers, advocates, agencies, neighbors, workplaces, civic organizations, and faith-based communities. Doing so leverages the power of social networks to influence those at risk and links people in need to those with resources to help. Credible sources enhance the chance that warning messages will be heeded.
- Train broadcast and warning media outlets on the importance of diversifying messages and the need to vary warning messages so that people with various levels of literacy comprehension and aptitude can understand the message.
- Ensure that media and meteorologists deliver warning messages with clear instructions on what action is most appropriate. Note that warning messages will vary depending on the population segment.
- Train meteorologists on which population segments need special consideration during an event. This includes ensuring that meteorologists face the television camera for those who read lips and that they use direct and specific references to hazards and locations. Also, be sure to check that graphics, closed captioning, and interpretation are clearly visible to those who are attempting to get information.
- Provide enhanced 9-1-1 or reverse 9-1-1 systems that are compatible with TDDs.
- Use local organizations to activate a phone tree or buddy system to reach clients.
- Issue warning messages as far in advance as possible. Delays in transmission can result in problems for some people with disabilities who cannot complete tasks or activities quickly, such as sheltering in place or evacuating.
- Personalize the message so it is appropriate for people with various kinds of disabilities. Be sure to urge people with disabilities to take protective action immediately, and describe the appropriate actions.

- Include transportation information in warning messages and, when appropriate, content on shelters and other reception centers (note those that are equipped for people with disabilities).
- Ensure that shelters are in desirable and accessible locations.
- Verify that warning messages reflect cultural and linguistic diversity within the disability community. Written and audio messages should be in the languages understood and used locally.
- Follow FCC policies when it comes to providing real-time captioning or sign language interpretation. Ensure that captioning includes all emergency information, not just what the broadcaster or meteorologist is saying.
- Involve people with disabilities and disability organizations in issuing warning messages.
- Secure funding to provide weather alert radios with strobe, audio, and vibrator capabilities, along with adaptors, for use in vehicles. Educate the disability community, particularly those who are deaf or hard of hearing, on the need to use these adapted devices.
- Implement alternative warning systems or devices in public locations, such as parks, hospitals, clinics, schools, libraries, and other facilities.
- Require that alternative warning systems or devices be used in workplaces and privately owned establishments, such as malls, grocery stores, and other similar locations.
- Stay abreast of new technologies and their potential for issuing warnings, such as video phones, webcams, social networking sites, and computer delivery.

Registries can provide a way to identify those at risk and in need of assistance during an emergency. *Registries should be up do date, readily available to first responders, and linked to those involved in transportation and evacuation support.* Although concerns exist over the practicality and sustainability of registries, basic guidelines to developing one include the following:

- Educate those at risk about the registry; make sure to mention that information is kept confidential, and discuss the value of participation.
- Secure funding for staff and costs related to developing and maintaining the registry.
- Specify the type of person who should be eligible for inclusion in the registry and the number of people that a given jurisdiction can manage.
- Identify alternative ways to establish registries, given the costs and time that can be involved. Registries maintained by voluntary organizations or social service agencies may be an option. Client lists and phone trees may be another option. Using 2-1-1 call-in systems for specific evacuation requests may be yet another option.
- Identify the full range of agencies and personnel (first responders, emergency managers, etc.) that will need access to the list in an emergency, and ensure that they will be able to obtain the list. Train those individuals on confidentiality issues related to the registry.
- Cross-check registries with available transportation inventories and map out how needs link to resources. Prioritize those at highest risk with regard to the local hazard.
- Involve those at risk and their advocates in creating a registry.
- Carefully spell out and educate all parties, including long-term care facility staff, on their roles and responsibilities when a registry is in use.
- Launch regular public relations campaigns to update the registries and to gather new names and addresses.

Even if a registry or similar system is put in place, it is important to implement protective actions that include shelter in place options, in case the registries and transportation systems fail.

An alternative to public assistance with transportation and evacuation, and an option either with or without a registry, is the use of a buddy system. Buddy systems have been criticized as unnecessary for many people with disabilities and as unreliable or limited in a true emergency. They should be recommended after an individual who is potentially at risk **conducts a self-assessment to determine need**. Should they be needed, buddy systems **should involve first family, guardians, caregivers**, and others most knowledgeable of the needs of the person at risk, including his or her physical condition and preferences for moving or lifting, as well as medical and nutritional needs. Buddy systems **should involve more than one person** in any given location, whether at home, work, or in a public location. **Communication systems need to be developed** between the individual and the buddies. At a minimum, a buddy system should—

- Be established between familiar, trusted individuals and the person at risk.
- Follow United States Fire Administration (USFA) standards.
- Include multiple backup people who are properly trained to assist someone with that particular disability.

Evacuation of people with disabilities might include individuals with permanent, temporary, or episodic disabilities. People with disabilities are not always entirely helpless in the face of an evacuation, but their needs may vary and the evacuation effort could be complex. *Preplanning is essential* for efforts to be successful. The Federal Highway Administration is reviewing draft guidance on its evacuation protocols.

Recommendations for Evacuation

- Identify accessible evacuation routes, including public locations that can serve as collection points as well as location-specific residential units.
- Inventory transportation assets that offer accessible features and identify trained staff members who are available to assist if needed. Map assets in relation to collection points and/or registries of people who might require evacuation.

- Consider involving social networks that link to people with disabilities, including faith-based partners, advocacy organizations, school systems, and similar organizations with accessible vehicles. GAO reports indicate that the involvement of such partners requires attention to reimbursement and legal responsibilities. However, these issues can be addressed by creating a memorandum of understanding (MOU) before disaster strikes.
- Designate a place to which people should evacuate during an emergency. Advertise that the location is ready to receive people with specific kinds of disabilities and can accommodate their equipment, nutritional needs, service animals, medical needs, and support personnel. Provide chairs for people who cannot stand for long periods.
- Train transportation staff and practice evacuation procedures ahead of time. Involve people with disabilities and disability organizations in all exercises, and welcome their input.
- Conduct advance evacuation whenever possible for special needs groups so they are not overlooked and can be properly assisted before the majority of people depart in an evacuation.
- Conduct airlifts where feasible to avoid highway congestion and the possibility of accidents.
- Identify and develop written agreements with distant reception centers, especially at facilities in other states, to ensure smooth patient transfer.
- Mandate that insurance companies cover nursing homes during evacuation procedures.
- Provide advance assistance to nursing homes so they can properly conduct evacuations.
- Keep families intact during evacuations to reduce transfer trauma and enhance continuity of medical and nutritional protocols.
- Ensure that service animals, medical devices, and equipment are transported to safety with their handlers.

- Follow recent U.S. Postal Service efforts to release entitlement checks before an event so that recipients are more willing and able to evacuate.
- Offer financial incentives to encourage evacuation, including gas cards, food vouchers, and similar items to reduce the financial impact on low-income households.
- Use FEMA contracts for paratransit support.

Recommendations for High-Rise Building Evacuation

- Increase emergency exit and related signage in high-rise buildings.
- Establish buddy systems. Train individuals willing to serve as buddies to people with disabilities during emergencies; focus on lifting and communication techniques, and make sure to rehearse evacuation procedures.
- Practice evacuations using primary and alternative means of escape.
- Consider designating certain elevators to be used for evacuating only those people with physical disabilities, and designate other elevators for general use.
- Purchase alternative evacuation devices that deploy from higher floors, and train occupants and first responders in the use of such devices.
- Develop a registry of those in need of assistance during a high-rise evacuation.
- Register and coordinate emergency plans for high-rise buildings with local emergency management offices.
- Encourage hotels and businesses to discuss self-identification procedures with guests, customers, and clients when they check in or arrive, in case they need assistance with evacuation in an emergency. Train staff accordingly.
- Create and train evacuation teams on floors that house people with disabilities so they can be properly assisted during emergencies.

When rescue is required, these procedures should be undertaken by emergency personnel trained in lifting, communicating with, and supporting people with all types of

disabilities. Rescuers need to be *trained on disability etiquette*, including how to interact and communicate with people with disabilities to reach the most beneficial outcome. In addition, *specialized equipment may need to be purchased or shared* among jurisdictions to rescue people from various locations. The following practical steps can be taken to enhance such rescue efforts:

- Increase training and exercises for rescue teams. Groups can range from local first responders to urban search and rescue (USAR) teams to military teams available for deployment in an emergency.
- Involve people with disabilities and service animals in training and exercises.
- Ensure that rescuers understand the importance of rescuing medical equipment, devices, and service animals and of ensuring that they are kept with their owners.
- Devise alternative, prioritized strategies for rescuing lives (human and service animal), followed by equipment and devices.
- Develop systems to tag and monitor locations of medical equipment and devices so that if they become separated from people with disabilities they can be returned quickly.
- Involve disability groups and other relevant organizations in the rescue of service animals and medical equipment and devices.

By following recommended procedures, people with disabilities should be able to reach shelter locations, whether it is a general population shelter or a special needs shelter. Though limited research exists on shelters, a number of general principles taken from the literature and available guidance documents can inform shelter establishment and operations. The following suggestions apply to general population shelters:

• Involve disability organizations in planning and supporting the establishment of general population shelters.

- Ensure that all shelters are accessible, offer multiple means for communication, involve volunteers and staff trained to support people with disabilities, and accept service animals.
- Accept people with disabilities into general population shelters.
- Ensure that intake procedures include screening for medical conditions that should be handled at a special/medical needs shelter. Triage protocol per CPG 301 should be followed.
- Ensure that intake procedures identify agencies with which individuals typically interact. Contact those agencies to inform them that their clients are in the shelter.
- Identify the functional needs (e.g., those involving communication, nutrition, medical support) that must be addressed for those in the shelter.
- Establish transfer procedures in case it is necessary to move someone to a special needs shelter or a health care facility. Train staff on managing emergencies that may arise that concern people with disabilities. This could include recognizing personal neglect (e.g., dehydration, nutritional deficiencies, medication interruptions) in people with cognitive disabilities.
- Train volunteers and staff on issues involving a full range of disabilities, including disability etiquette, service animals, and communication procedures. Take steps to ensure the dignity, privacy, and independence of shelter residents.
- Establish a routine time and place for communicating in alternative formats.
 Involve social networks in transmitting information. Remember to account for the diversity of language and literacy levels in a given community.
- Orient people to shelters and procedures.
- Keep families and other groups intact. Provide space for these people even if they were not displaced by the disaster to provide support to shelter residents.

- Allow social units (families, households, and friends) to develop areas within a shelter to suit their needs. Ensure that the setup of the shelter does not change in such a way that it hinders those with mobility and visual impairments.
- Permit those with medical and nutritional needs to have access to kitchens.
- Provide resources that support disability-related needs per the DOJ guidance (e.g., higher cots, special mattresses).
- Offer low-stimulation "stress-relief zones" per the DOJ guidance.
- Stockpile medical equipment and devices as well as alternative modes of communication. Train staff on how to offer and use these resources. Ensure that equipment and devices are workable and safe to use.
- Make sure that people who need to generate power for equipment and refrigerate medications are able to do so.
- Offer nutritional options for a range of conditions that could affect human residents, and provide food for service animals if the owner doesn't have any on hand.
- Offer medical support and veterinary support.
- Conduct discharge planning with each shelter resident with a disability to determine the viability of his or her return to the original home or an alternative location. Involve local agencies in identifying and securing accessible and appropriate shelter, as well as the resources and services necessary to help people maintain their independence.
- Begin working on temporary or permanent housing arrangements as soon as possible to reduce the time a person spends in a shelter environment. However, remember that securing accessible accommodations may take time and plan accordingly.
- Refer residents, as needed, to local recovery organizations and unmet needs case managers.

Special or medical needs shelters are among the least researched areas of emergency management. Even the FEMA comprehensive preparedness guide *Interim Emergency Management Planning Guide for Special Needs Populations* (CPG 301) (FEMA 2008), fails to address this topic. Special needs or medical shelters require *significant advanced planning and support. Well-trained, professional health care staff with adequate resources should be used* to support shelter residents and to transfer residents to general population shelters (if appropriate) or to advanced health care facilities.

Two types of facilities are likely to develop as special/medical needs shelters. The first is a unit located fairly close to the disaster site. The second facility is usually established in a more remote location and serves as a reception center for displaced evacuees. The first type has a higher potential to keep residents connected to important social networks that can assist with handling medical issues and disability concerns. The second type is more likely to cause disrupted relationships. The following are basic protocols for special/medical needs shelters:

- Keeping families and social networks intact as long as possible. Families can provide important information and sources of comfort in traumatic situations, reducing the potential for death caused by transfer trauma.
- Evacuating people with medical equipment and service animals in the event of a secondary evacuation.
- Maintaining low ratios of staff to residents.
- Ensuring continuity of care for a range of conditions. Such care might include physical therapy, respiratory therapy, occupational therapy, nutritional protocol, medication regimens, dialysis, and cancer treatment.
- Providing oversight of staff working with shelter residents to ensure quality of care.
- Stockpiling a wide range of medications, medical equipment, and other resources necessary to run a special needs shelter.

- Ensuring accessibility.
- Prioritizing special/medical needs shelters for restoration of utilities and communications. Backup systems for utilities and communications should be in place.
- Setting up alternative spaces or separate locations for specific conditions, including hospice, dementia, and dialysis.
- Providing security or staff to watch over patients with a range of conditions, particularly those with dementia, to prevent them from leaving the facility.
- Establishing a locally appropriate way to identify health care workers to each other and to patients, keeping in mind the negative impact that uniforms have on some populations.
- Creating a means to ensure hygiene procedures (cleaning of facilities, personal hygiene for staff and residents), laundry, and adequate and accessible bathrooms.
- Creating a response plan in case of a secondary emergency to protect patients and allow for a safe evacuation.

Recovery

Recovery is the least researched phase of disasters and mass emergencies, and the recovery concerns of people with disabilities have received even less attention. Although extensive research is needed to identify issues in the recovery phase and possible solutions, a number of areas can be cited as needing improvements. Such areas should receive significant attention from both practitioners and researchers.

It seems that people with disabilities have never been a primary concern of recovery planners, recovery organizations, or recovery efforts, although many recovery-oriented organizations are willing to assist if concerns are pointed out. Much work remains to be done to address the concerns of people with disabilities when it comes to recovery practices, policies, programs, and research. To start, some basic steps could help improve this situation. First, research indicates the need for a *holistic approach to recovery strategies*. Unfortunately, aid is often experienced as piecemeal and separated; the need in recovery is to integrate and connect various parts of the community. Recovery plans rarely consider the needs or concerns of people with disabilities. A holistic recovery plan would integrate housing reconstruction with accessible transportation systems that connect to employment sectors.

Next, recovery is often viewed as a "window of opportunity" in which a *community can be rebuilt to better standards and a higher quality of life*. Many communities pass new building codes after a disaster to mitigate future risks. The revision of building codes is an opportunity to require that *all reconstruction (and infrastructure) be built to meet or exceed accessible standards*.

Imagine the situation of an individual with a disability and what he or she might face in a recovery context. Policies and programs could be created to address the following issues.

Identify Needs Early On and Link People to Resources

- Link people with disabilities in shelters to case managers and service organizations that can help with searches for accessible housing. This can be accomplished through intake and follow-up procedures during shelter stays. The goal is to reduce the amount of time spent in shelters, which can be prolonged for people with disabilities.
- Create a communications link between shelter managers and providers of temporary housing assistance. Establish federal teams (consisting of HUD, FEMA, local housing authorities, local realtors, etc.) to visit shelters to identify those in need of accessible housing and expedite their transfer to temporary or permanent housing.
- Establish disability organizations and advocates as liaisons between federal teams and those in shelters or other interim locations.

Leverage Social Networks to Enhance the Recovery Process

- Develop family support programs to help caregivers, guardians, and others remain intact as a unit throughout the displacement experience.
- Link residents to local resources, which can be accomplished through the intake process at a shelter or through a case manager.
- Involve local, community-based organizations and experts who have experience with disabilities.

Organize and Conduct Aid-Related Outreach

- Launch rapid information dissemination programs that target individuals with disabilities to inform them of available assistance.
- Ensure that recovery centers and telephone helpline staff are trained to provide accessible locations, communications, and support. Sensitize staff to tactfully ask questions about disabilities, including the loss of key resources that need to be replaced.
- Expand the FEMA website and informational materials meant for dissemination to specifically address the recovery needs of people with disabilities. Include information on the replacement of durable medical equipment and related resources.

Hire Staff to Specifically Support People with Disabilities

- Strengthen the role of the federal disability coordinator.
- Hire regional disability coordinators for all 10 regional FEMA offices. Establish special needs subcommittees under regional advisory committees.
- Task the regional coordinator to work with the FEMA voluntary agency liaison (VAL).
- Involve the FEMA VAL to ensure that disability organizations are present, active, and informed on ESF #6. Task the VAL with holding regular meetings to identify

disability concerns and to work with organizations that can offer solutions or resources to address those issues.

 Continue the collaboration among the Interagency Council on Emergency Preparedness and Individuals with Disabilities, NCD, NVOAD, and others to implement key initiatives.

Ensure Rapid Transfer Into Accessible Temporary Housing

- Stockpile an inventory of accessible trailers and mobile homes. Expedite transfer of these temporary units to affected locations. Ensure that temporary locations are set up near accessible public transportation, health care facilities, and social service agencies. Formalize programs that check for mold, formaldehyde, and other toxins that can have a heightened effect on those with disabilities or medical conditions.
- Ensure that temporary sites have emergency evacuation and protective action locations that are accessible and that can handle service animals and medical equipment and devices.
- Provide accessible public transportation from trailer parks to grocery stores, places of employment, pharmacies, and health care centers. Or devise a way to bring mobile teams of representatives from social and health care services to temporary housing locations, including rental units, motels, and other locations.
- Recognize the diversity of housing needs: renters, homeowners, public housing, congregate care, residential schools, and work-related settings.
- Support congregate care facilities to ensure continuity of care (including medical treatments), transportation to other facilities, and transfer of records/documents. Require congregate care facilities to establish and train staff and residents on evacuation plans and temporary housing solutions to minimize transfer trauma. Train staff at these locations on how to develop mutual aid agreements and continuity of operations plans, including predisaster identification of backup locations where residents, clients, and patients can go after evacuating. Help staff at these facilities understand the importance of involving families in transfers
and ensuring that those who are displaced stay connected to important social relationships. Specifically concentrate on higher risk locations, particularly congregate care facilities that are not part of a franchise and, thus, lack resources to properly cope with a disaster. Develop a volunteer cadre of medical and social service providers who can provide assistance during long-term displacement of a congregate facility. Encourage voluntary organizations (e.g., faith-based groups and organizations such as Best Buddies) to provide religious, social, and emotional support to congregate care facilities as an extension of their work.

Train Task-Specific Teams on Disability Issues

 Work with debris management teams to identify concerns and circumstances that may unduly affect people with disabilities. Such issues could involve access to homes, debris removal (interior and exterior), and the impact of incineration and hazardous materials. Develop a public relations campaign to inform the public of debris procedures, risks, and safety precautions. Make sure people with disabilities are a priority for receiving assistance with debris removal.

Conduct Inclusive Recovery Planning

- Revise FEMA materials on recovery planning to ensure that people with disabilities and disability organizations are included as stakeholders in recovery planning processes.
- Identify various means for upgrading the built environment (e.g., homes, businesses, transportation systems, etc.) so that it is more accessible.
- Include examples of disability-friendly planning in FEMA planning materials. For example, encourage planners to increase accessibility and the number of routes for public transportation, particularly paratransit.

Focus on Health Care

- Provide health care tax rebates, financial supplements, and other economic programs to ensure that people with disabilities do not experience a disruption in receiving health care because of loss of income, employment issues, or problems getting to banks or receiving entitlement checks.
- Involve home health care agencies in providing additional care to people with disabilities. Most home health care agencies require that the individual be homebound to qualify for care. It might help to provide incentives to home health care agencies that agree to develop a disaster policy that allows care to be provided to people with disabilities who can leave their home under normal circumstances but are experiencing disrupted health care access because of a disaster. Some groups, like the Visiting Nurse Association of Central New Jersey, have committees of staff and community representatives that oversee programming. Perhaps an emergency management official could sit on that committee.
- Involve Veterinary Medical Assistance Teams (VMATs) or local volunteers in providing extended care to service animals that experience a disruption in receiving health care because of a disaster.
- Fund programs that provide psychological or psychiatric care to people with disabilities who are affected or traumatized by a disaster. Require that professionals with disabilities be involved in psychological response teams, if they are available.
- Fund programs that provide health care to the poor.
- Fund programs that specifically provide for those with cancer, diabetes, and other conditions that require continuity of care.
- During a disaster, waive limits on SSI, Medicaid, and other benefits.

Support Businesses Owned by People with Disabilities

• Currently, federal business disaster recovery programs provide loans only for getting small businesses up and running again. Develop grants that can be

allocated to the recovery of businesses owned by people with disabilities. A rationale for this exception is that people with disabilities often have disproportionately lower incomes, are harder hit by disasters, and must make difficult decisions concerning whether to fund basic needs, health care, housing recovery, or business recovery.

 Develop federal programs to fund specific businesses that provide work to people with disabilities. Ensure that disaster jobs funded by FEMA and others encourage hiring people with disabilities.

Rely on the Voluntary Sector to Participate in Disaster Recovery

- Train voluntary organizations that are active in reconstruction on disability etiquette and working with clients who are disabled, as well as ways to collaborate effectively with disability organizations and how to prioritize the needs of individuals with disabilities.
- Encourage voluntary organizations to develop outreach programs for people with disabilities in all kinds of circumstances, including those living in trailer parks or rental units as well as those who are rebuilding their homes. Programs could offer assistance with debris removal, transitioning into temporary or permanent housing, building ramps, making locations more accessible, providing child care, offering employment opportunities, case management, and recreational care, to name a few. Since permanent housing is the focus of many disaster voluntary organizations, this represents an expansion of their traditional role. Because voluntary organizations provide a significant cadre of personnel and resources, they can be of considerable assistance during the recovery process. Many voluntary organizations active in disaster specialize in some dimension of recovery; disability concerns could become one of those specializations.
- Create a disability training course for voluntary organizations and agencies that handle case management for those with disabilities.
- Train and fund case managers to work with people with disabilities and disability organizations in an effort to develop recovery plans.

Focus on Permanent Housing Recovery

- Set aside a percentage of federal housing assistance for disability-specific initiatives that address the range of housing needs and locations for people with disabilities.
- Fund programs to develop state housing disaster task forces (per the draft National Disaster Housing Strategy) and require that disability organizations be active participants.
- Expedite local building permit processes and inspections for people with disabilities by moving them to the head of the line when it comes to pending permits and inspections. Doing so can move people into more stable and permanent environments at a faster pace.
- Expedite public housing reconstruction.
- Support voluntary organizations that consider people with disabilities and their housing reconstruction a priority. Find unique ways to use donated funds and materials to assist these organizations with rebuilding efforts.
- Identify federal strategies to help homeowners, business owners, and those involved in providing congregate care to people with disabilities secure affordable insurance in high hazard areas; look to the National Flood Insurance Program as a model.

Mitigation

Mitigation has been even less well examined for disability issues than recovery. Considerable work remains to be done in the areas of practice, policy, and research to ultimately reduce the impact of disasters on people with disabilities. Implications and suggestions from the literature include the following:

• Require that federal actions include a scoping process for the impact of the project on people with disabilities and the identification (and funding) of accessible alternatives.

- Set aside a portion of Hazard Mitigation Grant Program funding to go toward mitigation of disasters for people with disabilities.
 - Recognize that a diverse array of housing and workplaces could benefit from such mitigation efforts. Housing can include rental units, public housing, private homes (tax incentives), congregate facilities, and residential homes and schools. Workplaces could include locations with significant numbers of people with disabilities as well as home-based and small businesses owned by people with disabilities.
 - Develop Ready Business brochures and other materials that demonstrate how to mitigate the impact of a disaster on business employees and customers.
- Ensure review of local mitigation plans by FEMA and assess submitted plans for specific inclusion of disability organizations and reduction of threat for those with disabilities.
- Establish state and local incentives for mitigation of risks to people with disabilities.
- Require low-income areas, public housing, congregate facilities, and other similar locations that might host large populations of people with disabilities to have accessible safe rooms, elevated accessible locations, and other protective features.
- Revise building codes to require that safe rooms constructed inside new or postdisaster housing be accessible.
- Revise FEMA 361 on safe room construction to include building plans for safe rooms (above and underground, for use when it is necessary to shelter in place) that are accessible for people and service animals.
- Offer insurance supplements to low-income households or families of people with disabilities to help offset the financial impact of a disaster to both renters and homeowners, as the National Flood Insurance Program does. Include replacement of equipment, devices, generators, and service animals.

• Integrate these recommendations and examples (case studies) into the FEMA website section on best practices for mitigation.

Future Research

In the field of disaster and emergency management research, studies on vulnerable populations have increased dramatically over the past 20 years; this includes studies on women, children, racial and ethnic minorities, senior citizens, and people with disabilities. However, relevant disability research studies occurred mostly toward the end of that time span, resulting in fairly recent findings that have not yet been applied to emergency management practices.

Much of what is available in terms of disaster research has been criticized as being atheoretical and lacking in conceptual content. Theory is critical to guide research and allow data to be interpreted. Concepts enable researchers to convey findings in an expedient, meaningful form. The lack of theory and concept raises concerns about disaster disability research. To address these concerns and enhance the meaningfulness and usefulness of research in this area, a marriage must be forged between the disaster and disability research communities.

Disaster disability research must be expanded and expedited, infused with funding, and leveraged to transform emergency management practices. Considerable research remains to be conducted. A comprehensive interdisciplinary effort should be undertaken that produces practical content on the full life cycle of emergency management: preparedness, response, recovery, and mitigation.

A number of mechanisms exist, or could be generated, through which research can be funded and encouraged:

• The National Institute on Disability and Rehabilitation Research (NIDRR) has emerged as a leader in providing funding specific to disabilities and emergency management research. However, researchers in the field report that the NIDRR funding is insufficient and only allows for a minimal number of grants. The odds of securing a grant are low, and applying may not be viewed as worth the required time and effort. Some NIDRR grant programs demand lengthy grant proposals and require that extensive partnerships be formed in a very short time from issuance of the request for proposals (RFP) to submission of a proposal. Though the grant foci and partnerships are sound ideas, the time frame (and the low odds of securing a grant) seem to deter qualified researchers.

- General National Science Foundation (NSF) competitions have produced grant submissions on disability issues. However, such applications must compete with other topical proposals. Because NSF funds less than 8 percent of all disaster research proposals submitted, a separate competition for disability and disaster research should be developed. NSF has partnered with other governmental organizations to issue RFPs on special topics. NSF should be approached about possible joint efforts on disaster research and disability studies. Such a program would produce a larger number of grant proposals specific to the topic.
- The next generation of researchers focused on disability issues needs to be nurtured. NSF has two vehicles through which that effort can be supported. First, NSF offers a Research Enhancements for Undergraduates (REU) site program, which brings qualified students into research centers and academic departments for research training. Second, NSF funds a next generation program for promising junior faculty working in the field of disaster research. Both programs could be solicited to emphasize disability issues in their program announcements.
- A National Board for Disability and Emergency Management Research should be convened; perhaps this could be done through the Natural Disasters Roundtable of the National Academies. The board should solicit input from disability organizations and emergency managers to generate appropriate research questions and produce an annual progress report on findings.
- The federal government should establish a grant competition for a Disability and Emergency Management Research Center of Excellence, preferably through

NSF. Care should be taken to ensure that experts in relevant fields receive grants and that such centers incorporate interdisciplinary efforts between emergency managers and disability experts (including people with disabilities). Existing centers should involve people with disabilities as researchers and incorporate disability issues into their investigations and products.

- Mechanisms exist through which research funding can be provided as a way to generate rapid research with immediate practical benefit. A number of disaster research centers exist around the nation with experienced faculty or networks through which funds can be generated. One model for the latter is the Natural Hazards Research and Applications Information Center at the University of Colorado-Boulder (www.colorado.edu/hazards). The Hazards Center offers several thousand dollars in quick response research funding to qualified faculty, practitioners, and students so they can get into the field quickly to gather perishable data. The center's Quick Response Report series is posted on its website for quick and easy access. NSF has historically offered another vehicle for quick funding—the Small Grants for Exploratory Research (SGER) program—which is currently in transition. The program offered, at times, up to \$50,000 so researchers could gather perishable data. Officers in charge of the new SGER program should be contacted to explore the possibility of adding an emphasis on disability disaster research.
- A number of federal grants solicit information on the participation of people with disabilities in funded research. It is clear from these studies that the inclusion of people with disabilities in such research is minimal to nonexistent. This pattern of exclusion must be changed by requiring that people with disabilities be invited to serve as meaningful participants in funded research projects. Principal investigators must be accountable.
- The Department of Homeland Security and FEMA routinely contract with consultants and corporations to produce guidance documents, booklets, and other strategic materials. Such contracts should require, as a minimum, (1) expert researcher(s), (2) disability researchers, (3) disaster researchers, and (4)

experienced practitioners so guidance materials include the best science and practice this nation has produced.

- Most federal grants (but few contracts) require review by experts in the field, either as independent reviewers or as members of expert panels. Such panels require the participation of disaster researchers, disability experts, and seasoned practitioners. Extraordinary efforts should be made to ensure that knowledgeable reviewers examine proposals—and, when possible, contracts—using the principles recommended in this document. Key principles include the leadership of knowledgeable researchers, the participation of disability experts, and the practical, expedient application of the findings.
- Funded grants and contracts should require clear and efficient information dissemination plans within the research community, throughout the field of emergency management, and to disability organizations. Such plans should be carefully developed as part of any grant or contract, adequately funded, and monitored for compliance.
- Funding should be generated for faculty conducting research to attend and present findings at relevant events, including emergency management and disability conferences.
- An annual National Conference on Emergency Management Practice and Disability Research should be convened to facilitate knowledge transfer. Funding should be provided so experts, practitioners, and disability organizations can participate. State leaders in relevant organizations should be invited to participate and such participants should be required to demonstrate the integration and application of research into practice.

Conclusion

Disability advocates, researchers, and organizations are beginning to have a promising impact on the practice of emergency management. Yet, in spite of all the headway they have made, there is still a long way to go. People with disabilities deserve and require

the best scientific findings that can be produced, because they are often at greater risk then others when disaster strikes. The lack of a significant body of research compels us to glean general principles from what little is known and to identify current practices consistent with those principles. Ideally, a science of disability-oriented emergency management practices would produce a foundation on which significant progress could be made to generate knowledge, improve practice, and inform policy, as well as to reduce threats to lives, resources, and property. Such an empirical foundation would generate confidence in the practices that truly make a difference and should be used in dire circumstances.

Looking ahead, Chapter 9 (Initiatives in Progress) will identify promising practices and current initiatives that appear to be consistent with the principles gleaned from the literature. Chapter 10 will describe and assess policy, program, and practice trends. Chapter 11 will elaborate on Chapter 9 by specifying interventions that should be undertaken or at least considered to generate significant change at the local, state, national, and organizational levels.

CHAPTER 9: Initiatives in Progress

Introduction

The purpose of this chapter is to identify initiatives in progress that offer promising practices across the life cycle of emergency management when it comes to serving people with disabilities. The chapter is divided into the four phases of the life cycle: preparedness, response, recovery, and mitigation. Examples are drawn from recent or ongoing initiatives and efforts that are consistent with the principles identified in Chapter 8 (Implications from the Research). Each section contains a summary of an initiative, followed by bulleted information that explains why the effort is considered a promising practice. The intent of this chapter is to identify exceptional examples of best practices rather than to provide an overview or a comprehensive set of best practices. These examples can serve as models to compare with other ongoing or emerging efforts.

Preparedness

Preparedness encompasses a variety of activities: education, outreach, planning, and registries. In this section, we examine best practices for each of these areas and identify outstanding examples of recent practices.

Educational Materials

Developing educational materials on preparedness is perhaps the largest single effort that has been undertaken for the benefit of people with disabilities, though much work remains to be done. This section describes some of the best educational materials that target individuals, organizations, and emergency management professionals. For a broader review of educational materials, see the appendices.

The most current and comprehensive materials available today on this subject are those targeted at individuals. Emergency Management Ontario (Canada 2007) recently issued the *Emergency Preparedness Guide for People with Disabilities/Special Needs*. The following elements of the guide illustrate promising practices:

- Availability in relevant languages, including English and French (locally spoken languages).
- Availability in alternative formats upon request.
- Large font size.
- Pictures/visuals of key points and action steps.
- Checklists supplemented with photographs of the items.
- Service Animals Emergency Kit checklist.
- Photographs of people with disabilities actively participating in the recommended activities throughout the guide and on the cover.
- Tips for people who are assisting someone with a disability.
- Photographs of assistive equipment and adaptive devices, demonstrating proper use.
- Details on how to fix equipment (e.g., repairing wheelchair tires) or support medical needs (e.g., providing latex-free gloves or catheters).
- Disability-specific information related to those with mobility, vision, hearing, or nonvisible disabilities (e.g., diabetes, multiple sclerosis) and to seniors; tips on high-rise safety, along with recommendations for planning, etiquette, and creating survival kits, along with accompanying photographs.
- Information on preparedness for a variety of locations outside the home, including work, travel, and recreation, along with photographs.
- List of contacts for more information.

Organizations of all types—including disability organizations, social service providers, health care providers, advocacy groups, and voluntary organizations (e.g., civic, community, and faith-based)—seem to have only minimal educational materials available to them on internal emergency and disaster planning for continuity of operations, how to work with and contribute to emergency management agencies, and how to best prepare clients for disasters. The lack of materials creates a significant gap

in preparedness efforts, particularly since such organizations and providers are key to maintaining and continuing services to many people with disabilities. Of this group, health care organizations have the best materials, although the focus tends to be on hospitals and major care facilities. Note the following recommendation:

Developing a comprehensive set of continuity of operations planning guidance materials for community-based organizations that connect to the disability community is crucial.

The role of organizations cannot be underemphasized when it comes to preparedness. They can be key partners during a disaster. As recounted at an NCD meeting in Arizona, the State Independent Living Council has been an integral partner and resource in the creation of preparedness plans [excerpted and edited for brevity]:

The Arizona SILC has been very actively engaged with the Arizona Department of Emergency Management in planning exercises, participating in exercises, and bringing people with disabilities into the planning, execution, and all other phases of emergency preparedness. Arizona SILC received a grant from the Arizona community foundation. We purchased evacuation chairs, portable ramps, assistive listening devices, and portable captioning devices that can be plugged into a laptop computer. Then we took this equipment on the road—we demonstrated it to county planners and local first responders, and provided them with hands on experience. We brought people with disabilities along to talk about specific disability related issues. We provided spec sheets that included how much the equipment costs and where to get it. Several jurisdictions subsequently bought these pieces of equipment to add to their inventory.

Disability organizations and related service providers across the nation are increasingly willing to be partners in preparedness efforts. It is crucial to ensure that they themselves survive a disaster, through internal preparedness. The New Jersey Office of Emergency

Management and the New Jersey Special Needs Advisory Panel (NJSNAP) offered business continuity planning for such service providers in 2007. Approximately 75 organizations participated. The best practices drawn from their efforts include these:

- Partnerships among state agencies.
- Involvement of a specific task force dedicated to linking emergency management personnel or information to organizations representing people with disabilities.
- Offering specific business continuity training to sustain vital organizations throughout an emergency.
- Providing business continuity training as part of a broader series of emergency and disaster awareness workshops for the service sector.

Emergency management professionals have the benefit of an extensive set of materials that are available to educate themselves and their staffs on disability issues. Unfortunately, most of the materials are dated and require revision because of new terminology (e.g., the "functional" approach), new procedures (e.g., the DOJ shelter guidelines), or new approaches (e.g., partnerships with disability organizations). A number of other educational methods have been used to disseminate information on these topics:

- FEMA, EMI, and USFA courses
- Disability-specific conferences, workshops, and presentations at emergency management venues
- Contractors and consultants that offer workshops
- Guidebooks and other resources.

Although these methods have been useful, many are limited to direct attendance, professional interest or need, staff expertise, or having the time to secure, learn, and apply the content. Much of the content that is made available by the federal government, for example, is offered as stand-alone courses (e.g., at the EMI campus or through a nonresidential course or independent study). A good alternative could be the integration and infusion of disability-specific content throughout all emergency management courses. Further, there is currently no requirement that emergency managers earn certification on disability content. A best practice to change that could rely on existing structures to deliver content follows:

- FEMA offers certification through its Professional Development Series (PDS) of courses on its Independent Study website. The PDS could include the IS-197 Special Needs Planning course as part of the requirement (although IS-197 requires revision to be up to date).
- The International Association of Emergency Managers (IAEM) offers a credentialing process that allows a person to become a certified emergency manager (CEM). CEM content could be revised to recommend an up-to-date IS-197 as a precertification course, and CEM exams could incorporate disabilityspecific content. The recertification process could also require understanding of disability-specific issues.

A recent trend demonstrates the potential to reach large numbers of people through web-based training. In late 2008, the American Association of People with Disabilities (AAPD) partnered with the Community Emergency Preparedness Information Network (CEPIN) to offer web-based training. The program is self-applied, emphasizes functional needs, and promotes collaboration and interaction between emergency managers and the public. Best practices in this effort include the following:

- A partnership between two expert organizations dedicated to disability issues.
- Adoption of functional needs language.
- A focus on collaboration with and involvement of the population at risk.
- Widespread access for many interested individuals through the Web.

The vast number and dispersed locations of people in need of education and training requires that new formats, such as web-based training, be used to disseminate

information. Health Canada provided funding to the Sunnybrook Health Sciences Centre to create a two-day pandemic exercise that involved a variety of agencies and government offices in mass immunization and mass casualty exercises. Participants were given online role-playing exercises that brought in anywhere from 200 to 700 participants at a time. Evaluations indicated that the exercise was overwhelmingly successful and "highlighted the need to identify vulnerable people and provide services/programs to protect them and meet their needs in emergencies" (Public Health Agency of Canada 2008, p. 25). A key finding was that retired citizens want to volunteer and are capable of doing so. The factors that made this exercise a best practice are—

- Easily accessible format.
- Involvement of a wide range of players.
- Live, interactive format, which enhances understanding, makes the learning more realistic, and promotes retention.
- Realistic scenarios linked to populations at risk.
- Illumination of the potential of those at risk as partners in risk reduction.
- Results that included significant awareness-raising and potential for transformation in practice.
- Potential to network people through rapid, web-based means.

Education and Outreach to the Community and Individuals

Preparedness outreach efforts work most effectively when they occur through trusted, credible organizations and involve those at risk. Recruiting individuals who are similar to those at risk to conduct outreach increases buy-in and participation. For example, the City of Winnipeg, Canada, created a "For Seniors, By Seniors" workshop to "foster resiliency and community/healthy networks for seniors" (Public Health Agency of Canada 2008, p. 15). The effort connected the city with a local senior center and involved the seniors in creating an hour-long group presentation in plain language. The

effort was designed to promote positive action rather than fear among seniors and taught them how to create a home survival kit. Best practices in this effort include—

- Direct involvement of the population at risk.
- Targeting a presentation to the needs of the audience and making sure it was on their level.
- Moving from information to action.
- Collaboration between government and community-based resources.
- Using diverse means to reach people, such as public meetings, organizationbased meetings and websites, door hangers, handouts, grocery bags, radio talk shows, chat rooms, recreational and social events, and various locations (e.g., restaurants, health care centers, social service organizations, parks, malls, workplaces, public transit vehicles, and paratransit vehicles).

In New Jersey, the Progressive Center for Independent Living (PCIL) participates on the New Jersey Special Needs Advisory Panel (SNAP) and offers links to emergency preparedness information on its website. The center's connection to a potentially at-risk population provides a foundation of trust and enables emergency managers to reach these individuals with important information. The New Jersey Council on Developmental Disabilities and the PCIL also collaborated (through a grant) to create a specific curriculum on emergency preparedness. They then recruited and trained individuals in several counties to serve as community disaster liaisons. Those individuals spread out through the CIL network to educate both people with disabilities and first responders. The New Jersey effort demonstrates that—

- Grants that require partnerships linked to the grassroots level can have beneficial results.
- Involving disability advocates and organizations in outreach efforts is key.
- The train-the-trainer approach can work with disability populations.

• Creating a system through which information can flow (i.e., from the state to the SNAP to trainers to individuals in the community) can help educate people with disabilities.

Planning

In recent years, critically important guides for use in planning have been developed at the federal level (see Chapter 3 for information on general population and special needs shelter planning). But perhaps the single best resource to date is the Department of Justice's *ADA Best Practices Tool Kit for State and Local Governments* (Chapter 7, Addendum 2: The ADA and Emergency Shelters). The following factors make this publication a best practice:

- Explanation of why it is relevant.
- Availability on a federal website (although it is not easy to find—a more visible and accessible format would be ideal).
- References to the original rules and policies on which the recommendations are based.
- Specific principles (boldfaced) with follow-up explanations.
- Consideration of service animals.
- Inclusion of a broader set of guidelines than typically found in guides (e.g., the section on reasonable modifications addresses kitchen access and sleeping arrangements).
- General guidance on communication (although more specific examples or links to examples would be ideal).
- Links to additional materials, such as the "ADA Checklist for Emergency Shelters."
- Straightforward explanation of disability issues and practical accommodations.

CPG-301, *Comprehensive Preparedness Guide 301: Interim Emergency Management Planning Guide for Special Needs Populations* (version 1.0, draft status as of January 2009), was designed as a tool to help emergency managers develop operations procedures for special needs populations. The document has 46 pages of planning considerations that include roles, assessments, registries, communications, shelters, evacuation, transportation, medical issues, congregate care, recovery, and related training and exercises. The document, which received the DHS Director's Award in 2008, demonstrates the following best practices:

- Clearly demonstrates federal commitment to special needs planning.
- Offers overall planning guidance and identifies necessary areas for operational planning.
- Situates FEMA as a potential central agency for offering critical information on planning for issues related to disabilities and disasters.
- Defines key terminology with preference given to functional needs planning.
- Offers practical links to useful resources (annexes B and C). Provides useful annexes, including HIPAA guidance (annex D). Lists questions that need to be asked when developing plans, such as questions about the viability of a registry (annex E). Connects civil rights considerations to special needs planning (annex F).

The Kansas Association of Local Health Departments (2007) developed a Special Needs Assessment Tool Kit for pandemic influenza mapping and outreach. The tool kit provides detailed instructions on how to assess the needs of the elderly, people with disabilities, non-English-speaking people, and people living in congregate settings (homeless shelters, institutional settings, etc.). Tool kit items include agency and household assessments. The University of Kansas Research and Training Center on Independent Living created an online course to train hospital staff, health care workers, emergency personnel, and other workers to assist people with disabilities during disaster events. The online training is currently available to 22 states and the Medical

Reserve Corps, including a version in large font. The course, "Ready, Willing, and Able" is eligible for continuing education credit by the Kansas Nurses Association and is available free at the Public Health Foundation's Train National website (other disability and emergency courses are also available on the site; see <u>www.train.org</u>). What makes these initiatives examples of promising practices is that they—

- Are easily available over the Internet and free of charge.
- Offer clear instructions.
- Provide useful and practical tools (mapping, etiquette, communication, etc.).
- Are offered with the incentive of continuing education credit.
- Are available in alternative formats.
- Address a diverse set of potentially at-risk populations.
- Have content based on both research and practitioner knowledge.

Registries

Registries have emerged as a possible means to identify and conduct planning for citizens with needs for transportation, evacuation, and other kinds of assistance. To date, no empirical research exists on the value or effectiveness of registries. Reports suggest that registries can be expensive and hard to maintain; that they need to be well integrated into a careful division of labor among participating agencies; and that adequate access can be a problem. Several examples offer insight into how to manage a registry.

The St. Pierre-Jolys Emergency Measures Committee in Manitoba, Canada, was created by six seniors who were retired professionals. They took on the challenge of creating and maintaining a database and a communication system. They collaborated with groups and organizations to form the District Guardian Program in 2004 (Public Health Agency of Canada 2008). As part of this program, volunteer "guardians" have been trained to alert those at risk; there are six districts, each with a guardian and two

assistant guardians. The best practices features of the District Guardian Program include these:

- A cadre of people dedicated to updating the database.
- Involvement of peers in contacting and alerting seniors, which generally inspires interpersonal trust, credibility, and a higher compliance rate.
- A network that connects to key resources and has been formalized into a new entity that everyone supports.
- Its status as a helpful grassroots, community-based effort that links individuals and households to response efforts, resources, and agencies.

In 2008, New Jersey's Office of Emergency Management launched a "Register Ready" effort to sign up people with disabilities who may need help during an evacuation or emergency. The registry is part of a multistep education initiative that urges citizens to create a kit, develop a plan, and register if they anticipate needing assistance. As of October 2008, registration efforts had resulted in more than 6,400 individuals signing up. The following registry features show promise as best practices:

- Web-based registration.
- 2-1-1 telephone service support to register people who unable to use web-based systems, along with free translation and TTY.
- Distribution of registration forms at 10 county emergency management offices, with the intent to expand to 21 counties.
- Ads on billboards and in newspapers.

Response

The response period covers the time during which a disaster or mass emergency is under way. In this section, we give examples of initiatives in progress that illustrate best practices for warnings, transportation and evacuation, search and rescue, sheltering, service animals, and health care. Because of the specific challenges that people with disabilities may face, the first few sections address the problem of securing sufficient resources to respond and the value of involving community-based organizations.

Providing Resources

Low incomes may prevent people with disabilities and seniors from purchasing needed resources to receive warnings, respond, mitigate risk, or recover from a disaster. Fortunately, a number of efforts can be identified in which various agencies have secured resources to help. Emergency Social Services of Toronto, Canada, secured funding for the Vial for Life, a refrigerator magnet that includes information on medications and can be easily viewed by arriving paramedics or taken along in an evacuation (Public Health Agency of Canada 2008). New Jersey's Mercer County Office for the Disabled offers a similar resource called the File of Life, which also has a place for insurance information. OK-WARN of Oklahoma's Office of Emergency Management (OEM) provides low- or no-cost alternative warning messages through texts and pagers for people who are deaf or hard of hearing. The OEM worked with the National Weather Service to design and implement the service. The following factors distinguish these examples as best practices:

- They move beyond providing information.
- They recognize the economic challenges faced by populations at risk.
- They connect individuals to emergency management and first responder professionals.
- They are simple, direct, and convenient.
- They are efficient for use in an emergency context.
- They provide a means to secure necessary lifesaving devices.
- They empower an individual to be actively involved during the response period.

Using Community-Based Organizations

As an example of using organizations to conduct outreach during the response period, particularly in a pandemic emergency, the San Mateo (California) Health Department partnered with CBOs that link to seniors, people with cognitive or mobility disabilities, the homeless, undocumented immigrants, non- or limited-English-speaking people, and people living in rural areas. After a survey of these special populations and a series of community forums, specific CBOs were identified in relation to each population of concern. Aging and Adult Services, for example, can reach thousands of clients through a phone tree system that can be activated during an emergency. The effort subsequently included training for CBOs, development of a communication system for use during an emergency, and a formal MOU (for a sample MOU, go to www.pandemicpractices.org/practices). The promising dimensions of this effort include the following:

- Using trusted and credible CBOs to inform those at risk, which should result in greater response and compliance with protective action protocols.
- Using organizational-level links to distribute critical emergency information to atrisk populations.
- Providing training for the CBOs on pandemics, emergency planning, continuity of operations, and communications.
- Developing a formal MOU to clearly specify each organization's roles.

Warnings

Previous chapters have noted issues and concerns with regard to warnings. The following are best practices for warnings:

- Involve people with disabilities in crafting, creating, and disseminating the warning message.
- Include diverse, redundant warning systems so people have multiple options to learn about and verify a warning message.

 Use trusted, credible authorities, including disability advocates and organizations, to disseminate warning information. Involve trusted figures and organizations in transmitting the warning message, translating the message, developing prerecorded messages, and personally contacting those at risk.

A careful review of warning protocols for the chapter on response indicated that effective warning systems for people with disabilities include these best practices:

- Disseminate the warning through social networks, especially neighbors, coworkers, friends, health care providers, disability advocates, and others who are likely to reach out to those at risk.
- Issue the warning as far in advance as possible so the message can be widely and diversely disseminated, confirmed, and acted on—it often takes people with disabilities longer to act.
- Issue the warning in clear, simple language than can be understood by people with cognitive disabilities.
- Include in the warning information on appropriate protective action, as well as alternative means for protection if mobility is limited.
- Issue warnings in compliance with FCC policies.
- Use alternative systems to issue warnings (besides sirens, radio, television, and text messages) to reach a broader range of people with disabilities.
- Use reverse 9-1-1 systems and make sure the systems purchased are in compliance with TDDs.

After Hurricane Katrina, a report by the Government Accountability Office said that health care professionals and voluntary organizations played an important role in notifying and convincing their clients and patients of the need to evacuate. Because a number of clients and patients lacked transportation, those same professionals and organizations were able to link those at risk to transportation and evacuation resources. Other organizations, such as the Louisiana School for the Deaf, used their webpages, text paging capabilities, and

social networks to find and support students who were displaced. Emerging technologies that connect to younger students are also promising (Young 2008) for people with disabilities. The University of Maryland at College Park recently set up a Facebook group for emergency preparedness and other information, an effort that has been emulated by Purdue and Notre Dame. In January 2009, FEMA launched its Twitter account, FEMA in Focus, "to highlight the value of social media tools in emergency management and disaster response" (FEMA 2009). On the basis of these examples, best practices that link warnings to protective actions include the following:

- Involve organizations and agencies that are routinely linked to people with disabilities, including professional associations and organizations that represent recreational, social, or other important dimensions in the life of a person with a disability.
- Use alternative means (but not as the sole means) to contact and inform people about emergencies; for example, Facebook, MySpace, Twitter, and YouTube.

Transportation and Evacuation

Recent disasters have revealed issues with evacuating those with special needs. Many people with disabilities can evacuate with public transportation support, especially paratransit vehicles. After Hurricane Katrina, FEMA contracted with American Medical Response (AMR) to provide paratransit evacuation services for New Orleans and 12 other Louisiana parishes during the hurricane season of 2006. FEMA awarded an exclusive contract to AMR in 2007 to provide a variety of services to 21 states along the Gulf and Atlantic Coasts, with optional services to the West Coast and the central portion of the United States. Services include triage, treatment, transportation, hazard recognition, symptom surveillance and reporting, on-scene medical standby, transport of hospital patients, immunizations, shelter staffing, staffing of hospital emergency departments, and setup of mobile medical clinics. AMR was activated for Hurricane Dean in August 2007; it deployed 300 ground ambulances, 25 air ambulances, and enough vehicles to provide transportation for 3,500 passengers (Office of Emergency

Preparedness 2008). AMR received high evaluation scores from FEMA and the National Institutes of Health. Involving paratransit assets is a best practice because—

- Local paratransit systems have drivers who are already familiar with client needs and locations, and can be used as key assets in an emergency (National Service Inclusion Project, n.d.).
- It uses a predisaster agreement developed and implemented by FEMA and the General Services Administration (GSA), with a considerably larger and more diverse set of assets than most jurisdictions have.
- It uses a service that has expertise in both disabilities and disasters.

The following are best practices for evacuation:

- Direct involvement of people with disabilities and disability organizations in evacuation planning.
- Education of people with disabilities and disability organizations on evacuation procedures, personal responsibility, and public transportation options.
- Assessment of the appropriateness of a buddy system as well as predisaster planning and training, including any contingency plans for absent buddies.
- Creation of an evacuation planning task force that includes those at risk and disability-related organizations.
- Planning for a point-to-point evacuation procedure, from pickup location to evacuation shelter or other protected location.
- Planning for a complex array of evacuation and transportation needs, including evacuation of people with medical or mobility equipment and service animals.
- Evacuation planning for a wide variety of settings: school, work, home, stores, recreational venues, high-rise buildings, and highways. Ensure that planning is done in compliance with ADA.
- Purchasing evacuation devices for use in an emergency in a variety of settings.

- Continual monitoring for new devices that can be implemented in an emergency.
- Coordination with federal assets, such as AMR, and other local, state, or regional transportation resources.
- Inventory of primary and contingency transportation assets that are accessible.
- Careful training of evacuation personnel who will work with people with disabilities.
- Careful use, development, and maintenance of a focused registry that has been tested. Also, consider alternatives to registries, such as window placards, outdoor lockboxes, individual alarm systems, and other notification options.
- Predisaster planning, training, and exercising (with MOUs) with local paratransit agencies.
- Involvement of paratransit drivers and dispatchers in notifying regular riders of emergencies and evacuation procedures.
- Carefully preplanned evacuation procedures, training, and exercises with group homes, nursing homes, schools for children with disabilities, sheltered workshops, and other congregate settings.

Search and Rescue

A lack of research on search and rescue makes it challenging to identify best practices. In many contexts, rescue requires creative thinking and rapid action that may not be consistent with recommended practices for moving a person with a disability. First responders tend to focus on rescue techniques that can be adapted to the situation. Considerable work remains to be done to develop evacuation devices that are known and trusted in both the disability and first responder communities. High-rise buildings are a particular area of concern. Currently, people with disabilities are directed to go to an area of refuge and await rescue. Despite the dearth of research, the following best practices can be identified:

- Train first responders on lifting and moving people with various kinds of disabilities.
- Train first responders on disability etiquette.
- Train first responders on basic communication that is appropriate for a variety of types and levels of disability.
- Train first responders to be able to rescue medical or mobility equipment and service animals.
- Provide adaptive rescue devices to first responders as basic equipment.
- Understand that people may not be able to hear or respond to verbal or audio search technologies.
 - Use thermal imaging devices to locate victims.
 - Use live scent search dog teams as a possible resource for assistance.
- Train first responders to recognize certain building designs. For example, an
 outside ramp should alert search teams to the possibility that people with mobility
 impairments live there.
- Try to "rescue" assistive technology (e.g., wheelchairs) along with the individual, if manpower is available, or at least record the location of the technology for later recovery.
- Look for indicators that a service animal may be residing at that location.

The U.S. Fire Administration has created a detailed guide titled *Orientation Manual for First Responders on the Evacuation of People with Disabilities*. It is the single best guide available to date on this subject. Another guide, *Social Etiquette—Tips for Firefighters*, was developed by OK ABLE Tech and by firefighters. These guides identify the following best practices:

 Involve firefighters in creating disability guides for search and rescue to ensure greater acceptance in this community. The same is true for other first responders.

- Identify and involve people with disabilities and related organizations in developing rescue plans, training first responders, distributing information, and building strong, trusted relationships before a disaster.
- Include people with disabilities in the selection and purchase of rescue equipment.
- Plan, train, and exercise with those at risk prior to the onset of an emergency.
- Learn disability-specific techniques for appropriate communication, lifting, and moving and supporting equipment and service animals during a rescue. (Providing additional content that specifies the context of the rescue would be helpful.)
- Consult with disabled persons about any issues that should be considered in nonemergency rescue operations, although rescuers may not have sufficient time or equipment to work around these issues when a quick response is necessary.
- Reassure and inform disaster victims of the situation and what they will need to do. Pay particular attention to visually impaired individuals, who may not be able to see the hazards present after an event (e.g., downed power lines, trees, or damaged buildings)

Sheltering

A number of new practices on sheltering have emerged in recent years. Overall, general population shelter services are increasingly adopting a functional approach along with the following: evaluating accessibility, educating shelter staff on disability issues, providing communication access, organizing the shelter environment to make it accommodating, and using volunteers with disabilities (National Service Inclusion Project, n.d.). The single best set of practical resources related to accessibility and accommodation regulations and recommendations for shelters is located on the Department of Justice website, although the information can be difficult to find without using the search function. DOJ has developed a set of guidelines and practical illustrations of reasonable accommodations that can be made in general population

emergency shelters. These practices, available in a downloadable guide and checklist format, offer useful guidelines for those involved in shelter planning.

More specialized shelters serve those with needs that cannot be routinely accommodated in general population shelters. New York State convened a series of Shelter Summits in 2007 to develop a functional and medical needs shelter guide. Standout practices associated with their efforts include the following:

- Adoption of a functional needs approach for sheltering, which streamlines services, provides key support to people with disabilities, and enables independent living in shelters.
- A focused set of procedures outlined in a 28-page document with extensive references.
- Clear definitions and distinctions between general population and functional/medical needs shelters.
- Specific delineation of responsibilities for shelter staff by specialty and for participating organizations.
- Recognition of a state functional and medical needs sheltering task force as a key partner, along with phase-specific responsibilities (initial, continuing, and demobilization).
- Consistency with NIMS, ICS/Unified Command as a management strategy.
- Articulation with agencies (e.g., the Red Cross) regarding roles and responsibilities.
- Clear and concise sets of procedures for selecting, opening/activating, securing, and staffing the shelter, as well as for triage.
- Carefully detailed descriptions of staff positions and responsibilities.
- Appendices with forms that can be used during shelter operations.
- A list of specific equipment needed during shelter operations.

- Job action sheets for critical staff positions.
- Attention to service animal and pet issues during sheltering.
- Efforts to reach out to and involve a variety of partners in planning for sheltering operations, including state government and nonstate and nongovernment agencies, coupled with clear delineation of responsibilities.

The States of Missouri and Mississippi have also created exceptional guides for special needs shelters. In addition to the best practices listed above for New York, these guides offer some additional best practices:

- Missouri
 - Specification of staff-to-shelteree ratios for nursing staff, mental health staff, and others.
 - Checklists for key staff positions.
 - Delineation of security and safety roles for personnel working in shelters that are specific to people (e.g., dementia cases) and service animals (who may become frightened or confused).
 - Strong connections among a variety of government agencies and service providers, including health services, aging divisions, and disability organizations.
- Mississippi (General Medical Care Guidelines and Emergency Medical Care Guidelines)
 - Extensive lists of medical emergencies and recommended treatment protocols for disabilities, chronic conditions, and injuries.
 - Information on lifting and moving people with disabilities.
 - Isolation procedures and infection control guidelines.
 - Injury-specific treatment protocols.
 - Safety and related hygiene procedures.

Taken together, these guides form a comprehensive set of materials that can be used as models for functional needs shelters.

Service Animals

The topic of service animals has recently attracted concern and attention. A number of organizations and agencies provide general support for animals during disasters, including Veterinary Medical Assistance Teams (VMATs) and the Virginia State Animal Response Team or Best Friends Animal Sanctuary. Their focus tends to be on general preparedness and emergency care for animals; they typically care for pets, but their assets and interests could be leveraged further. Other organizations, such as the Humane Society of the United States, the American Red Cross, the National Organization on Disability, the American Veterinary Medical Association (AVMA), and the Interagency Coordinating Council for Emergency Preparedness and Individuals with Disabilities (ICC) have begun to post information on this subject. However, the AVMA's 413-page guide mentions service animals only in limited contexts. The VMAT websites support working dogs (noncanine animals are not listed). Disability organizations tend to be those most likely to focus on service animals and to provide guidance and support. Best practices for service animals include the following:

- Distinction between pets and service animals.
- Clear, accessible brochures (in diverse formats and languages) for various disaster phases that service animals may experience. Brochures should include information on creating emergency kits and protective actions (stay in place or evacuate), transportation, identification, shelter life, and temporary relocation (and renavigation of a new environment).
- Involvement of a variety of organizations that are dedicated to animal safety including veterinary organizations, VMATs, humane societies, and state agencies—and that can disseminate information.
- Integration of organizations that can train and support working animals to be part of emergency preparedness efforts.

- MOUs with veterinarians and veterinary colleges to provide care for service animals in shelters.
- MOUs with pet supply companies and service animal support organizations to provide food and supplies during emergencies.
- Training shelter staff to accept and work with service animals.
- Support for a diverse array of working animals that may be affected by disaster.
- FEMA Comprehensive Planning Guide 302 is to include service animals.

Medical and Health Care

- It is likely that a disaster will disrupt health care services. Mobile health care and mental health care services have been used in some disasters, though they are interim services that may not be widely available (particularly when a large population is displaced). Interim health care best practices should include the following as a minimum:
- Backups of medical records so they can be transmitted electronically to a new location.
- Careful education of those at risk regarding the need to safeguard and evacuate with their medications and medical records.
- MOUs with pharmacies to provide medications for shelter providers or to replace lost medications; funding to purchase lost medications (federal support may be required for this).
- Assistance to help people stay connected to health care and mental health care providers.
- Assistance to help evacuees avoid disruptions to their medication regimens, especially for those taking medicine for serious illnesses or psychiatric conditions.
- Keeping evacuees connected with family, medical staff, caregivers, guardians, and those from familiar social networks.

- Careful planning for medical needs shelters and for medical needs at general population shelters.
- Continuity of operations planning for the full array of health care providers, from home-based health care to major medical facilities.
- Training the full set of personnel involved in response activities to identify medical emergencies, including the effects of disrupted medications (medical or psychiatric) and how to respond appropriately.

Recovery

The recovery period is an underaddressed area when it comes to people with disabilities. As Hurricane Katrina revealed, considerable postdisaster challenges exist in housing (temporary, permanent, and low-income), health care, transportation, restoration of social and home-based support services, education (especially for the developmentally disabled), personal care services (e.g., restoration of adult day care), case management specific to disability issues, and necessary alterations to programs offered by the federal government, especially FEMA (e.g., better website information, more specificity regarding what FEMA funds can cover, extended coverage for replacement of necessary medical equipment or devices, and support for service animals). Some relatively new efforts that have emerged since the storm offer promising practices. Recommended changes for the recovery period can be found throughout the previous chapters and are summarized in Chapter 11 (Interventions).

FEMA's Disaster Housing Recovery Strategy, released January 16, 2009, has garnered considerable internal and external recognition as a promising document. The strategy must be developed further to provide not only principles but more specific guidance to federal, state, and local partners. The separate annex for special needs (located on page 74 of the annexes) needs to be listed by page number in the main document and in the annex, and key special needs principles should be embedded throughout the main strategy document to bring attention to disability issues. The following elements of the strategy seem particularly promising:

- Recognition of the need for state-level task forces on postdisaster housing to incorporate disability organizations and other community partners.
- Integration of efforts to provide accessible temporary housing to people with disabilities, seniors, and others with special needs. Integration of efforts brings disability concerns into mainstream strategizing and planning.
- A functional annex that offers promising potential and should be further developed to bring attention to disability housing issues. The annex should provide not only principles but specific guidelines on a variety of subjects (e.g., accessibility and code compliance, integration with health and transportation services, connection to case management services, the diverse types of disabilities that require accommodation, and the needs of various types of service animals). Many emergency managers and housing providers do not understand the needs of people with disabilities; this guide must incorporate information and guidance that enables them to move forward with postdisaster housing efforts.

Major disasters tend to bring about change. Legal action may do the same. In the case of *Brou v. FEMA* (and DHS), the settlement resulted in significantly higher numbers of accessible trailers being provided to people with disabilities. The following practices that resulted from this lawsuit need to be retained and expanded upon in future disasters:

- Integration of disability organizations, advocates, and people with disabilities in identifying available temporary housing options so they can assess the utility, functionality, and barriers of available housing units.
- Recognition of housing accommodations required by people with disabilities, seniors, and others who may have "special needs" (the term is used throughout the document). This recognition is thoroughly embedded throughout the document.
- Empowerment of local, community-based disability organizations to participate in FEMA housing efforts, including inventorying housing options, matching FEMA applicants with available housing, assisting with transitions from shelter to

temporary housing, and identifying and resolving housing issues once an individual or family has moved in. Disability organizations should be an integral part of the FEMA special needs desk when the National Response Framework is launched, as well as ESF #6 (mass care, voluntary organizations) and ESF #14 (recovery).

- Establishment of a hotline through local disability organizations working in concert with FEMA so that people with disabilities have a number they can call or connect with to begin the case management process for temporary and permanent housing assistance.
- Case management processes that take disability issues into consideration and connect the applicant or client with appropriate recovery resources. Those with expertise and experience in case management, including people with disabilities and disability organizations, should be hired to manage the cases.
- Careful record-keeping that documents need, resolution, and remaining areas of concern.
- A postevent evaluation.

Also as a result of Hurricane Katrina, FEMA and the United Methodist Committee on Relief (UMCOR) partnered to create professional case management processes and posted the materials on the Katrina Aid Today website (<u>www.katrinaaidtoday.org</u>). These case management materials are a significant step forward in professionalizing community- and organization-based recovery assistance. The National Disability Rights Network participated as an agency, and its affiliates incorporated disaster case management into their activities, which was a new role for all (Stough and Sharp 2008). An evaluation of the NDRN's case management process found that "a substantial and significant number of NDRN cases were closed for the reason 'unable to resolve because of lack of resources' and were also statistically less likely to report that their needs had been met at the time of case closure" (Stough and Sharp 2008, p. 77). These disability cases required "deep casework" that "involved multiple needs," particularly durable medical equipment and health care services. The extensive case
management process cut into organizational resources and staff time considerably. However, it was clear in the evaluation that the experience contributed by a disability organization provided clients with knowledge and resources that made a difference. On the basis of Stough and Sharp (2008), the following best practices are recommended to institutionalize and strengthen case management services for people with disabilities:

- Updating the Katrina Aid Today (KAT) materials using insights from the various evaluations undertaken for KAT, including those concerning the National Disability Rights Network. This may require federal funding and support.
- Training case managers in disability organizations on disaster roles before an event to expedite case management afterwards.
- Paying careful attention to assessment procedures to identify unmet needs.
- Providing funding to involve disability organizations that are willing to engage in the case management process to offset their expenses, including staff wages.
- Supporting disability organizations in creating predisaster plans for postdisaster case management, continuity of operations, and MOUs to support their predisaster services in a postdisaster environment.
- Educating KAT partners on the roles of disability organizations and on disability issues in the case management process.
- Increasing the role of disability organizations in providing technical assistance to KAT partners.
- Training long-term recovery committees on their critical role in working with case managers on disability client issues. "Less than 5% of clients were recorded as having been referred to a long-term recovery committee" (Stough and Sharp 2008, p. 77).
- Linking disability case managers to concrete resources so they can help their clients.
- Reducing the paperwork required for the Coordinated Assistance Network to secure resources for clients.

Unfortunately, Katrina Aid Today has recently closed, and the case management materials and reports are no longer available. The website is no longer functioning. Efforts should be made to encourage the renewal of this critical resource.

Experts concur that the best approach to recovery, overall, is one that links all parts of an individual's personal, public, and professional life into an environment that affords greater protection. Toward that end, the following are general best practices for recovery:

- A holistic effort that links home, work, transportation, environmental equality, health care, and other critical services in a way that enhances and enriches the person's quality of life.
- Rapid debris removal that allows for a quick return home, restoration of utilities, and key services—all done in a way that does not jeopardize anyone's health further or cause new harm.
- Specific attention from and by voluntary organizations, including faith-based organizations that are active in providing resources and in rebuilding or advocating for displaced evacuees.
- Mitigation of future risk through structural and nonstructural means that do not cause displacement, can be affordably maintained, and are accessible (see next section).
- More diverse economic opportunities that allow for fuller involvement of people with disabilities.
- Attention to the economic and workplace issues and needs of people with disabilities, including job loss, loss of workplace owing to temporary relocation, and home-based work.
- A rebuilt community that features more accessible sidewalks, transportation, and workplaces.
- Participation of people with disabilities as volunteers, recovery managers, federal employees, and key players in the recovery process.

• Access to health, social, civic, cultural, and recreational opportunities during dislocation and in a rebuilt community.

Mitigation

As noted in Chapter 5 (Mitigation), this phase of the emergency management life cycle is another underexamined and minimally addressed area of concern. Publications and guidelines that emphasize mitigation and disabilities, such as the FEMA mitigation guides, address the topic only peripherally. Several best practices stand out as stellar examples of affording a higher degree of protection to people with disabilities, although only one is currently being implemented (see below).

Workplaces and public locations appear to be increasingly incorporating alternative warning devices as a way to mitigate risks for people with disabilities, although the extent of that effort remains unknown and is suspected to be low.

FEMA has issued a grant to the Baldwin County (Georgia) Association for the Mentally Retarded to build a safe room and harden a sheltered workshop. This appears to be the first grant of its kind. This is a best practice and should be fully funded and expanded because—

- It has the potential to save lives.
- It links mitigation protection directly to the population at risk on a daily basis and increases the likelihood that the population will be protected in a disaster event.
- It stands as a clear demonstration of federal commitment to the safety of people with disabilities.
- It has the potential to serve as a model for enhancing the public safety of extremely vulnerable populations.
- It has the potential to inspire other communities.

The Alabama Department of Senior Services has committed to opening a safe center for senior citizens. This involves the modification of a senior center so that it is a hardened and supported facility that can withstand high-wind events (tornado, hurricane). With its specially designed blue roof, the facility can be seen easily from a distance and can be used not only by local seniors but also by those traveling through the state. This is a best practice because—

- It provides a structural mitigation protection specific to a population with a high prevalence of disabilities. This practice is rare.
- It combines existing needs for senior centers with disaster protection features. This provides an economic benefit by using a facility for dual purposes.
- It links mitigation protection directly to the population at risk on a daily basis and increases the likelihood that the population will be protected in a disaster event.

Along the Gulf Coast, seniors and people with disabilities have been displaced because of post-Katrina rebuilding codes that require elevations. Such elevations have reportedly caused displacement specifically among populations with mobility disabilities and have undermined both independence and access to social networks and service providers. In the past, some voluntary organizations have provided support in building elevated homes with elevators for access. This is a promising practice because—

- It allows an individual to remain in his or her home and close to important sources of social and health support.
- It allows an individual to retain a connection to places that are culturally and historically meaningful.
- It allows an individual to remain independent.

However, it is unknown whether the elevator may cause the homeowner to incur additional expenses for maintenance or replacement. This may be a concern.

Mitigation best practices for people with disabilities include the following:

- Strategies that reduce future risks, such as bracing items that could fall and block exit from buildings.
- Enhancing rebuilt or newly built buildings (e.g., homes, offices, businesses, gyms, restaurants) with warning devices beyond standard fire alarms or smoke detectors.

CHAPTER 10: Policy, Program, and Practice Trends

Introduction

The purpose of this chapter is to identify, describe, and illustrate trends in policies, programs, and practices that affect, inform, or support people with disabilities in disaster situations. The chapter unfolds in three main parts. First, we examine trends related to policy and offer recommendations for improvements. Next, we describe programs that reveal promising trends already under way and recommend strategies to further institutionalize these trends to sustain transformative change. Finally, we look at practices that suggest that emergency management is headed in a promising direction. Examples consistent with the principles discussed in Chapter 8 (Implications from the Research) illustrate each area in policy, program, and practice trends.

This chapter also lays a foundation for Chapter 11 (Interventions). Several trends are clear. The first is that disasters tend to drive policies, programs, and practices, which is a reactive rather than a proactive trend. The second trend is that existing policies, programs, and practices tend to favor inclusion and partnerships as the initial strategies that will transform circumstances for people with disabilities in disaster contexts. The third trend is that efforts appear to be moving toward institutionalization of organizational structures (e.g., policies, committees, personnel positions) that can drive more significant change. The fourth trend is that some states are emerging as agents of change, although the means and the focus of those state-level efforts vary, especially those involving special needs shelters and evacuation. What appears to drive those trends is the nature of the local hazard, the availability of funding, and the willingness of partners to participate in preparedness efforts over time. The fifth trend is that relevant policies, programs, and practices tend to be developed by emergency management agencies, consulting companies, or similar organizations rather than by communitybased or local partnerships that include disability organizations and advocates. A stronger incorporation of these local partners is needed; evidence suggests that such a trend may be emerging, although it is somewhat limited at present. A sixth trend is that existing policies, programs, and practices tend to focus on integrating disability issues

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into disaster contexts. As an important agent of change, it is necessary for nondisaster policies, programs, and practices to reflect disability issues to a greater extent. New funding or efforts for infrastructure, economic aid, tax incentives, health care, child care, domestic violence, education, housing, sheltered workshops, and the like could and should reflect greater resilience to disasters. Initiatives could address structural and nonstructural mitigation efforts and feature accessible and affordable protective action options. By building stronger, disaster-resilient, and more accessible communities, facilities, and homes, we provide greater protection and a better quality of life for people with disabilities.

Policy Trends

Public policy primarily describes "what governments choose to do or not to do" (Dye 1987, p. 3). However, this simple definition may be just the tip of the iceberg as far as the impact of public policy. Public policy is more than just a set of rules or actions that governments choose to follow. Rather, it has the power to guide the direction and actions of an entire society. For example, monetary policy decisions concerning interest rates have a dramatic impact on the economy of the United States. This impact is evident across multiple sectors of our society. This indirect power is the most significant characteristic of public policy. Another example is Presidential Executive Order 13347. The order has been used by agencies, organizations, and advocates as proof of federal support for disability and disaster issues, and as a framework for actions and related practices. Though it is practically impossible to link change directly to this executive order, it is clear that the policy reflects a number of trends that have formed in the field, such as a push for inclusion, partnerships, and more comprehensive attention to disability and disaster issues. The order is also consistent with implications from research and encourages comprehensive transformation across the life cycle of emergency management. Therefore, Executive Order 13347 (and similar policies—see the section below on FCC policies) should be retained, strengthened, and enforced.

Public policies are generally crafted as reactions to an event or occurrence that has negatively affected a segment of society. One example was the impact of 9/11 on people

with disabilities, who experienced particular problems relating to evacuation, communication, search and rescue, and recovery. However, policies can also be the direct result of pressure from citizen groups, lobbyists, and other organizations looking to correct a perceived or actual inequality. These policies develop along various avenues, including presidential directives, legislative action, and legal rulings. In some cases, a policy may employ a proactive approach to an anticipated problem by instituting measures designed to prevent it altogether or mitigate its potential impact on society. Disasters historically have prompted change as opposed to policy serving as the transformative agent—a trend that is evident in much disability- and disaster-related policies, programs, and practices. To illustrate, policies in the field of emergency management tend to develop in response to issues and concerns. For example, portions of FEMA's Disaster Housing Strategy (released in January 2009) evolved as a result of issues that arose in connection with a lack of accessible temporary housing after Hurricane Katrina. This reactive trend needs to be replaced by more proactive efforts.

Changes in political leadership at all levels of government can have a dramatic impact on public policy. As the pendulum swings toward a new direction in government, opportunities to reshape and redirect public policy (not to mention society itself) abound. We stand on the doorstep of such an opportunity today. As our nation's leaders seek a new direction for this country, emergency management policies affecting people with disabilities must be evaluated and overhauled, when necessary, to reduce vulnerability to disasters. An opportunity now exists for policy to become a proactive tool, to serve not only as a reflection of past disasters but also as a means of significant transformation. Recommendations for policies described in this chapter are presented in the hope of encouraging such a movement; additional recommendations are presented in the final chapter, Chapter 11 (Interventions).

From a review of policies relevant to disasters and disabilities, it is clear that disabilityspecific policies can make a difference in improving emergency management procedures and protocols. In this chapter, we illustrate that potential by looking at three key policies: Executive Order 13347, which created the Interagency Coordinating Council (ICC); the

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draft Disaster Housing Strategy; and the Post-Katrina legislation, which created a disability position in FEMA. From the examination of these three initiatives, it is clear the trend in policy is one that may institutionalize disability matters into the federal and state bureaucracies associated with emergency management. Such policies may also offer a means by which partnerships can be created and strengthened, although some work may be needed to support ongoing development. On the other hand, policies that could transform nonemergency management sectors, especially those that are community-based and involve stakeholders with disabilities, have lagged.

Traditional policy evaluation seeks to measure a particular policy against specific criteria to determine its effectiveness. This is often a complicated task because of the broad influence of public policy. Many public policies can produce both positive and negative results. Thus, determining whether or not a particular policy or group of policies is effective may be a matter of perspective.

The ICC

One of the trends evident in policies related to disabilities and disasters is the creation of entities and positions that could institutionalize disability concerns. Institutionalization is key—it embeds concerns related to disability matters in organizational protocols or staff responsibilities so they are a permanent part of the federal bureaucracy. Executive Order 13347 (Individuals with Disabilities in Emergency Preparedness), issued on July 22, 2004, describes the establishment and function of the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC). The creation of the ICC was a significant step to ensure that the needs of people with disabilities are addressed in emergency management activities. However, since the ICC was established via executive order, it is vulnerable to extinction through similar executive action. The following is a list of recommendations pertaining to the ICC:

 The creation and function of the ICC should be made permanent. This could be accomplished by amending current legislation, such as the Stafford Act, or passing new legislation for this specific purpose.

- Additional power could be given to the ICC to oversee coordination of web-based portals, annual conferences, and/or an extended advisory board.
- The ICC should be broadened to include disability organizations and advocates and tasked with facilitating partnerships among government and nongovernment organizations, academia, policymakers, and practitioners.
- The ICC needs sufficient funding to serve as a coordinating entity and transformative agent.

Granting permanent status to the ICC will strengthen its status and further demonstrate the importance of disability issues to all levels of government.

National Disaster Housing Strategy

Now that the National Disaster Housing Strategy and its annexes (including special needs) have been published, it is recommended that the next steps—such as forming the National Disaster Housing Task Force and developing the Implementation Plan—begin right away. The following recommendations support this trend toward inclusion and accessibility regarding disaster housing:

- The intergovernmental working groups convened under the National Disaster Housing Task Force should include agencies/organizations with expertise on housing for people with disabilities. At the federal level, this would include representatives from agencies such as NCD and HUD, which have expertise in accessibility requirements and compliance. The strategy also recommends development of a state-level Housing Solutions Task Force, with representation from disability housing experts. These should include protection and advocacy agencies, state housing advocacy groups, State Independent Living Councils (SILCs), and other disability groups that manage housing issues for clients.
- Disability experts should be involved in the pilot programs referenced in the strategy from the outset, to ensure that disability issues are considered in all aspects of the program—development, implementation, and evaluation. The

National Centers for Independent Living should be a key partner at the federal level.

Task forces at the federal and state levels should adhere to a holistic, integrated approach to disaster housing in their work. The strategy addresses the importance of ensuring that infrastructure is in place where interim and permanent housing is located. This is critical for all persons but particularly for people with disabilities. For example, for some people with disabilities, physical accessibility of a housing unit is a requirement. However, that alone will not necessarily enable the person to live independently or safely. The person must also be able to access everyday resources, such as mailboxes, water stations, food distribution locations, and so forth. In addition, people with disabilities must be able to access employment, school systems, medical care, and other services. If the individual is cut off from these resources, he or she is likely to become isolated. The draft strategy must take this holistic approach into consideration.

The strategy also outlines the challenges to meeting the needs of people with disabilities in shelters. Several solutions are proposed that would likely increase capabilities at the local, state, and federal levels. The following recommendations support this important trend in postdisaster housing:

- In developing sheltering plans, emergency managers must work with representatives of special needs populations to ensure that their particular needs are addressed. This will help emergency management personnel identify a range of viable solutions to any potential problem and will enable them to harness resources that are readily available to special needs groups but not to emergency management professionals. This is necessary for both general population and special/medical needs shelters designed to support functional, medical, or other special needs.
- Since many shelter operations use existing building structures, funding needs to be made available to ensure that retrofitting and other modifications can be made so that any barriers are removed to make the facility more accessible when it is

used as a shelter. For example, public schools are often used as shelter locations. When a school undergoes modifications for any reason, accessibility standards can be implemented at the same time. This would require revision of local and state building codes for new school construction standards. Funding could occur in conjunction with the recently passed American Recovery and Reinvestment Act (the economic stimulus package of 2009).

The strategy refers to the importance of taking special needs populations into consideration when identifying interim or permanent housing stock.

- All interim or permanent housing that is built or rebuilt/reconstructed should meet at least minimal accessibility requirements. Exceeding those requirements will greatly benefit people with disabilities, those impacted by the disaster, and senior citizens. However, during a catastrophic disaster, when most or all of the infrastructure is destroyed, there is a strong urge in the community to rebuild quickly, and having to meet minimal accessibility standards when rebuilding is often seen as an impediment that slows down the process. Instead, this should be viewed as an opportunity to improve on the infrastructure's condition and ensure greater accessibility at the same time. When accessibility is taken into account from the outset, the cost and time factors are manageable and the overall rebuilding process goes more smoothly. Using universal design concepts when rebuilding communities benefits the general public as well as people with disabilities.
- Financial or other assistance provided to individuals for disaster housing should include supplements to the standard housing assistance and support and funding for accommodations and retrofitting. This assistance may include SBA loans, FEMA grants, and USDA and HUD funding streams.

National Disability Coordinator

Another notable change has been the creation of the national disability coordinator position in FEMA. The selection process for and responsibilities of the coordinator are defined in Section 513 of the Post-Katrina Emergency Management Reform Act of 2006.

- Recommendation: To institutionalize the trend toward staff positions representing disability interests, a description of this position's knowledge, skills, and abilities (KSAs) should be included in this section. At a minimum, the qualifications for this position should be similar to those of the regional FEMA administrators found under Section 507(b)(2). Special consideration should be given to applicants with emergency management experience coupled with extensive knowledge of disability issues.
- Similar positions should be included in the structure of the regional FEMA offices. Regional disability coordinators could enhance the effectiveness of the national disability coordinator by addressing more localized disability issues. Emergency management offices at the state, local, and tribal levels should be encouraged to establish similar positions in their respective jurisdictions.
- To strengthen the network of national and regional disability coordinators, these individuals should liaise closely with the voluntary agency liaisons to build connections to voluntary organizations that function under ESF #6 in the National Response Framework.
- Regional offices should create disability task forces led by the regional disability coordinator.

FCC Policies

Although policies have the potential to inform, mandate, and foster change, the gap between the ideas or concepts in a policy and achieving the intended result can be significant. An example of a non-emergency-management agency attempting to address disability-related issues in disasters can be seen in FCC policies. FCC rules generally require that the national emergency alert system (EAS) use both visual and aural alert methods. According to Section 79.2 of the Telecommunications Act of 1996, emergency information provided in the audio portion of the programming must be made accessible using closed captioning or other methods of visual presentation, such as open captioning, crawls, or scrolls that appear on the screen during emergencies. Emergencies have been broadened to include disasters, severe weather, civil disorders, and even school closings (FCC 2006). Other solutions include putting a written message on the screen, posting a map, or directly tracing the evacuation route.

According to an earlier Public Notice, FCC has received complaints from residents in several states regarding noncompliance (FCC 2001). Since 2003, the FCC has been making an effort to more aggressively monitor the accessibility of emergency notifications. As a result, following the 2003 California wildfires, three broadcasters were fined for noncompliance. In 2004, another broadcaster was fined for not complying during a severe weather event in Washington, D.C. Similar fines have been charged against broadcasters over the past several years. Unfortunately, compliance is so rare that the FCC decided to issue another Public Notice in both 2001 and 2006 to remind broadcasters of the regulation (FCC 2006). Although the FCC seems determined to increase compliance, it has received a number of complaints of noncompliance since the last Public Notice (NCD 2005). In short, policies can provide the potential for change, but enforcement for compliance is key. The following recommendations relate to FCC policies:

- Continue building awareness and understanding of the mandate among media outlets to increase compliance. Build awareness among public information officers (PIOs) who work with the media during emergencies.
- Build awareness of the FCC regulations in the disability community, particularly in the deaf and hard of hearing community, so individuals understand the regulations and the process for filing a complaint.
- Ensure that the FCC makes public the fines that are charged against broadcasters that do not comply with this regulation. This would serve to make

an example of the broadcaster's noncompliance and bring greater awareness to this issue.

- Require television stations to report the percentage of people with disabilities in their viewing area to increase awareness of local needs for captioning and audio description.
- The National Center for Accessible Media and the Rehabilitation Engineering Research Center on Telecommunications Access (RERC-TA), in testimony to the FCC in January 2006, stated that part of the problem is the ambiguous language in the regulations; they made several recommendations. One recommendation was that the commission "harmonize these various rules and requirements in clear and unambiguous language,"...in the belief that "a single, comprehensive, coherent and mandatory system of national, state, and local emergency alert requirements will provide effective and reliable delivery of accessible information." The testimony, along with their recommendations, is available for viewing at

http://tap.gallaudet.edu/Policy/FCC/WGBH%20and%20RERC%20EAS%20Com ments.doc.

- Continue to support recommendations that address concerns in the 2005 NCD report *Saving Lives*, including the implementation of more oral descriptions and aural tones for blind and low-vision individuals, enhanced nighttime coverage (disasters do not recognize time limits), the reading of emergency text information, and fines for those not in compliance.
- Add content on FCC policies to relevant courses (university, college, FEMA, USFA, and others) regarding accessible broadcasting for journalism, meteorology, emergency management, social science programs, and others that link to practitioners involved in emergency messaging.
- Encourage Congress to have the GAO investigate noncompliance with FCC policies.

As a related matter, the draft CPG 301 special needs guidance from FEMA also notes the importance of making 9-1-1 systems (including reverse 9-1-1) accessible via TTY or TDD; some limitations are expected among Internet-based forms of TRS (see FEMA 2009).

 Encourage adoption of the FEMA CPG 301 recommendation to "designate an alternative 9-1-1 PSAP [public safety answering point] that is more than 200 miles away to answer calls when the primary and secondary PSAPs are disabled."

On June 19, 2008, H.R. 6320 was introduced by Representatives Edward J. Markey (D-MA-7) and Heather Wilson (R-NM-1) to ensure that individuals with disabilities have access to emerging Internet Protocol-based communication and video programming technologies. The bill was introduced and sent to committee, but did not proceed further. It remains in committee and is gathering cosponsors. The bill summary amends two areas related to emergency communications:

- First, it revises provisions concerning any apparatus designed to receive or display television pictures broadcast simultaneously with sound to require that such apparatuses be capable of decoding closed captioning, delivering video description, and conveying emergency information, including EAS messages, in an accessible format for blind or visually impaired individuals.
- Second, it requires identification of methods that will be used to convey emergency information in an accessible format for blind or visually impaired individuals.

For these reasons, it is recommended that H.R. 6320 be reintroduced in the 2009 Congress.

Program Trends

This section addresses several trends and related concerns about some of the federal programs that influence both research and practice. In previous chapters, we identified

some other concerns with federal programs. For example, Chapter 4 (Recovery) examined federal programs such as Individual Assistance. This chapter looks at several major trends that indicate where attention is warranted, particularly with federal programs, in relation to people with disabilities.

A number of federal programs that fund research and practice make specific requests to potential grantees to increase the participation of people with disabilities. For example, the National Science Foundation encourages proposal writers to include people with disabilities on their team of researchers and graduate students. Despite this effort, participation numbers remain low. On the basis of comments from federal funders and reviewers, it is clear that a minimal number of proposals have been submitted that target disability issues specifically; in a highly competitive grant environment, such proposals may not receive funding. Some disability-specific mechanisms exist for funding (e.g., NIDRR grants, FEMA contracts), and they have been slowly increasing in number, a trend that requires additional support. Still, many funding streams could further expand their consideration of and requirements for disability issues in grants and contracts for both research and practice.

Since 9/11 and Hurricane Katrina, trends suggest that identification of problems has been followed by innovative efforts in subsequent disasters, including the activities of non-DHS agencies, to avoid or resolve such issues. At the height of Hurricane Katrina, members of low-income households, including seniors and individuals with disabilities, may have failed to evacuate because federal programs that provide entitlement checks do so only in the first few days of the month, and Katrina hit at the end of the month. Many of the individuals who receive these funds live from paycheck to paycheck and cannot afford to miss one. A recent trend that stemmed from Hurricanes Gustav and Ike was to release those checks early through the U.S. Postal Service. This is a positive example of a forward-thinking effort that spurs evacuation and should be supported. In addition, the checks should be cashable upon arrival. Research to assess the impact of that effort (e.g., to determine whether recipients run out of money for food and medicine earlier in the subsequent month) should be undertaken, coupled with appropriate recommendations for continuing the policy (e.g., the possibility of supplemental funds).

Overall, trends related to programs appear to be similar to trends involving policies in that programs are reactive rather than proactive. When it comes to funding grants and contracts, additional work is necessary to enhance compliance.

Transformative Recommendations for Federal Grant Programs

Federal grant and funding programs usually require recipients to meet certain requirements or goals to receive the funds. For example, Homeland Security Presidential Directive (HSPD)-5 (Management of Domestic Incidents) established the National Incident Management System (NIMS). This system is to be used by all federal, state, tribal, and local government agencies. In addition, the private and nonprofit sectors are strongly encouraged to adopt this national standard to ensure uniformity of operations during emergencies, especially complex multijurisdictional events. The adoption and implementation of NIMS by state, tribal, and local governments has become a mandated requirement to receive continued federal assistance with certain grants, contracts, and other activities.

The following recommendations address this area:

- Disability issues should receive similar attention. State, tribal, and local governments should be required to meet specific benchmarks with regard to addressing the needs of people with disabilities in emergency management activities. These benchmarks should then be included as conditions for continued federal assistance, much like the adoption of NIMS.
- Grants for research and community education should include similar guidelines for addressing disability issues. For example, federally funded research for studying the readiness of communities throughout the United States must include people with disabilities, since their data will differ from that of those without

disabilities. In addition, this requirement for including disability issues must be reflected throughout the entire grant process, from request to review.

To assist state, tribal, and local governments in their implementation of NIMS, FEMA has developed several guidance documents, such as the *2008 NIMS Compliance Objectives* and *the NIMS Five-Year Training Plan*. The documents outline specific benchmarks along with target completion dates.

The following recommendations support and extend these trends:

- Similar guidance documents could be developed to assist state, tribal, and local governments in addressing disability issues. Once these documents are developed, state, tribal, and local governments could be required to achieve and maintain certain levels of protection for people with disabilities as a condition of receiving assistance from the federal government.
- Additional incentives or bonuses could be used to entice state, tribal, and local governments to hasten full inclusion of disability issues in emergency management activities. Entities that commit additional resources to this effort would be rewarded for beating time lines for completing particular objectives.
- First responders should be required to develop, implement, and practice specialized rescue techniques for people with disabilities. This requirement could be included in the eligibility criteria for certain Homeland Security grants.

Federal Benefit Programs

Millions of people depend on federal benefit programs—such as Social Security Disability Insurance (SSDI), Social Security, Supplemental Security Income (SSI), Medicare, Unemployment Insurance (UI), Medicaid, Food Stamps, and Temporary Assistance to Needy Families (TANF)—to sustain themselves and their families. The loss of access to these life-sustaining programs often prevents individuals from acquiring necessary medications or medical services. Many people will go without proper nutrition and could become homeless without the aid of such programs. Disasters can create major disruptions in access to federal benefit programs. This was especially evident in the mass evacuation and relocation that followed Hurricane Katrina. Many problems occurred with regard to these programs after the storm, such as how to provide benefits to recipients who relocated throughout the 50 states, how to meet increased demand resulting from an increase in applicants, and how to rebuild damaged or destroyed office buildings, to name a few (GAO 2007). Many disaster survivors had to wade through hours and days of red tape to apply for or reestablish access to benefits.

A number of Katrina-specific bills and amendments were introduced to temporarily ease this situation. Among them was the Temporary Medicaid Disaster Relief Act of 2005, which was never passed. While the intent was commendable, such an effort would not fix the problem, as it centers on distribution. Lawmakers must instead adopt a proactive approach to solving disaster-related access to federal benefit programs.

Fortunately, some innovative trends and practices have arisen as a result of some of the major disasters that have occurred over the past few years. On December 31, 2008, FEMA launched the first phase of a new website, <u>www.disasterassistance.gov</u>, for use by individuals after federally declared disasters. The purpose of this website is to "improve and simplify access to information about disaster assistance by creating a central online location for all forms of federal disaster aid," and it allows for online registration for FEMA assistance as well as other programs. Currently, the following activities can be carried out:

- Applying for FEMA assistance and SBA loans through a single online application.
- Checking the status of applications.
- Having Social Security benefits redirected to a new address.
- Accessing federal student loan information.

FEMA plans to expand the website and include other forms of assistance and online applications (FEMA 2009a). (This website was developed as a direct result of Executive

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Order 13411, which was issued in response to problems accessing federal benefits after Hurricane Katrina.)

The following recommendations support this website:

- Ensure that all aspects of the website are 508-compliant, including information and online application processes.
- Be sure to distribute information about the website to the disability community at the federal and state levels, with instructions to pass it down to the local level.
- Test the website with individuals with disabilities and identify any barriers they
 experience. Use this feedback to make improvements to the website. Specifically
 test programs that people with disabilities are likely to access, in addition to the
 general disaster assistance programs, such as SSI or SSDI.

During Hurricanes Ike and Gustav in 2008, the Commissioner of Social Security released benefit checks ahead of the regularly scheduled payment date so they would get to recipients before the storms arrived and could be cashed immediately. With strong cooperation from the Postal Service, the Social Security Administration was able to deliver nearly 400,000 checks before Hurricane Gustav and more than 40,000 before Hurricane Ike (SSA 2008).

The following recommendations support this effort:

- The early release of benefit checks should become a standard operating procedure in the event of an imminent disaster (such as a hurricane).
- Additionally, efforts must be made to increase the number of recipients who
 receive benefits through direct deposit, so there is less dependency on mailed
 checks. This will be especially helpful in rapid onset events, when there is no
 time for early mailing.

Disaster assistance/recovery centers are established after a disaster and staffed with representatives from multiple agencies to make various disaster programs and forms of assistance available, such as emergency food stamps, emergency Medicaid, and Social Security. For people with disabilities to access these services, the facilities must be accessible and accommodations readily made. Often, the sites are not accessible, as documented after the 1994 Northridge earthquake (NCD 2005). These sites are often critical to accessing benefits that help people through recovery; without access to these sites (although access is increasingly being offered through phone and websites), many people will not receive the assistance for which they are eligible. In many instances, people would benefit from speaking directly with providers in person at a one-stop center rather than having to visit multiple sites or make repeated phone calls over a period of weeks.

Recommendations:

- When disaster centers are established, a combination of federal, state, and local assets can be used to ensure that site selection complies with accessibility requirements, such as those outlined by the ADA and ADAAG. People with expertise in this field should be brought in as part of the site selection team; this may include representatives at the federal level, including staff from the Equal Rights Office (working out of the joint field office during disasters); compliance experts from the General Services Administration (GSA); and staff from the Access Board. At the state and local levels, representatives from state protection and advocacy agencies such as SILCs, ILCs, and state and local offices of disability services can supply the expertise necessary to ensure compliance.
- In addition, these center staffing plans must include experts on working with people with disabilities who can help identify accommodation needs and fulfill requests to ensure equal access to available programs. Disability awareness training should be mandatory for all staff working in the center.

As examples of a promising trend (exhibited during several disasters, including the 9/11 terrorist attacks, Hurricane Katrina, and Hurricane Gustav), waivers were applied to various programs—such as Food Stamps, Unemployment Insurance, and Medicaid—to ease reconnection to existing benefits and expedite the processing of new applications. The waivers helped accelerate the review process to grant benefits to those who were eligible under their home state's programs but not the host state's programs. These waivers were instituted on a large-scale basis following Katrina. The need for reciprocity among benefit application processes from state to state has emerged as a major issue during recent large-scale disasters in which evacuees crossed state lines to relocate temporarily or permanently and experienced delays or denials in accessing benefits (Litaker Group 2006). Further complicating the matter is that some of the programs, such as SSI and SSDI, are administered through federal offices in each state, while others, such as Medicaid and TANF, are administered by state offices that have the authority to adjust eligibility criteria and benefits. As a result, the programs administered at the local level differ from state to state, and supplemental benefits that are available in one state (e.g., assistance with prescription drugs) may not be available in another. Each state delivers benefits differently, and coverage and eligibility often differ from state to state. This makes it difficult for evacuees to access services such as health care, durable medical equipment, and prescription medication after relocating. Funding for these programs has also been a problem, particularly when states exceed their budgets because of a sharp, unexpected increase in beneficiaries after a disaster.

According to the GAO, federal agencies have been required since 1999 to have plans in place to ensure that they could continue essential functions, such as benefit payments, in the event of an emergency. FEMA has provided guidance to federal agencies on this matter; however, the guidance does not specifically address continuity of operations planning (COOP) for state-administered programs. Some examples exist of federal mandates to ensure planning at the state level. The USDA, for example, is mandated by the Food Stamp Act to have plans in place at the state level; the USDA reviews these plans annually and runs exercises to test them. A report published by the GAO in 2007 indicated that because the Social Security Administration had strong continuity of

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operations plans in place (including alternative ways to access benefits, such as over the Internet), it was able to adjust staffing and meet the increased demand better than most state-administered programs. To date, there are no federal requirements for states to develop plans for programs such as UI, DIA, and TANF.

Fortunately, much work is being done through DHS and HHS to address these issues and improve access to these programs during disasters. The following recommendations could strengthen these efforts:

- Develop federal mandates that programs such as those listed above as well as those administered at the state level have strong emergency plans and continuity of operations plans in place.
- Encourage development of redundant or more flexible systems for processing applications and accessing benefits, such as Internet applications, debit card systems, and call centers. (As noted in the GAO report, these delivery options proved valuable after Katrina, although they were not without problems.) Ensure that these options are accessible and compliant with ADA regulations.
- Targeted research is necessary in this area to determine how to ensure ease in getting assistance from benefit programs for both existing and newly eligible recipients. Further research is warranted on how these issues were handled during recent disasters, such as Hurricanes Katrina, Rita, and Ike, in which large numbers of evacuees relocated temporarily or permanently outside of their states. Each benefit program needs to be looked at separately, as each is handled differently and has its own set of complications.

As a result of Medicaid policies limiting prescription drug supplies, many people go without access to necessary medications after a disaster. To counter this trend, it is vital to support NIDRR's recommendation that "more than the one month support for Medicaid drugs that are vital to maintain health is needed. A drug program for disasters needs to be developed" (NIDRR 2007). Disaster Relief Medicaid has been provided after a range of disasters, from the 9/11 terrorist attack (Kaiser Family Foundation 2002) to Hurricanes Katrina and Rita (Urban Institute 2006). More research needs to be conducted specifically regarding the implementation process, policies, enrollment, cost, and impact on disaster victims.

The Road Home

The Road Home program offers a unique approach to incorporating and addressing disability issues and other disaster-related special needs issues. The Road Home program, a multimillion-dollar HUD-sponsored disaster housing program created in Louisiana after Hurricanes Katrina and Rita, is a unique example of a recovery program for a number of reasons. The State of Louisiana, because of the enormity of the program (it is the largest disaster housing program in U.S. history), contracted a firm to carry it out. This strategy was unique in and of itself. However, even more interesting is that another firm was subcontracted to serve as special needs advisors to the director for all facets of the program. Initially, the role of this group was to focus on physical access to assistance centers around the state. But within days the role was expanded to include identifying and assessing ways to ensure that the entire program was accessible to all persons with disabilities as well as other special needs populations, such as the elderly, immigrant communities, and individuals with low literacy levels. This team's sole purpose was to look at all aspects of the program—the application process, hotlines, outreach, centers, and financial assistance—to identify and assess barriers to access. The team formed a steering committee made up of representatives from state and local disability organizations, government agencies, and other special needs populations to assist in identifying barriers and solutions. The trend toward inclusion of those with expertise in disabilities in such efforts needs to be integrated across all federally funded initiatives after a disaster.

Practice Trends

Since all disasters begin as local events, practice trends at this level tend to have the greatest impact on the direction of an event. As noted in Chapter 6 (Working with Emergency Managers), local emergency management offices are usually understaffed, and staff members spend most of their time addressing all the mandates and program

changes that flow down from the federal and state chains of command. For example, following the devastation of Hurricane Katrina, all jurisdictions were required to develop a mass evacuation plan. While this sounds like a good idea, most jurisdictions will never need to evacuate the majority of their population. Hundreds of staff hours were spent developing these plans while ignoring more practical planning at the local level.

Federal and state leaders could reduce these impediments to quality local planning by tailoring their mandates to fit the jurisdiction type instead of implementing blanket requirements, thus freeing up time for critical needs. For example, mass evacuation plans are needed in the coastal regions threatened by hurricanes but are not as practical for inland communities that are commonly threatened by sudden onset disasters such as tornados. Local hazard analysis should guide such planning, and it should include consideration of disability issues. Similarly, the likelihood of a terrorist attack is slight in many jurisdictions, yet emergency managers say it is easier to secure vehicles and protective equipment for biohazards than a stockpile of durable medical equipment for people with special needs. In addition, it is relatively easy to secure training grants for a radiological incident but not to train special needs shelter personnel.

The greatest stumbling block to local disability planning (besides manpower and funding) is finding people in the area who have expertise. This section briefly reviews basic trends that have increased expertise in disability issues among emergency managers, then reviews some promising practices in that area.

The Professionalization of Emergency Management

The FEMA Higher Education Program has pushed for the creation of professional degree programs across the United States, albeit without much funding. Despite the lack of funding, FEMA has been quite successful in developing college-level course materials and creating more than 100 programs that offer some type of certification or degree at the undergraduate or graduate level. These efforts have led to an annual conference that turns away applicants, a website and listserv (with more than 18,000 email addresses), and the formation of a network of people dedicated to

professionalizing the field. This FEMA program has funded the development of the first set of college course materials on socially vulnerable populations, which will be published as a textbook in 2009.

As Wayne Blanchard, director of the FEMA Higher Education Program, has written, there are two general types of emergency managers: the "older manager," who has not been exposed to education or training on issues of social vulnerability, including disability, and the "newer manager." Many of the newer managers have been exposed to the ideas of social vulnerability and to practices that can benefit people with disabilities. However, existing educational offerings fail across the nation to incorporate issues of disabilities as core content; rather, such content may be addressed in a single lecture or as a topic within a lecture on social vulnerability—and even that occurs only if a faculty member has expertise in the topic, which few do. To spur the progress necessary to update and transform the field of emergency management, the following actions need to be taken:

- Fund/sponsor the FEMA Higher Education Program so it will place disability issues on its annual conference agenda.
- Offer funding to faculty members at higher education/emergency management institutions and related programs across the country to create college courses, extension courses, and workshops to educate and train emergency managers in their respective geographic areas on disability issues.
- Offer scholarships and funded internships to students in degree programs who want to pursue careers in disability and disaster settings.
- Offer funding to faculty members in non-emergency-management programs to develop curriculum integration projects that put disability content into courses on meteorology, engineering, veterinary medicine, computer science, and other disciplines that contribute to an understanding of disaster practices (e.g., warnings, building performance and egress, service animals, communication technology).

Other drivers of professionalization include conferences and FEMA courses held at the EMI campus and online. As noted by NCD (2005, p. 12), "Information related to the emergency needs of people with disabilities...is not widely integrated into a number of general emergency management courses." A key recommendation is to do this through EMI residential courses, nonresidential courses, and online independent study courses. To propel the development of understanding and to inform practice, it is necessary to expand and update courses on disabilities:

- Update the G197 Special Needs FEMA course and offer the content via video streaming on the FEMA website or via DVD.
- Expand offerings of National Fire Academy course W275 (Fire Prevention for High-Risk Populations: Age and Disability Factors) as an off-campus course at regional or state locations, online, and as a DVD.
- Integrate long-term recovery issues into National Fire Academy pilot course P526 (Long-Term Recovery Planning).
- Build a connection among NCD, Fire and Emergency Services Higher Education (FESHE), and the FEMA Higher Education Program, and participate in their annual conferences to help transform relevant fields.
- Link NCD with other organizations and conferences or events that aim to promote an understanding of disability concerns, such as the National Hurricane Conference, the International Association of Emergency Managers, the National Emergency Management Association, and the National Voluntary Organizations Active in Disaster. These links could occur under the ICC umbrella.
- Provide cross-training and continuity of operations planning for disasters to disability organizations at all levels, from national to local.
- Identify key courses that require integration of disability content. FEMA's Independent Study Program, for example, could incorporate disability content into IS-1 (Emergency Program Manager), as well as the courses that address voluntary organizations, planning, recovery, animals in disaster (including service animals), citizen preparedness, incident command (special needs officer),

exercise design, and individual and public assistance. To expedite this, supplemental chapters could be offered as addendums until complete revisions are undertaken.

Preparedness

The most obvious trend in the preparedness phase has been to create and disseminate preparedness materials, primarily to individuals and households. While these documents have the potential to offer excellent advice, they can sometimes be hard to find, tend to disappear over time (especially those that are not on dependable websites), and may not make their way to intended audiences. It seems advisable that the extensive set of materials already produced be—

- Collected into a library or clearinghouse on disability and disaster preparedness—preferably one that is dependably online, such as FEMA, DHS, NCD, or NCIL. If one website serves as the primary location, all relevant websites should be clearly linked to it in order to connect the community of users to these materials.
- Disseminated widely to disability organizations and advocates, for use with their clients.
- Provided free to state and local emergency management agencies as hard copies for local distribution. Suggestions for how, when, and where to distribute these materials should be offered. It is not unusual to attend a state conference or visit a local office and find it difficult to locate many preparedness materials on disabilities.
- Offered as part of the range of materials available at all state and professional emergency management agency conferences as well as conferences hosted by disability organizations. A concerted outreach effort should be made to distribute these materials widely.
- Disseminated through utility statements, on grocery bags, at public locations, and through the faith-based community.

• Placed in municipal libraries throughout the nation; consider funding disability preparedness programs at libraries.

A second emerging preparedness trend is to train people with disabilities on emergency preparedness. The efforts in Pittsylvania County, Virginia, and Denver, Colorado, to train people who are deaf or hard of hearing to be members of Community Emergency Response Teams (CERTs) are shining examples of a promising trend. These efforts should be expanded. Recommendations to encourage others to join in this trend include providing the following:

- Funding for interpreters for local CERT training, including training exclusively for people who are deaf or hard of hearing, and better integrating people with disabilities into CERT and related training.
- A train-the-trainer program to increase the cadre of people across the nation who are able to offer disability-friendly preparedness training. Topics would include understanding accessibility issues, functional needs approaches, communications, and disability-specific needs during training.
- Funding for local training opportunities for CERT, Fire Corps, and related groups/efforts to include people with disabilities.
- Incentives for emergency managers and disability organizations to increase preparedness levels among local residents with disabilities. Examples include funding travel to professional conferences on disability issues, creating a Disability Preparedness Best Practices award to be awarded by FEMA CRCL/DHS Secretary/NCD, funding student interns to assist with disability preparedness initiatives, and funding (partially or fully) a disability issues position in an EMA. Benchmarks should be included to measure achievements and compliance.
- Funding for Go Kits for people with disabilities. The FEMA office for the federal disability coordinator indicates that these kits are currently under development.

This effort should be promoted. The Go Kits could be used as a reward to local jurisdictions that engage in best practices for disability preparedness.

A third preparedness trend is to tap into social networks to build capacity and create a more effective response and recovery system. The Division of Aging and Seniors within the Public Health Agency of Canada has focused on building bridges between gerontology and emergency management. As described in Chapter 8 (Implications from the Research), the effort involves creating networks to share knowledge and expertise. As a result, seniors have been increasingly involved in emergency management. The Guardian Program uses retired citizens to create a registry and an emergency alert system, and to communicate when telephone and power outages occur. A similar senior citizens group in Quebec involves seniors who are respected community leaders to help with home care, accompaniment, communications, matters of family crisis, and recreation. In the City of Winnipeg, the Good Neighbour Seniors Centre developed plain language programs and scavenger hunts to help seniors create home preparedness kits (Public Health Agency of Canada 2008). In the United States, the Western Illinois Agency on Aging established a Homeland Security Team using its Retired Senior Volunteer Program (RSVP) to involve people 55 years and older in creating preparedness materials and participating in preparedness and response efforts. "During the past year, more than 900 RSVP volunteers provided more than 125,000 hours of service to more than 100 community agencies or programs in their respective communities" (Western Illinois Agency on Aging 2008). In short, the trend is to increasingly involve people from vulnerable populations in their own preparedness efforts. This trend is consistent with principles described in Chapter 8 (Implications from the Research), which recommends the involvement and empowerment of those at risk and suggests the use of familiar and trusted social networks to motivate preparedness efforts. Such efforts should be monitored, evaluated, and modeled for widespread use.

An example that incorporates all of these trends (education, training, and involvement) comes from the Bergen County, New Jersey, CERT. In May 2008, Bergen County graduated its second Special Needs Emergency Response Team—

20 people with various disabilities were trained to be part of this team. The effort to integrate people with disabilities into preparedness activities should serve as a national model for best practices.

Response

Since Hurricane Katrina, the response phase has received more attention, in connection with disabilities, than any other phase in the life cycle of emergency management. Considerable efforts have gone into increasing capacities and training personnel on evacuation, transportation, and special/medical/functional needs sheltering procedures. Toward that end, FEMA and the DHS office of Civil Rights and Civil Liberties (CRCL) released a draft of the Comprehensive Preparedness Guide 301: Special Needs *Planning* (CRCL 2008, released August 15) as part of the Post-Katrina Emergency Management Reform Act. The intent of the guide is to focus on disabilities and other "special needs," as they are called in the plan. A very promising trend is found in this document on pages 4–5, where it mentions "special needs" as a "function-based approach...that addresses a broad set of common function-based needs irrespective of specific diagnosis, statuses, or labels (e.g., children, the elderly, transportationdisadvantaged)" (based on Kailes and Enders 2007). Functional areas typically include maintaining independence, communication, transportation, supervision, and medical care. However, the term "functional needs" is not in widespread use across the nation, except in jurisdictions that have engaged in considerable research and planning (e.g., New York, because of its functional/medical needs shelter approach).

CPG-301 provides general guidance for planning, including in the areas of registries, communications, sheltering and mass care, evacuation, transportation, human services and medical management, congregate settings, recovery, training, and exercises. The brevity of the guide does not allow for specific directions or protocols. Rather, the plan offers general guidance. Local jurisdictions, in particular, need detailed guidance on how to conduct basic planning for handling disability matters.

Other policy and planning initiatives under way include efforts to define terms for the National Response Framework and to add a special needs advisor to the incident command structure of NIMS; guidance for mass care; and a review of DHS grants programs to emphasize special needs. At the end of 2008, "the CRCL Disability and Special Needs team...received a Secretary's Team DHS Excellence Award along with the Federal Emergency Management Agency's (FEMA) Planning and Assistance Branch with whom they collaborated to develop [CPG 301]. This is one of the Department's most prestigious awards, as it identifies outstanding team achievements by employees working in a group to advance the mission of DHS. Cross-component teams are especially important in enabling the Department to meet and sustain its mission" (CRCL 2008).

The following recommendations support the trend of assisting with planning that includes disability concerns:

- Efforts should be made to ensure that guidance materials include sufficient and specific planning information that can be widely disseminated to state and local jurisdictions. For example, CPG-301 recommends that emergency managers "know the demographic profile of the community" (p. 7), but it does not specify how that can be accomplished. A more detailed approach to implementing CPG-301 is needed.
- Empirical research should be undertaken to verify that the recommendations in CPG-301 are sound. For example, the guidance describes the development of a registry but not the scientific basis for doing so. Such registries may be difficult or financially impossible to implement, or they may ineffective if not undertaken with sufficient care, interorganizational planning, and resources.
- Training must accompany these guidance materials.
- Funding and incentives will be required to support training on these guidance materials.

It is recommended that the cross-component teams within DHS and FEMA continue to collaborate and connect with other government and nongovernment entities, such as the NCD, ICC, National Organization on Disability, National Council on Independent Living, U.S. Administration on Aging (AOA), VA, and other relevant agencies, as well as disability and disaster researchers. Some of these agencies and organizations have developed guidance that can be adapted and updated for broader use, such as NOD's "red booklet" for state and local emergency managers. The ICC or CRCL could be vehicles through which collaboration can be facilitated.

A particularly noteworthy trend is that detailed guidance has been forthcoming from the federal government in key areas; for example, guidance from the Department of Justice that includes ADA-based recommendations for sheltering; and guidance from the FEMA CRCL on accessibility that is based on policies such as the ADA of 1990, the Fair Housing Law of 1968 as amended, the Rehabilitation Act of 1973 as amended, the Architectural Barriers Act of 1968, the Communications Act of 1934 as amended, and the Individuals with Disabilities Education Act of 1973 as amended. The trend has been to use existing laws and policies to provide guidance and motivate change. Much of this work has been triggered by events like Hurricane Katrina, supported by disability organizations and advocates, and pushed forward by federal agencies. It may be worthwhile to review these policies for applicable amendments and updates, including language that connects well with emergencies and disasters.

State-Led Efforts

Efforts move forward at the state level because of the persistence of disability advocates, the availability of funding, or the impact of a disaster. Sometimes change occurs because of the presence of a key person tasked with the responsibility of improving the circumstances of those at risk. The Emergency Management Ontario (Canada) office (EMO), for example, has a full-time diversity officer. In order to institutionalize a culture-wide change, the diversity officer convinced the office to financially support a service animal in training to raise awareness. The EMO also provides voluntary sign language

lessons at lunchtime. The intent behind these efforts is to sensitize emergency management personnel to basic issues in emergency management, such as communication, etiquette, and the importance of service animals and equipment, and to transform the perspectives and approaches of these staff members.

As described in Chapter 7, the State of Missouri established a Government, Faith-Based, and Community Partnership through an executive order issued by the governor. The order called for the creation of an emergency preparedness task force that would include people with disabilities. In going beyond sensitivity training to inclusion, the state took an important step. Organizations represented on the task force included state agencies, state-level collaborative groups, associations, councils, and the State Independent Living Council. The governor charged the task force with identifying and resolving gaps and barriers. As a result, cross-training occurred. The Missouri Centers for Independent Living helped by developing continuity of operations plans. Several agencies participated in creating strong sets of guidance materials for special/medical needs shelters (NCD 2008b). The task force has relied on existing training programs, including FEMA's G-197 course on special needs. In the end, Missouri established a set of best practices by—

- Using policy and government power to mandate an organizational structure to take on disability and disaster issues.
- Including an appropriate and strong set of partners with disability and disaster expertise.
- Building capacity by training nondisaster organizations.
- Bringing disability expertise into emergency management planning.
- Creating disaster-resilient partnerships through continuity of operations planning.
- Developing state-of-the-art guidance materials for targeted needs.

As another example of this trend, New Jersey's Special Needs Advisory Panel (SNAP) has partnered with the Statewide Independent Living Council and 12 independent living
centers, along with Project Freedom (an advocacy organization that promotes barrier-free housing and equality) to develop inclusive emergency preparedness plans. The panel helps to involve people with disabilities at all levels of government. The group recognizes that a disaster has the potential to cause individuals to lose their independence. Thus, the vision that drives their effort is the acceptance of personal preparedness as a tool for empowerment so people with disabilities can continue to live independently. This effort directly addresses the fear many people with disabilities have of losing their independence and reduces that fear by engaging them in planning and preparing.

Recovery

The recovery period typically garners the least attention, but this chapter identifies several promising trends and practices for both the short- and long-term recovery periods. As noted earlier, FEMA and DHS were sued over issues of accessibility involving temporary trailer units used after Hurricane Katrina. That lawsuit resulted in bringing disability advocacy organizations into the process to examine units, identify concerns, and support efforts to find accessible solutions. By involving local organizations that had expertise, dedication to the affected population, and a desire to resolve the problem, the recovery experience improved and well over 1,000 accessible trailers were provided. The trend to involve disability organizations in recovery efforts is completely defensible.

In concert with efforts to secure temporary housing, FEMA and the United Methodist Committee on Relief (UMCOR) partnered to develop a professional case management process through Katrina Aid Today. Case management after a disaster can be conducted by a wide range of persons, from local citizens trying to help to people with social work and related credentials. What changed after Hurricane Katrina was that a dedicated public-private partnership tackled a particularly challenging dimension of emergency management by ensuring that individuals, families, and households developed and implemented personal recovery plans. Another significant outcome of the Katrina Aid Today project was the creation of materials (made available online) to guide case managers through the recovery process, from intake and assessment to plan development, implementation, and evaluation. These materials are disasterspecific as opposed to being adapted from nondisaster contexts. They were used by disability organizations and case managers who worked with people with disabilities.

The following recommendations support the recovery phase:

- High-quality case management materials should be secured and disseminated widely. (The Katrina Aid Today project has ended and the website is no longer functional.)
- A training process should be implemented immediately after (and preferably before) a disaster to ensure that case managers conduct outreach to and work specifically with people with disabilities and disability organizations so that recovery plans are expedited and effective.
- Disability organizations should be informed of the availability of these materials for potential use with their clients.
- Federal funding to pay case managers who are trained and certified, particularly
 on issues of disability and recovery, should be made available (perhaps as part
 of the FEMA funding for those who experienced job loss). Preference should be
 given to survivors who have disabilities and to personnel in disability organizations.
- A cadre of local social workers and related professionals should be developed who are able to undertake case management after disaster. They should be integrated into predisaster recovery planning, training, and exercises. This cadre could be similar to the FEMA "gypsy corps" hired after a disaster to help with applications and disaster assistance.

Another promising practice that may be emerging in the recovery period is an effort to develop specific plans for those with special needs. After Hurricane Ike, DHS's Office for Civil Rights and Civil Liberties (CRCL 2008) assessed the impact as part of ESF #14 (long-term community recovery). The report said that "advocacy and case management" for people with disabilities could be needed for months or even years to "restore their

ability to live independently" (p. 11). Housing was another need; it will be partially addressed through the FEMA/HUD Disaster Housing Assistance Program for Ike by using public housing capabilities to help survivors regain permanent dwellings. The significant economic impact of the hurricane was recognized as another problem, particularly for those with low-incomes and marginal housing. The involvement of vocational rehabilitation agencies and community-based organizations was deemed crucial to identify qualified people with disabilities for new employment and economic opportunities. Although the report noted the significance of disability and community organizations as key participants in the recovery effort, it also noted the impact of the disaster on those partners. For example, independent living centers in East Texas sustained damage just when they were needed most. The rapid return of other resources, such as adult day care programs, was identified as a particular need.

The following recommendations to support the practice of after-action reporting:

- The impact and needs assessment report as conducted after Hurricane Ike should be retained as a crucial practice in ESF #14 and should be conducted after every presidentially declared disaster.
- ESF #14 should be linked with ESF #6 (mass care) to work jointly on identifying resources and linking them to long-term recovery organizations, task forces, and VOAD efforts.
- The federal government should recognize the significant role of community and disability organizations in postdisaster recovery, and these efforts should be supported financially.
- The after-action report (AAR) format should be retained and expanded. In addition to the topics of case management, housing, economics, health care, transportation, individual support, child and family support, education, and community access, the AAR should include psychological recovery and medication disruptions, Medicare/Medicaid disruption, infrastructure repair, mitigation measures (structural and nonstructural), caregivers and respite care, interpersonal violence, and communications.

Mitigation

The mitigation phase in the life cycle of emergency management is an area of significant concern. Although many structural and nonstructural mitigation measures increase the safety of people with disabilities, disability-specific mitigation efforts are underexamined and underfunded. Mitigation, in general, has sustained funding losses as the nation has swung its attention to preparedness and response, particularly after 9/11 and Hurricane Katrina. Ultimately, the cost of mitigation efforts will reduce the costs of response and recovery, although those benefits may not be observable in the near future in many locations. However, future generations will benefit from mitigation efforts we invest in now, and this could be done as part of a national effort to reinvigorate and strengthen the infrastructure. As bridges, roads, dams, and other structures are repaired or strengthened, the impact on people with disabilities must be considered. For example, making transportation arteries more accessible and providing more public options (which are more affordable) is one way to increase the potential for efficient evacuations in disaster.

To help safeguard those most at risk, the government should consider funding safe rooms in congregate care settings, shelter workshops, schools dedicated to students with disabilities, public housing, senior centers and senior housing, trailer parks and other low-income housing units, public housing, and other locations that serve people with disabilities or low incomes (such as seniors with disabilities). The Alabama Safe Center/Senior Center initiative is a stellar example of combining mitigation efforts, disaster safety initiatives, and senior support services in disaster and nondisaster settings. FEMA's funding of a safe room and a hardened workshop for the Baldwin County Association for the Mentally Retarded is another example.

At the same time, new mitigation measures must be assessed for the impact they could have on people with disabilities, such as the ramifications of elevations that reduce accessibility. Alternatives must be pursued, when warranted, so people can keep living independently and safely. The following are two brief examples of trends that could be supported:

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- A structural mitigation measure that involved elevations could also require affordable elevators or ramp alternatives for access (along with federal funding to defray the cost to an individual with a disability).
- A nonstructural mitigation measure could be the development of an insurance policy program for people with disabilities to reduce their overall losses and spur recovery.

It is essential that NCD and other agencies push for a new approach to disaster safety: the reduction of risk through mitigation measures.

Conclusion

Overall, practitioners and policymakers are moving in the right direction with regard to disability issues and emergency management. Policies are becoming more inclusive and are stressing the importance of addressing disability issues in all phases of emergency management. In practice, emergency managers are beginning to include people with disabilities in planning activities and address their needs in written plans.

However, disasters and the activities that surround these events test the strength and flexibility of even the best plans, and practitioners often revert to what they know best and return to old practices. While progress has been made, it has not yet been transformed into habit. Policies have laid the foundation to institutionalize some organizational forms (e.g., councils, committees, federal positions) and guidance documents (e.g., on housing, planning, shelters) that provide an initial pathway to transforming disaster experiences for people with disabilities. These policies must be retained, reinvigorated, funded, and expanded to truly embed change in the programs and practices of emergency management. As is often true after a disaster, opportunity exists for change. The next steps, which remain to be taken, are outlined in Chapter 11.

CHAPTER 11: Interventions

In this chapter, we transform recommendations from previous chapters into action steps for federal and state governments, starting with points of intervention that coincide with the Obama Administration's agenda (<u>www.whitehouse.gov</u>). The chapter offers local-level guidance by compiling and organizing recommendations for all four phases in the life cycle of emergency management: preparedness, response, recovery, and mitigation. The local section of the chapter can be seen as a checklist of action steps (from basic initial steps to the successful completion of rigorous efforts) that, when followed, can create a safer environment for people with disabilities. Other sections offer interventions at the organizational and individual levels. The final section outlines key recommendations for the type of research necessary to enhance our understanding of best practices for people with disabilities. All the interventions outlined in this chapter represent critical action steps that must be taken to ensure higher levels of safety for people with disabilities during an emergency or disaster.

The Obama Administration Agenda

President Obama's Administration could bring together key experts to leverage the existing work in the realm of disabilities and disasters. The White House could do the following:

- Convene a White House Summit on Disabilities and Disasters that includes government and nongovernment organizations, including disability organizations and leaders.
- Appoint and empower a permanent staff position to handle only disability-related matters inside the White House, including issues related to disasters.
- Fund capacity-building programs that tap community-based organizations linked to and actively involving people with disabilities in disaster preparedness, response, recovery, and mitigation activities.

Many problems faced by people with disabilities in disasters stem from income issues. By supporting and strengthening the economic independence of people with disabilities, it is possible to increase their disaster resiliency. President Obama's Administration offers a promising agenda that could benefit people with disabilities and foster such resiliency. Toward that end, some additional points deserve consideration in the existing agenda, many of which can be linked to disaster contexts:

- Affordable housing. Support and expand efforts to provide affordable, accessible, and disaster-resilient housing.
- **Civil rights.** Add disability discrimination protection to the current agenda, including in emergency planning and disaster service delivery.
- Disabilities. Integrate disaster management activities into the disability agenda. The Community Choice Act serves as a point of intervention by noting the importance of helping people with disabilities to remain independent after a disaster. Restore the preelection agenda item on the importance of special needs evacuation planning.
- Economy. Support businesses that hire or are owned by people with disabilities, including social enterprises that provide employment opportunities. Monitor job losses among people with disabilities after a disaster and offer new program solutions.
- Education. Create emergency planning and protective action training for teachers and staff working with students with disabilities, as well as for staff that have disabilities. Integrate these materials with those on the Department of Education and FEMA websites.
- **Families.** Offer an additional tax cut or vouchers to families with members who are disabled for purchase of emergency kits and related disaster supplies, including communication and evacuation resources.
- Health care. Support and expand efforts to provide those who are indigent or have low incomes with health and mental health care. Ensure that such care is available after a disaster. Offer additional funds to replace lost medications

through Medicare Part D. Create special insurance coverage or require insurance companies to cover equipment, assistive devices, and medical supplies lost in disasters. Help ensure that postdisaster health care is available to people with disabilities who are staying in shelters or temporary housing locations.

- Homeland security. Offer additional training for first responders and emergency managers on disability issues. Ensure that CPG-301 (special needs), CPG-302 (includes service animals), and DOJ shelter guidance are consistent with other planning guidance and that action steps are achievable. Hire qualified regional disability coordinators for the 10 FEMA regional offices. Require that all communication and warning systems have alternative formats and accessible features. Release the Federal Highway Administration guidance on special needs transportation evacuation.
- Infrastructure. Ensure that new or rehabilitated infrastructure includes significant accessible upgrades, such as additional accessible features, wider pathways, and audible alerts. Paratransit and public transportation should also improve accessibility. In addition—
 - As school construction projects are undertaken as part of any stimulus package, ensure that the structures are hardened for the probable hazards in the area and also have softer features that will support shelter operations.
- Poverty. Increase paratransit access for jobs. Include incentives to businesses to encourage them to hire people with disabilities. Increase the amount of accessible and affordable housing. Include areas with significant pockets of people with disabilities in the 20 Promise Neighborhoods.
- Seniors and Social Security. Protect both Social Security and Supplemental Security Income. Ensure that medical records are easily transferable after a disaster. Include supplements for disaster relief. Strengthen Medicaid, Medicare, and Medicare Part D—ensuring, in particular, that lost medications can be easily replaced at no cost to a disaster victim. Strengthen the long-term care options to include people with disabilities. Support volunteer efforts by seniors with disabilities.

- Service. Include volunteers with disabilities, especially in disaster contexts. Expand AmeriCorps to serve and involve people with disabilities in disasters. Engage people with disabilities in disaster training and provide funds to enable local emergency managers to do so. Create a disability position in the Corporation for National and Community Service and task that individual with overseeing disaster volunteerism.
- **Taxes.** Include a tax incentive or break to businesses that significantly enhance workplace safety for employees and customers with disabilities. Generate tax cuts for people with disabilities who engage in emergency preparedness or mitigation actions. Offer an additional tax cut to people with disabilities who are impacted by a disaster.
- Technology. In modifying the communications infrastructure, build in additional accessibility features and ensure that systems are in compliance with accessible devices. In the Lifelong Retraining Initiative, create opportunities for people with disabilities who want to switch careers to emergency management, and provide scholarships.
- Veterans. Ensure that veterans with disabilities return home with emergency preparedness training and kits relevant to their local hazards. Tap a VA administrator to liaise with FEMA and its national disability coordinator, and to serve on relevant boards and commissions.

Additional presidential interventions that should be considered:

- Strengthen Presidential Executive Order 13347. Mandate that the national disability coordinator liaise with the ICC. Develop a mechanism through which information can flow among the ICC, key national organizations (e.g., NVOAD), federal agencies, and state-level emergency management agencies.
- Reissue Executive Order 13411 (disaster benefits portal) to include federal agencies with disability expertise as members of the task force.

• Reissue Executive Order 12311 (disaster portal) to incorporate language specific to people with disabilities.

The American Recovery and Reinvestment Act of 2009 offers several inroads for improving the circumstances of people with disabilities. A search of the Act at <u>www.recovery.gov</u> (February 20, 2009) revealed no disability-specific initiatives. To leverage the Act to increase safety for people with disabilities in disasters, efforts might include the following:

- Incorporate accessibility features into infrastructure projects, including paratransit options, increased areas and seating for wheelchairs and other equipment, and wider pathways.
- Require that DHS and FEMA funding include disability initiatives.
 - For example, projects that fund Public Transportation Security Assistance, Port Security, and Railroad Security Assistance should consider people with disabilities, particularly their evacuation needs.
- Involve people with disabilities on review panels that consider requests for funding.
- Upgrade IT infrastructure at DHS and FEMA to expand accessibility.
- Involve people with disabilities, disability experts, and disability organizations on the arbitration panel under FEMA public assistance that is to expedite recovery from the Gulf Coast hurricanes.
- Use funding from the Hazard Mitigation Program to include safe rooms and other structural mitigation projects for people with disabilities.

Additional Federal Interventions

In this section, we present possible federal-level interventions, most of which are recommended for the Federal Emergency Management Agency. The lists do not imply

prioritization; rather, the numbers are inserted for ease of reading, especially for those using accessible formats.

General Interventions

- 1. Require that all DHS and FEMA grants and contracts require consideration of disability issues.
- 2. Recruit people with disabilities as volunteers in federal disaster projects or efforts and to serve on councils, boards, and similar entities.
- 3. Hire regional disability coordinators at all 10 FEMA regional offices. Ensure that the 10 coordinators have a wide range of expertise on disabilities, functional needs, and disaster management issues so they can better inform FEMA at the national and regional levels, and ensure a diversity of knowledge that can be drawn on from the full cadre.
- 4. Encourage all state governors to employ a state disability coordinator tasked with handling disability and disaster issues. Be sure this coordinator can work with county and local counterparts, and liaise with the regional disability coordinators to take issues up to the national disability coordinator.
- 5. Issue FEMA job position announcements with requests for knowledge of disability issues as a standard part of knowledge, skills, and abilities (KSAs).
- Review the authority in post-Katrina legislation (H.R. 5441) to strengthen the relationship between relevant federal agencies with disability expertise and FEMA; in addition to the National Advisory Council, task each regional administrator with creating a Regional Advisory Council.
- Involve relevant federal agencies with disability expertise on the National Disaster Housing Task Force.
- Integrate experts from FEMA, the National Science Foundation, the National Institute for Disability and Rehabilitation Research (NIDRR) and the National Academies Natural Disasters Roundtable, the National Fire Prevention

Association, and the American National Standards Institute into efforts to identify critical research questions and create new research funding streams.

- 9. Require FEMA and DHS to release all information and guidance materials in multiple types of accessible formats.
- 10. Involve the GAO in regular research on disability issues and disasters.

Training, Education, and Information

- 1. Establish a national clearinghouse for disabilities and disasters where information can be organized and archived into easily retrievable and accessible formats for individuals and organizations. Information should be organized into sections on preparedness, response, recovery, and mitigation. A federal agency should be tasked with routinely updating and disseminating content, including guidance materials, technical reports, and empirical research. Such a clearinghouse needs to provide information in multiple types of accessible formats. Include the International Association of Emergency Managers (IAEM) Special Needs Committee in an advisory capacity in this endeavor.
- 2. Offer grants for institutions to conduct curriculum transformation projects that integrate content on people with disabilities into courses in a meaningful and transformative way. When content is disaster-related, coordinate with the IAEM Special Needs Committee to be sure the message is consistent.
- 3. Develop empirically based, topical training materials on disability and disasters through a joint effort of relevant federal agencies and organizations such as the National Emergency Management Association and the International Association of Emergency Managers. Offer these materials through video streaming over the Internet and as DVDs for emergency managers and other trainers with minimal Internet resources.
- 4. Develop and offer a regular webinar series on disabilities and disasters, hosted by the Emergency Management Institute (EMI).

Preparedness

- Complete the Comprehensive Planning Guide (CPG) series that includes CPG 301 (special needs) and CPG 302 (includes service animals) to be consistent with CPG 101 (state and local guidance).
- 2. Adopt a functional needs approach to disability preparedness, response, and recovery efforts.
- 3. Continue to enforce and increase compliance with FCC policies regarding emergency communications and closed captioning.
- 4. Release (and update as needed) guidance materials on transportation evacuation of special needs populations through the Federal Highway Administration.
- 5. Develop even stronger relationships with faith-based and community-based organizations at the national level. Invigorate those relationships with mandates for increasing disability expertise and outreach.
- 6. Require the involvement of disability organizations and people with disabilities in any federal exercises (e.g., TOP-OFF).
- 7. Conduct annual reviews of the National Response Framework to update content for recent developments related to disability issues.
- 8. Fund research into evacuation devices for people with disabilities.
- 9. Fund collaborative initiatives between disability organizations and emergency management agencies.

Response

- Develop a cadre of FEMA personnel, coordinated under the national disability coordinator, who can deploy quickly to disaster sites to identify and address disability issues.
- 2. Task EPA with ensuring that debris management is carefully monitored for worker and public safety, and that accessible public information is disseminated

on the requirements for disposal and potential health effects of debris, particularly for people with disabilities.

- 3. Involve the U.S. Corps of Engineers (USACE), the military, and other relevant federal agencies in debris removal for prioritized areas, which may include congregate care facilities, health care centers, residential living centers, state schools, and similar locations.
- 4. Continue support of Katrina Aid Today case management processes and urge adaptation of these materials for disability issues.
- 5. Recognize case management as a critical response function.
- 6. Revise the FEMA website to offer more information to people with disabilities on all dimensions of disasters, particularly how to access Individual Assistance.
- 7. Expand the types of aid offered through Individual Assistance to support the purchase of critical medical equipment, assistive devices, and needs for service animals. Provide additional support to caregivers and guardians who may not have been directly affected by the disaster but do provide critical support to someone with a disability.
- 8. Flag Individual Assistance applications early to identify people with disabilities for follow-up contact by an employee with expertise in disabilities.
- Expand training at FEMA teleregistration and call locations to sensitize staff on disability issues and to ensure that critical information is captured for recovery assistance.
- 10. Expand temporary and mobile support of health care facilities, including mental health clinics.
- 11. Provide and expedite funding to allow for the purchase of lost medications and medical supplies and/or increase Medicaid or Medicare Part D coverage in disasters. Develop a Medicare Part D disaster policy to restore lost medications without cost to the patient.

- 12. Continue support of the Emergency Evacuation Task Force, especially to encourage the development of investigations into high-rise evacuations, including the use of elevators and alternative methods of exiting.
- Require a performance evaluation and assessment for all federal exercises and disaster responses as standard operating procedure for after-action reports on disability issues.

Recovery

- 1. Ensure that enough temporary housing units are available that are accessible and free from hazards (e.g., mold, formaldehyde).
- 2. Continue the use of the HUD National Housing Locator System in future disasters, especially because of its capability to inventory accessible units. Incorporate mapping features that show distance between units and accessible public transportation, health care facilities, banks, pharmacies, and other routinely used sources of support for people with disabilities. Include features that address issues related to service animals.
- 3. Mandate that congregate facilities have a recovery plan in place that expedites resident transfer to a new location.
- Provide disability supplements for Individual Assistance to help rebuild accessibility features in home construction. Offer additional grants with SBA funding for multifamily buildings to incorporate accessibility features.
- 5. Implement the National Disaster Housing Strategy, with particular attention to disability housing issues per the strategy's recommendations.
- Strengthen the relationship between the FEMA special needs desk and ESF #6 and ESF #14 when the National Response Framework is activated.
- Task the FEMA Voluntary Agency Liaison (VAL) to coordinate with the special needs desk and disability organizations, to identify disability concerns, and to link to resources.

- Strengthen the relationship between FEMA and the National Voluntary Organizations Active in Disaster (NVOAD). Integrate disability issues into regular meetings and conferences that involve NVOAD.
- Adopt a holistic approach to recovery and reconstruction that connects housing recovery to accessible public transportation, work environments, and health/social service sectors.
- 10. Require that recovery planning funded by federal agencies integrate and involve people with disabilities in a meaningful capacity.
- 11. Task SBA and other federal agencies to identify and provide recovery assistance to businesses that employ or are owned by people with disabilities.
- 12. Require that redesigned or rebuilt infrastructure offer more accessible features, such as wider pathways, auditory signaling systems, and tactile signage.
- 13. Require that the Access Board be involved when community redevelopment and planning takes place after a disaster to improve the level of newly built access; incorporate the concept of universal access when applicable.

Mitigation

- 1. Revise the FEMA 361 guidance material on safe rooms to include safe rooms that are accessible for individual, public, and congregate populations.
- 2. Fund mitigation projects to build or harden protective facilities for seniors and people with disabilities.
- Require mitigation-funded projects to undergo an impact assessment for the positive and negative consequences of such efforts and to identify alternative strategies.
- 4. Expand funding for mitigation projects, such as congregate safe rooms or hardened facilities for locations at risk (e.g., senior centers, sheltered workshops, group homes, and congregate settings). Replicate the Senior Center/Safe Center concept where applicable.

- 5. As schools are built, renovated, or substantially redesigned, require that the envelope be hardened according to the probable hazard (e.g. hurricane, tornado, ice storm, or earthquake) and that other measures be added to enable the facility to be used by the community as an accessible shelter. This includes matters involving power supply, the ability to hook up laundry equipment, and more restrooms.
- 6. Request that the International Code Council develop guidelines for safe rooms inside homes and public locations so that they are accessible.
- Continue to monitor and develop mitigation measures for newly appearing risks (e.g., pandemic, terrorism, and cyberattacks), and implement risk reduction techniques for people with disabilities.
- Revise the FEMA mitigation planning series to incorporate a fuller range of disability issues as well as the involvement of disability organizations and people with disabilities.
- 9. Develop a disability-specific mitigation planning guide.
- 10. Revise and reissue web-based informational materials on mitigation for public health and congregate care facilities.
- 11. Include consideration of people with disabilities in environmental justice assessments related to hazards.
- 12. In all federal facilities, require bracketing and other measures to secure cupboards, appliances, and other large items that can injure people or block egress when toppled.

State-Level Interventions

Again, the lists do not imply prioritization; rather, the numbers are inserted for ease of reading, particularly for those using accessible formats.

Preparedness

- Hire a disability and disaster coordinator for the state office of emergency management; task the coordinator with working with local emergency management agencies and liaising with the regional and national disability coordinators.
- Work closely with disability organizations and related social and health care organizations as well as independent living centers, state schools, and residential living facilities to build collaborative partnerships.
- 3. Create training programs for the media and area meteorologists on how to properly communicate information, particularly warnings, to people with disabilities.
- 4. Require the purchase of alternative warning devices along with any warning system purchase.
- Strengthen requirements for public places, including training personnel, installing alternative warning systems, and conducting disability-specific evacuation planning.
- 6. Develop state stockpiles and online inventories of assistive and adaptive equipment that can be deployed to support local efforts.
- 7. Task the state and local VOADs with increasing membership of disability organizations and volunteers with disabilities.
- 8. Task the state and local Citizen Corps with offering training on disabilities, integrating disability organizations, and involving volunteers with disabilities.

Response

- 1. Rescue service animals and equipment used by people with disabilities whenever possible as part of standard operating procedures.
- 2. Ensure that first responders deploy to rescues with proper equipment for locating, lifting, moving, and rescuing people with disabilities, their service animals, and equipment.

- 3. Involve disability agencies and organizations in sheltering efforts and, in particular, with case management and providing assistance in transitioning to the recovery phase.
- 4. Ensure compliance with the ADA and DOJ shelter criteria for shelters to promote access and accept service animals.
- 5. Involve social service agencies in outreach to identify health concerns and reduce the risk of prescription disruption, transfer trauma, and death.
- 6. Integrate public health agencies into assessments of new or worsening health problems (that may arise as a result of a disaster or that include disasters, such as pandemics) and linking clients to resources.
- 7. Prioritize debris removal and utility restoration to areas that serve people with disabilities, particularly those in congregate and residential living facilities.
- 8. Develop state programs to provide medical supplies and prescriptions to disaster survivors who lost theirs or who can no longer afford to replace them because of the financial burden of the disaster.
- Prioritize the development of accessible temporary housing for people with disabilities and ensure feasible connections to disaster assistance centers, workplaces, health care centers, pharmacies, rehabilitation centers, and public transportation.
- 10. Require a performance evaluation and assessment for all state exercises and disaster responses as standard operating procedure for after-action reports on disability issues.

Recovery

- Establish state task forces on disaster housing consistent with the National Disaster Housing Strategy.
- 2. Train case managers to work with Katrina Aid Today materials and to develop disability expertise. Monitor disability cases to ensure a high rate of closure.

- 3. Consider disability issues in preliminary damage assessments. Identify disabilityrelated needs when making requests for presidential disaster declarations.
- 4. Establish outreach programs for seniors and people with disabilities to support applications for Individual Assistance and case management.
- 5. Integrate disability navigators into recovery planning and case management.
- 6. Develop and support recovery task forces and case management processes that aim to conduct outreach and resolve disability-related issues.

Mitigation

- 1. Adopt stronger building codes that expand and strengthen accessibility standards for all reconstruction.
- 2. Promote underground burial of utility lines, where feasible, in direct relation to local hazards to reduce risk to power sources needed by people with disabilities.
- 3. Prioritize power restoration to congregate care settings, health care facilities, and other locations that host or provide critical support to people with disabilities.
- In all state facilities, require bracketing and other measures to secure cupboards, appliances, and other large items that can injure people or block egress if toppled.
- 5. Build public safe rooms in areas of high wind hazard and ensure that they are accessible.
- 6. Require safe rooms in all new construction and ensure that they are accessible.
- 7. Encourage the replication of Senior Centers/Safe Centers where feasible.

Local-Level Interventions—Organizational

Preparedness

 Create a working group that includes disability organizations and people with disabilities to review and recommend changes to existing or emerging plans for all phases of emergency management.

- 1.1. Planning must include emergency operations plans as well as long-term recovery planning.
- 1.2. Planning must incorporate reasonable accommodations per the ADA.
- 1.3. Assessments of local populations with disabilities, including the number of people with disabilities and their needs, should be conducted prior to planning. Regular updates of these numbers and needs should be incorporated into planning.
- 1.4. Review previous cases where emergency procedures have revealed issues in aiding disability populations (e.g., California wildfires, Hurricane Katrina), and incorporate the lessons learned and empirical research into current planning.
- 1.5. Plan on the basis of an understanding of the functional needs of people with disabilities. Emphasize strategies that maintain the independence of people with disabilities.
- 2. Conduct cross-training among emergency management agencies, first responders, and disability organizations on emergency procedures and disability issues.
 - 2.1. Diversify training to accommodate a range of disabilities and functional needs; include training on lifting, communications, interaction, and accommodations.
 - 2.2. Offer continuing education opportunities so personnel can stay abreast of changes in the field and new personnel can be prepared to assist when needed.
- Assess local organizational preparedness levels (including continuity of operations planning), conduct business continuity workshops, and create formal MOUs between disability organizations and emergency management agencies.
- 4. Identify funding sources for specific initiatives, such as the purchase of rescue and communications equipment for both organizations and individuals.
- 5. Organize collaborative efforts to write grant proposals to a wide variety of funders.

- Select, with the advice/consent of disability organizations, communications devices that are appropriate for a diverse set of disabilities, and conduct appropriate training on their use among relevant staff.
- Create educational programs on emergency preparedness and response actions for people with disabilities, and involve disability organizations in designing and disseminating such information.
- Involve people with disabilities in local training and make sure locations and communications are accessible (e.g., CERT, local emergency planning committees, Fire Corps, Medical Reserve Corps, VMAT).
- 9. Diversify warning messages by using a wider variety of technologies and partners to disseminate information. Train media and meteorologists on how to relay warning messages to people with disabilities. Involve disability experts in the creation and testing of warning messages. Ensure that 9-1-1 and reverse 9-1-1 systems are compatible with TTY use and with other technologies.
- 10. Inventory transportation assets, especially those that provide a diverse set of accessible accommodations and trained personnel. Develop MOUs with transportation agencies.
 - 10.1. Ensure that caregivers, guardians, assistive and medical equipment, and service animals are evacuated as needed with people with disabilities.
- 11. Evacuation planning
 - 11.1. Develop disability-specific evacuation protocols in advance of a disaster.
 - 11.2. Offer training to staffs at public places (e.g., shops, workplaces, recreational and sport settings, clinics) on how to write evacuation plans that include people with disabilities.
 - 11.3. Develop MOUs with local transportation companies and paratransit agencies for disaster evacuation. Develop and implement driver certification programs.

- 11.4. Identify the full range and number of people who may be in need of transportation. Map those populations in relation to transportation assets, evacuation routes, and reception centers or shelters.
- 11.5. Work with congregate care settings to design evacuation procedures for extremely high-risk populations under adverse conditions.

12. Registries

- 12.1. Carefully determine whether a registry is an appropriate means for supporting special needs populations. Among other questions, ask these: Can the registry be updated and maintained sufficiently to be of use? Is the registry coordinated with transportation agencies, first responders, and other organizations participating in evacuation or other response capacities?
- 12.2. Develop careful criteria to safeguard confidential information and to share the information appropriately with partners during use.
- 12.3. Conduct a thorough information-gathering and marketing campaign annually to keep the registry current.
- 12.4. Identify alternatives that may be more realistic and feasible, such as personal alert systems, use of 9-1-1 and 2-1-1, and use of placards.
- 13. Shelters
 - 13.1. Advertise information about the accessibility and support available in public shelters before an incident to convince potential evacuees that shelters are ready for them and can accommodate their equipment and service animals. Create a desirable evacuation destination but make clear that shelters are a last resort when all other personal options are not appropriate.
 - 13.2. Develop accessible general population shelters and consider functional needs shelter plans, such as those created during the drafting of the Target Capacities List.

- 13.3. Implement DOJ-recommended practices for ADA compliance in both general population and special needs shelters; support local and regional authorities in this effort.
- 13.4. Distinguish between general population and special needs shelters, and carefully develop protocols for intake and assignment to one or the other. Train staff and volunteers on disability issues, including lifting, functional needs, communication, maintaining independence, and service animals.
- 13.5. Provide information in a variety of communication formats, including sign language, written messaging, large-print displays, and tactile maps (to navigate in a shelter).
- 13.6. Designate times of day and places where foreign language and sign language interpretation will be available.
- 13.7. Stockpile additional supplies, including assistive devices, medications, equipment, and items for animals. Make every effort to reunite people with disabilities with their service animals, equipment, and family as quickly as possible.
- 13.8. Accept and accommodate all kinds of service animals.

Response

- 1. Activate response planning with the participation of disability experts, disability organizations, and people with disabilities.
- 2. Link response to community-based organizations that can provide support during warning, evacuation, and sheltering.
- 3. Activate diverse warning strategies to reach a wider population.
 - 3.1. Technologies to consider: television, radio, sirens, loudspeakers, tonealert radios, devices that provide vibration or visual strobe alerts, text messages, websites (accessible format), print media (including Braille and large-print), roadside electronic signs, placards, social networking sites,

open and closed captioning, phone trees (TTY), reverse 9-1-1 (TTYcompatible), sign language interpretation (and related devices), and email.

- 3.2. Interpersonal links to consider: social networks, health care providers, advocates, community organizations that link to people with disabilities, and people with disabilities or disability advocates.
- 3.3. Issue warnings as far in advance as possible to allow sufficient time for appropriate response. Clearly identify the risks of noncompliance.
- 3.4. Personalize messages for people with disabilities. Provide disabilityspecific information on what to do, how to take protective action, and what the risks are for noncompliance.
- 3.5. Provide support for taking protective action, including evacuation.
- 4. Evacuation
 - 4.1. Issue evacuation information in accessible formats, including alternative visual and audio formats (see warning checklist below for more ideas).
 - 4.2. Ensure that exit route signs are sufficiently diverse, including Braille, raised print, large print in high contrast, infrared systems with receivers and emergency power backup, and audible indicators at point of exit.
 - 4.3. Evacuate people with their medical equipment, assistive devices, motorized equipment, service animals, and (if relevant) caregivers or guardians.
 - 4.4. Involve people with disabilities in their own evacuation by asking them for advice and information on lifting, transfer, transportation, and related matters, if necessary.
- 5. Search
 - 5.1. Use alternative devices and strategies to alert or search for victims who may be unable to hear or see search and rescue personnel.

- 5.2. Look for signs that a person with a disability or a service animal may be trapped inside (e.g., ramps, assistive devices, door signs alerting personnel).
- 5.3. Interview neighbors and family members to locate people who are among the missing.
- 6. Rescue
 - 6.1. Incorporate special training in rescue techniques for first responders who may encounter people with disabilities, their service animals, and their equipment.
 - 6.2. Plan alternative places of refuge so people with disabilities have options to help them escape and survive.
 - 6.3. Use alternative rescue devices to avoid injury to people with disabilities.
 - 6.4. Ask people with disabilities about the best ways to lift, move, and transfer them, their service animals, and their equipment.
- Require a performance evaluation and assessment for all local exercises and disaster responses as standard operating procedure for after-action reports on disability issues.

Recovery

- 1. Become familiar with the limitations of federal and state assistance programs for people with disabilities.
- 2. Establish outreach strategies to encourage seniors and people with disabilities to apply for available aid packages.
- 3. Support the development of a local long-term recovery committee that includes people with disabilities and disability organizations.
- 4. Develop case management strategies that are sensitized to disability issues.
- 5. Advocate with state and federal officials for the needs of people with disabilities.

- 6. Work with local housing providers to ensure that both accessible and affordable temporary and permanent housing is available after a disaster.
- 7. Manage debris to reduce health hazards to the local population, especially those with health concerns that could be exacerbated through exposure.
- 8. Include disability organizations in grant applications.
- 9. Remember to involve workplaces that hire people with disabilities and include such businesses in efforts to provide postdisaster job and job loss assistance.
- 10. Require that recovery planning involve people with disabilities and disability organizations.
- 11. Build recovery on environmentally sensitive standards that reduce future exposures to hazardous materials.

Mitigation

- 1. Involve people with disabilities and disability organizations in mitigation planning.
- Secure funding to provide structural mitigation measures to increase safety (e.g., safe rooms, elevations that include ramps or elevators).
- Lobby workplaces and public locations to increase the number of alternative warning systems and implement protective actions, including evacuation planning for employees and customers.
- Invite community-based organizations to become involved in conducting mitigation assessments and risk reduction efforts (e.g., installing shelters, bracketing cupboards) in the homes and congregate care settings of seniors and people with disabilities.

Local-Level Interventions—Individual

Preparedness

1. Educate yourself about local hazards and emergency procedures. Take a class, request and read emergency preparedness materials, and think through the

implications for personal action. Take personal responsibility for emergency preparedness. Be prepared for a minimum of 72 hours on your own.

- Create individual preparedness plans for local hazards, along with appropriate emergency kits. Surveys indicate that up to 60 percent of individuals with disabilities do not have an emergency plan (National Organization on Disability 2001). Diversify your planning to include home, work, and public settings.
- 3. Identify and create emergency shelter-in-place and evacuation procedures for yourself and, if appropriate, your service animal. Ensure that personal equipment (assistive or medical devices and other items) can be taken along in an evacuation. Identify specific needs for additional supplies or equipment that should also be secured and taken during an evacuation (e.g., tire repair kit, batteries).
 - 3.1. Assess your personal need for support networks to assist with evacuation, and develop multiple backups for an assisted evacuation.
 - 3.2. Participate in local registries designed to support evacuation efforts, and update registry information when any changes occur (e.g., phone number, email, personal and work addresses, emergency contacts).
- 4. Create a special emergency preparedness kit and evacuation plan for service animals and pets.
- 5. Volunteer to help others (e.g., individuals, disability organizations, emergency management organizations) with emergency preparedness, response, and recovery actions.

Response

- 1. Evacuation
 - 1.1. Develop a personal evacuation plan for yourself, your service animal, and your medical equipment. Develop a backup plan in case the first plan fails.
 - 1.2. As needed, participate in registry efforts to assist with evacuation.

- 1.3. In case of a rapid onset event, know in advance the best ways to take shelter for yourself and your service animal.
- 1.4. Create a family and friends communication plan, including sending key paperwork and medical records to an out-of-state friend or family member. Follow other protocols described at <u>www.ready.gov</u> and related websites.
- 2. Shelter
 - 2.1. Work with the shelter staff to arrange appropriate accommodations. Explain your needs and expect ADA requirements to be followed.
 - 2.2. Take medical/mobility equipment, materials for a service animal, and other necessary items, including medications and medical records, to the shelter.
 - 2.3. Work with shelter case managers as needed to move out of the shelter and into temporary or permanent housing as soon as possible.
 - 2.4. Advocate for your best interests and those of others with disabilities in the shelter.

Recovery

- 1. Set aside funds in case you ever need money to replace critical equipment and other supplies/resources.
- 2. Retrieve copies of medical records from your family/friend as needed.
- 3. Replace lost copies of key paperwork, such as Social Security cards, Medicaid, and Medicare/Part D, as quickly as possible.
- Be assertive when contacting state and federal agencies to request assistance. Ask about additional support for lost items, service animals, and in recovering from the disaster.
- 5. Participate in the case management process of a long-term recovery committee, as needed, to address unmet needs.
- 6. Contact disability organizations so they can advocate for your needs and those of others with disabilities.

- 7. Monitor debris removal to ensure that there are minimal, if any, adverse effects.
- 8. Reestablish relationships with health care providers as soon as possible after a disaster.

Mitigation

- 1. Participate in local mitigation planning and advocate for the needs of people with disabilities.
- 2. Conduct a risk assessment of your home, workplace, and other routinely visited locations. Identify measures that can reduce your risks and implement them accordingly.
- 3. Support local emergency management agencies in their efforts to implement mitigation measures.
- Purchase insurance to cover all your significant needs, including home, car, service animal, and medical/mobility equipment. Assess insurance coverage for possible exclusions related to disasters.

Needed Research

To move forward the field of disabilities and disasters, a significant amount of research needs to be conducted. The list below is a summary of recommendations from previous chapters. A research agenda for disabilities and disasters could be honed for funding by the National Science Foundation, NIDRR, and the National Academies Disasters Roundtable. The following are initial questions for that agenda.

Preparedness

- What is the most effective emergency management office/division structure? Where should they be constructed and located? Should they be developed as independent offices or otherwise? What would be appropriate staffing levels for various population sizes/coverage areas/threats?
- 2. What type of credentials/education should staff in these offices have/obtain?

- 3. What are the most appropriate training procedures for people with disabilities and their effectiveness?
- 4. What is the effectiveness of buddy systems, and what are their failure points?
- 5. Registries, from initial setup through maintenance and implementation: Do they work?
- 6. Emergency management, homeland security, and fire protection/administration curricula, as well as related fields, including meteorology, engineering, and social services: Do they incorporate content on disability issues?
- 7. When it comes to congregate care settings, what are their levels of preparedness for rapid onset events, evacuating for major events, and implementing related patient or client support systems?
- 8. Emergency plans: Do they incorporate disability needs? To what extent do they involve disability experts and organizations, and service providers?
- 9. How well do emergency managers and first responders understand disability issues? Which knowledge transfer mechanisms work most efficiently to inform these key personnel?

Research or evaluation is also needed in the following areas:

- 1. Theoretical perspectives and models that do not comply with historically used models, including the medical model. In particular, research is needed on the functional model.
- 2. Curriculum assessments of existing content in relevant programs to discern the degree of integration of content on people with disabilities and to recommend solutions.

Response

1. Warning systems require assessments across the board for accessibility, alternative formatting, and use by people with disabilities and related

organizations likely to be involved in disseminating warning messages to people with disabilities.

- 2. What are the best strategies for conducting evacuations of nursing homes and other congregate or residential facilities?
- 3. Do registries work and, if so, under what conditions?
- 4. What kinds of evacuation procedures and systems are used by individuals, organizations, and jurisdictions? Which are the most effective?
- 5. How do people with disabilities evacuate from public buildings? What models can be designed to expedite egress? How can that information be transferred to the emergency management planner? What are the best strategies for evacuating from high-rise buildings or from public buildings such as malls?
- 6. What kinds of evacuation, search, and rescue devices work best from the perspectives of people with disabilities, first responders, and others who are likely to use them?
- 7. What are the best strategies for operating general population shelters so they can accommodate people with disabilities and service animals? What types of issues tend to arise, and how do shelter staff members accommodate those issues? What is the level of training for shelter staff on disability issues? What additional training must be developed and conducted?
- 8. What is the state of readiness in functional needs shelters at all levels, particularly rural locations? What existing plans for functional (medical, special) needs shelters exist, and how can they best be evaluated? What are the implications of the findings from such evaluations?

Recovery

 Recovery is the least researched phase overall, regardless of disability content. A thorough effort must be made to tap into all dimensions of recovery. These dimensions include the following:

- 1.1. Temporary housing. What kinds of temporary housing can be put in place to expedite the movement of people with disabilities out of shelters and into accessible temporary locations? What barriers exist, and what strategies best overcome those barriers?
- 1.2. Case management. What existing case management materials work best with disability issues? What are the reasons why more cases are not closed? What strategies can be identified to ensure greater resolution?
- 1.3. Debris management. What are the health issues involving debris management when it comes to people with disabilities? How does debris management affect other dimensions of recovery, including the ability to return home or regain independence?
- 1.4. Business recovery. How are businesses owned by people with disabilities affected by disaster? What kinds of issues are experienced by employees with disabilities during the recovery period? How are their jobs affected? How do federal job programs help people with disabilities (or not)?
- 1.5. Health. How are health care and mental health care accessed by people with disabilities after a disaster? What kinds of disruptions occur? What kinds of financial costs are incurred with regard to health care and mental health care? What are the best strategies for temporary and permanent restoration of health care, mental health care, and medication regimens?
- 1.6. Infrastructure. How can the recovery period encompass more affordable and accessible public transportation and paratransit options during recovery planning and implementation?
- 1.7. Volunteering. How well are disability organizations and individuals tapped to support disability concerns from the federal through local levels?
- 1.8. Housing. What are the barriers to regaining permanent housing, including for homeowners and renters? How do voluntary organizations work with people with disabilities and disability organizations to assist with rebuilding efforts? What reconstruction gaps remain (e.g., with group homes)?

- 2. What is the level of involvement of disability organizations in umbrella organizations, such as the National Voluntary Organizations Active in Disaster?
- 3. How well are disability organizations and people with disabilities integrated into volunteer centers before a disaster?
- 4. How do voluntary agencies connect people with disabilities into volunteer opportunities? What mechanisms most effectively integrate volunteers with disabilities?

Mitigation

- Research on mitigation and disability concerns is nonexistent. Anecdotal evidence suggests that some mitigation measures (e.g., elevations) may have the potential to both safeguard and displace people with disabilities. Research needs to be undertaken on the following:
 - 1.1. Structural mitigation measures need to be evaluated. Measures that strengthen the built environment and protect items from falling and obstructing pathways, as well as the location of structural measures (e.g., dams and levees vis-à-vis congregate populations) all represent potential areas of inquiry.
 - 1.2. Structural mitigation efforts that can potentially impact people with disabilities, such as elevation measures and the affordability of accessible features (e.g., elevators) need to be examined. Alternatives need to be identified to allow people with disabilities to retain independence and familiar living arrangements.
 - 1.3. Nonstructural mitigation measures, such as the affordability and availability of insurance for disability-specific needs, require examination. Additional nonstructural measures, including evacuation planning, information dissemination, and training, are discussed previously in this chapter.

1.4. Location-specific mitigation measures need examination, such as measures that increase safety in the workplace, public settings, recreational locations, and people's homes.
References

- Abramson, D., Stehling-Ariza, T., Garfield, R., & Redlener, I. (2008). Prevalence and predictors of mental health distress post-Katrina: Findings from the Gulf Coast Child and Family Health Study. *Disaster Medicine and Public Health Preparedness*, *2*, 77–86
- Aguirre, B. E. (1988). The lack of warnings before the Saragosa tornado. *International Journal of Mass Emergencies and Disasters, 6*, 65–74.
- American Foundation for the Blind. (2005). Carl Augusto blog: Access to Emergency Information. Retrieved from <u>www.afb.org/blog/blog_posts.asp?FolderID=19</u>.
- American Legion. (No date). *American Legion National Emergency Fund.* Retrieved October 16, 2008, from <u>www.legion.org/veterans/assistance/nef.</u>
- American Legion. (No date). *American Legion.* Retrieved October 16, 2008, from www.legion.org/homepage.php
- American Lung Association in California. (2008). American Lung Association urges people living near wildfires to protect themselves against staggering levels of unhealthy air pollution. Retrieved May 15, 2009, from www.californialung.org/media-center/news-archive.

American Red Cross. (No date). *Disaster preparedness for people with disabilities.* Retrieved March 5, 2008, from <u>http://www.redcross.org/www-files/Documents/</u> <u>Preparing/A4497.pdf</u>.

- American Society of Civil Engineers. (2005). *Report card for America's infrastructure.* Retrieved May 14, 2009, from <u>www.asce.org/reportcard/2005/index.cfm</u>.
- American Society of Civil Engineers. (2009). *Report card for America's infrastructure.* Retrieved May 14, 2009 from <u>www.asce.org/reportcard/2009/grades.cfm</u>.
- American Veterinary Medical Association. (2008). *Emergency preparedness and response guide*. Retrieved January 10, 2008, from <u>www.avma.org/disaster/emerg_prep_resp_guide.pdf</u>.
- Andrews, J. (2001). Safe in the 'hood: Earthquake preparedness in mid-city Los Angeles. *Natural Hazards Review, 2*(1), 2–11.
- Arya, A. S., Mandal, G. S., & Muley, E. V. (2006). Some aspects of tsunami impact and recovery in India. *Disaster Prevention and Management, 15*(1): 51–66.
- Augusto, C. (2005). Access to Emergency Information. Message posted to www.afb.org/blog/blog_comments.asp?TopicID+876&FolderID=19.

- Australian Council for International Development (ACFID). (2006). Tsunami disability issues. Retrieved May 14, 2009, from <u>www.acfid.asn.au</u>.
- Baptist Child and Family Services. (2008). Retrieved November 20, 2008, from <u>www.bcfs.net</u>.
- Barton, A. (1969). Communities in Disaster. Garden City, NY: Anchor.
- Bascetta, C. A. (2006). *Disaster preparedness: Limitations in federal evacuation assistance for health facilities should be addressed*. DIANE Publishing.
- Baxter International Foundation for the MidSouth. (No date). Baxter International Health Recovery Fund. Retrieved May 14, 2009, from www.fndmidsouth.org/Baxter/Fund.htm.
- Berggen, R., & Curiel, T. (2006). After the storm: Health care infrastructure in post-Katrina New Orleans. *New England Journal of Medicine, 354*(15), 1549–1552.
- Best Buddies. (No date). *About us.* Retrieved October 16, 2008, from www.bestbuddies.org/best-buddies.
- Blanchard, W. (No date). *FEMA higher education project manager discusses the generation of emergency managers.* Retrieved from www.training.fema.gov/EMIWeb/edu/highpapers.asp.
- Blanck, P. (No date). *Disaster mitigation for persons with disabilities*. Center for an Accessible Society. Retrieved May 14, 2009, from <u>www.accessiblesociety.org/</u> <u>topics/independentliving/disasterprep.htm.</u>
- Block, M., & Siegel, R. (2005). Gulf Coast rebuild to include levees, wetlands. *NPR's All Things Considered*. Retrieved from www.npr.org/templates/story/story.php?storyID=4851768.
- Bolin, R., & Stanford, L. (1990). Shelter and housing issues in Santa Cruz County. In R.
 Bolin (ed.), *The Loma Prieta Earthquake: Studies of Short-term Impacts*. Boulder, CO: University of Colorado Institute of Behavioral Science, Program on Environment and Behavior.
- Bourque, L., Siegel, J., Kano, M., & Wood, M. (2006). Weathering the storm: The impact of hurricanes on physical and mental health. *Annals of the Academy of Political and Social Science*, *604*(1), 129–151.
- Brookings Institution and Greater New Orleans Community Data Center. (2008). *The New Orleans Index anniversary edition: Three years after Katrina*. Retrieved August 31, 2008, from <u>www.brookings.edu/reports/2007/08neworleansindex.aspx</u>.

- Burby, R. (2006). Hurricane Katrina and the paradoxes of government disaster policy. Annals of the American Academy of Political and Social Science. March 2006, invited paper.
- Burnside, R., Miller, D. S., & Rivera, J. D. (2007). The impact of information and risk perception on the hurricane evacuation decision-making of greater New Orleans residents. *Sociological Spectrum*, *27*(6), 727–740.
- Byrne, M., & Davis, E. A. (2005). Preparedness for all, why including people with disabilities in drills is a learning tool: Interagency Chemical Exercise (I.C.E.). *IAEM Bulletin* (April).
- Cahill, A. (2006). *Planning tools you can use to meet the needs of people with disabilities in an emergency: What to do, what not to do, and what difference does it make?* Paper presented at the Working Conference on Emergency Management and Individuals with Disabilities and the Elderly, Washington, DC.
- California State Independent Living Council. (2004). *The impact of southern California wildfires on people with disabilities.* Retrieved March 3, 2008, from <u>www.calsilc.org/impactCAWildfires.pdf</u>.
- Canadee, R. M. (1997). Social conflict and urban rebuilding: The Portsmouth, New Hampshire, Brick Act of 1814. *Winterhur Portfolio, 3*(2/3), 119–146.
- Cashen, K. M. (2006). A compilation of necessary elements for a local government continuity of operations plan. Monterey, CA: Naval Postgraduate School.
- Catholic Charities. (2008). *HHS case management pilot update*. Retrieved October 23, 2008, from www.nvoad.org/Portals/0/Catholic%20Charities%20Update%20HHS%20Pilot.doc.
- Center for an Accessible Society. (No date). *Supreme Court upholds ADA "integration mandate" in Olmstead decision*. Retrieved September 19, 2008, from <u>www.accessiblesociety.org/topics/ada/olmsteadoverview.htm</u>.
- Center for Independence of the Disabled in New York (CID-NY). (2004). Lessons learned from the World Trade Center disaster: Emergency preparedness for people with disabilities in New York, September 2004. Retrieved October 16, 2008, from www.closerware.net/content/cidnyweb/Files/CIDNY_Views/ Reports/2004/WTCpaper.doc.
- Centers for Disease Control and Prevention (CDC). (2002). Self-reported increase in asthma severity after the September 11 attacks on the World Trade Center— Manhattan, New York, 2001. Retrieved January 15, 2008, from www.cdc.gov/mmwr/preview/mmwrhtml/mm5135a1.htm.
- Chapman-Henderson, L. (2008). *Commentary regarding the state of windstorm reduction impact program efforts.* Testimony before the Subcommittee on

Technology and Innovation, House Committee on Science and Technology, July 24, 2008.

- Childers, C. (2008). Elderly female-headed households in the disaster loan process. In B. D. Phillips & B. H. Morrow (eds.), *Women and Disasters: From Theory to Practice*. Philadelphia, PA: International Research Committee on Disasters.
- Christensen, K. M., Blair, M., & Holt, J. M. (2007). The built environment, evacuations, and individuals with disabilities. *Journal of Disability Policy Studies, 17*(4), 249–254.
- Christensen, K. M., Collins, S. D., & Holt, J. M., N. (2006). The relationship between the design of the build environment and the ability of egress to individuals with disabilities. *Review of Disability Studies, 2*(3), 24–34.

Citizen Corps. (No date). Retrieved July 14, 2008, from www.citizencorps.gov.

- City Cares. (2002). The effective practices guide to creating inclusive and accessible days of services. Retrieved October 30, 2008, from http://nationalserviceresources.org/files/legacy/filemanager/download/711/ InclusiveAccessibleService.pdf.
- Civil Rights and Civil Liberties Office (CRCL). (2008). *ICC monthly update* (vol. 4, no. 12). Retrieved May 26, 2009, from <u>http://listserv.access.gpo.gov</u>.
- Civil Rights and Civil Liberties Office (CRCL). (2008). *Hurricane Ike: Impact report.* Washington DC: Department of Homeland Security.
- Cleary, P. D., & Houts, P. S. (1984). Psychological impacts of the Three Mile Island accident. *Journal of Human Stress, 10*(1), 28–34.
- Coker, A. L., Hanks, J. S., Eggleston, K. S., Risser, J., Tee, P. G., Chronister, K. J., et al. (2006). Social and mental health needs assessment of Katrina evacuees. *Disaster Management and Response, 4*(3), 88–94.
- Comerio, M. (1998). Disaster hits home. Berkeley, CA: University of California Press.
- Cornell University Law School. *Olmstead v. L. C. (98-536) 527 U.S. 581 (1999).* Legal Information Institute. Retrieved July 14, 2008, from <u>http://supct.law.cornell.edu/supct/html/98-536.ZS.html</u>.
- Crandall, W., Bentzen, B., Meyers, L., & Easton, R. *Emergency information for people with visual impairments: evaluation of five accessible formats: Part III.* Smith-Kettlewell Rehabilitation Engineering Research Center.
- Curry, M. D., Larsen, P. G., Mansfield, C. J., & Leonardo, K. D. (2001). Impacts of a flood disaster on an ambulatory pediatric clinic population. *Clinical Pediatrics*, *40*(10), 571–574.

- Cutter, S. (2005). *The geography of social vulnerability: Race, class, and catastrophe*. Retrieved September 18, 2008, from <u>http://understandingkatrina.ssrc.org/Cutter</u>.
- Daley, W. R., Brown, S., Archer, P., Kruger, E., Jordan, F., Batts, D., et al. (2005). Risk of tornado-related death and injury in Oklahoma, May 3, 1999. *American Journal of Epidemiology*, *161*(2), 1144–1150.
- Dash, N., Morrow, B. H., Mainster, J., & Cunningham, L. (2007). Lasting effects of Hurricane Andrew on a working-class community. *Natural Hazards Review, 8*(1), 13–21.
- Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN). (2004). *Emergency preparedness and emergency access: Lessons learned since 9/11 and recommendations*. Retrieved May 10, 2008, from <u>www.nad.org/atf/cf/{A2A94BC9-2744-4E84-852F-D8C3380D0B12}/</u> <u>DHHCANEmergencyReport.pdf</u>.
- Department of Education. (2005). *Emergency evacuation of people with physical disabilities from buildings: 2004 conference proceedings.* Retrieved December 20, 2008, from <u>www.ncddr.org/new/announcements/pwd-emergency-evac.html</u>.
- Department of Health and Human Services (HHS). (No date). *Office of Disability, ADA Act fact sheet.* Retrieved May 13, 2009, from www.hhs.gov/od/about/fact_sheets/adafactsheet.html.
- Department of Health and Human Services (HHS). (2005). *Hurricane Katrina Bulletin: HIPAA privacy and disclosures in emergency situations*. Retrieved September 5, 2008, from <u>http://privacyruleandresearch.nih.gov/pdf/HurricaneKatrina.pdf</u>.
- Department of Health and Human Services (HHS). (2008). *HIPAA Privacy Rule: Disclosures for emergency preparedness—a decision tool*. Retrieved September 5, 2008, from <u>www.hhs.gov/ocr/privacy/hipaa/understanding/special/emergency/</u><u>source1n.html</u>.
- Department of Homeland Security (DHS). (No date). *Disabilities and other special needs: Massachusetts Emergency Management Agency's emergency information compact discs for residents who are visually impaired*. Retrieved July 1, 2008, from www.llis.gov.
- Department of Homeland Security (DHS). (2005). *Individuals with disabilities in emergency preparedness: Executive Order 13347 Annual Report, July 2005.* Retrieved November 1, 2008, from <u>www.icdr.us/documents/AnnualReport05.pdf</u>.
- Department of Homeland Security (DHS). (2007). *Lessons learned information sharing newsletter (March 2007)*. Retrieved July 10, 2008, from <u>www.llis.gov/displayContent?contentID=23748</u>.

- Department of Housing and Urban Development (HUD). (2001). *Faith-based* organizations in community development. Retrieved November 10, 2008, from www.huduser.org/publications/pdf/faithbased.pdf.
- Department of Justice (DOJ). (2006a). Americans with Disabilities Act: Chapter 1: ADA basics: Statute and regulations. Retrieved December 20, 2008, from www.ada.gov/pcatoolkit/chap1toolkit.htm.
- Department of Justice (DOJ). (2006b). *An ADA guide for local governments*. Retrieved April 16, 2008, from <u>www.ada.gov/emergencyprepguide.htm</u>.
- Department of Justice (DOJ). (2006c). Access for 911 and telephone emergency services. Retrieved May 13, 2009, from <u>www.ada.gov/911ta.htm</u>.
- Department of Justice (DOJ). (2007a). *Americans with Disabilities Act: Chapter 3: General effective communication requirements under Title II of the ADA.* Retrieved December 20, 2008, from <u>www.ada.gov/pcatoolkit/chap3toolkit.htm.</u>
- Department of Justice (DOJ). (2007b). *Americans with Disabilities Act: Chapter 4: 911 and emergency communications services*. Retrieved September 15, 2008, from <u>www.usdoj.gov</u>.
- Department of Justice (DOJ). (2007c). *Enforcing the ADA: A status report from the Department of Justice*. Retrieved April 16, 2008, from www.ada.gov/julsep07.htm.
- Department of Justice (DOJ). (2008). ADA best practices toolkit for state and local governments. Retrieved December 20, 2008, from www.ada.gov/pcatoolkit/toolkitmain.htm.
- Department of Labor (DOL), Office of Disability Employment Policy. (2008). *Part III: Breakout sessions: Individualizing emergency plans*. Retrieved July 3, 2008, from <u>www.dol.gov/odep/pubs/ep/part3g.htm</u>.
- Department of Transportation (DOT). (2006). *Catastrophic hurricane evacuation plan evaluation: A report to Congress*. Retrieved July 3, 2008, from www.fhwa.dot.gov/reports/hurricanevacuation/rtc_chep_eval.pdf.
- Disabilityinfo.gov. (No date). *Disability information*. Retrieved November 8, 2008, from www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=203.
- Disaster Center. (No date.) *The Disaster Center (1997–2007).* Retrieved November 1, 2008, from <u>www.disastercenter.com/agency.htm</u>.
- District of Columbia. (No date). *Fire and emergency medical services.* Retrieved May 14, 2009, from <u>http://fems.dc.gov/fems/site/default.asp</u>.

- Drabek, T. E. (1985). Managing the emergency response. *Public Administration Review, 45* (special issue), 85–92.
- Drabek, T. E. (1987). *The professional manager: Structure and strategies for success*. Denver, CO: University of Colorado.
- Drabek, T. E., & McEntire, D. A. (2003). Emergent phenomena and the sociology of disasters: Lessons, trends, and opportunities from the research literature. *Disaster Prevention and Management, 12*(2).
- Dye, T. R. (1987). Understanding public policy. Englewood Cliffs, NJ: Prentice Hall.
- Dyer, C. B., Regev, M., Burnett, J., Festa, N., & Cloyd, B. (2008). SwiFT: A rapid triage tool for vulnerable older adults in disaster. *Disaster Medicine and Public Health Preparedness 2* (supplement), S45–S50.
- Dyregrov, J. K., Kristofferson, A., & Gjestad, R. (1996). Voluntary and professional disaster workers. *Journal of Traumatic Stress, 9*(3), 541–555.
- Edward, F. L. (2007). Recovering from Katrina: A work in progress—2007. *The Public Manager, 36*(4), 67–72.
- Edwards, F. L., & Goodrich, D. C. (2007). Organizing for emergency management. In W. Waugh & K. Tierney (eds.), *Emergency management: Principles and practices* (2nd ed.). Washington, DC: International City/County Management Association.
- Elder, K., Xirasagar, S., Miller, N., Bowen, S. A., Glover, S., & Piper, C. (2007). African Americans' decisions not to evacuate New Orleans before Hurricane Katrina: A qualitative study. *American Journal of Public Health* 97 (supplement 1), S124–S129.
- Emergency Management Ontario, Canada. (2007). *Emergency preparedness guide for people with disabilities/special needs*. Retrieved May 14, 2009, from <u>www.ontario.ca/emo</u>.
- Enarson, E., & Morrow, B. H. (1997). A gendered perspective: The voices of women. In W. Peacock, B. H. Morrow, & H. Gladwin (eds.), *Hurricane Andrew: Ethnicity, gender, and the sociology of disasters* (pp. 116–140). London: Routledge.
- Enos, E. (2008). Custom frame. *Fire Chief.* Retrieved, from <u>http://firechief.com/leadership/public-education/custom_frames_0501</u>.
- Environmental Protection Agency (EPA). (1995). *Planning for disaster debris*. Retrieved January 15, 2008, from www.epa.gov/osw/conserve/rrr/imr/cdm/pubs/disaster.htm.

Erikson, K. (1976). *Everything in its path*. New York: Simon & Schuster.

- Fairbrother, G., Stuber, J., Galea, S., Pfefferbaum, B., & Fleischman, A. R. (2004). Unmet needs for counseling services by children in New York City after the September 11th attacks on the World Trade Center: Implications for pediatricians. *Pediatrics*, *113*(5), 1367–1374.
- Fazio, R. H. (1979). Motives for social comparison: The construction-validation distinction. *Journal of Personality and Social Psychology*, *37*, 1683–1698.
- Federal Communications Commission (FCC). (2001). *Public notice: Reminder to video* programming distributors of obligation to make emergency information accessible to persons with hearing or vision disabilities. Retrieved January 8, 2009, from www.fcc.gov/cgb/dro/reminder.pdf.
- Federal Communications Commission (FCC). (2006). *Public notice: Reminder to video* programming distributors of obligation to make emergency information accessible to persons with hearing or vision disabilities. Retrieved January 8, 2009, from http://hraunfoss.fcc.gov/edocs_public/attachmatch/DA-06-1483A1.pdf.
- Federal Emergency Management Agency (FEMA). (No date, a). *FEMA listing of disability needs*. Retrieved November 8, 2008, from www.fema.gov/plan/prepare/specialplans.shtm#resources.
- Federal Emergency Management Agency (FEMA). (No date, b). *IS 632: Debris* operations Retrieved January 15, 2008, from <u>http://training.fema.gov/EMIWeb/IS/is632.asp</u>.
- Federal Emergency Management Agency (FEMA). (No date, c). *FEMA's Project Impact making a difference*. Retrieved February 20, 2009, from <u>www.hurricaneville.com/project_impact.html</u>.
- Federal Emergency Management Agency (FEMA). (1995). *Emergency procedures for people with disabilities in office occupancy*. Retrieved April 19, 2008, from www.usfa.dhs.gov/downloads/pdf/publications/fa-154.pdf.
- Federal Emergency Management Agency (FEMA). (1999a). *Project Impact: Building a disaster-resistant community*. Retrieved, from www.fema.gov/news/newsrelease.fema?id=8895.
- Federal Emergency Management Agency (FEMA). (1999b). *FEMA lends an ear to the deaf on St. Croix in the aftermath of Hurricane Lenny.* Retrieved May 14, 2009, from <u>http://www.fema.gov/news/newsrelease.fema?id=8603</u>.
- Federal Emergency Management Agency (FEMA). (2002). *Orientation manual for first responders on the evacuation of people with disabilities.* Retrieved April 19, 2008, from <u>www.eadassociates.com/fa-235-508.pdf</u>.

- Federal Emergency Management Agency (FEMA). (2003a). *FEMA and the National Voluntary Organizations Active in Disaster partner in Citizen Corps.* Retrieved October 22, 2008, from www.fema.gov/news/newsrelease.fema?id=3060.
- Federal Emergency Management Agency (FEMA). (2003b). *G197: Emergency planning and special needs populations—student manual.*
- Federal Emergency Management Agency (FEMA). (2004). *Preparing for disaster for people with disabilities and other special needs*. Retrieved February 25, 2008, from <u>www.redcross.org/images/pdfs/preparedness/A4497.pdf</u>.
- Federal Emergency Management Agency (FEMA). (2005a). *Louisiana unmet needs committees bring help to Katrina survivors*. Retrieved October 22, 2008, from www.fema.gov/news/newsrelease.fema?id=21498.
- Federal Emergency Management Agency (FEMA). (2005b). *Mold can be a danger when evacuees return home*. Retrieved May 14, 2009, from www.fema.gov/news/newsrelease.fema?id=19302.
- Federal Emergency Management Agency (FEMA). (2007). *IS-1: Emergency manager: An orientation to the position*. Retrieved January 15, 2009, from <u>http://training.fema.gov/EMIweb/IS/is1Ist.asp</u>.
- Federal Emergency Management Agency (FEMA). (2008a). *FEMA History*. <u>www.fema.gov/about/history.shtm</u>.
- Federal Emergency Management Agency (FEMA). (2008b). *Rock Springs to host town meeting on flood recovery*. Retrieved September 27, 2008, from www.fema.gov/news/newsrelease.fema?id=45784.
- Federal Emergency Management Agency (FEMA). (2008c). SBA disaster loans can include money for mitigation. Retrieved February 20, 2008, from www.fema.gov/news/newsrelease.fema?id=41494.
- Federal Emergency Management Agency (FEMA). (2008d). *Interim emergency management planning guide for special needs populations*. Retrieved September 2008, from <u>www.fema.gov/pdf/media/2008/301.pdf</u>.
- Federal Emergency Management Agency (FEMA). (2008e). *Press release: FEMA launches consolidated website for disaster applicants*. Retrieved January 7, 2009, from www.fema.gov/news/newsrelease.fema?id=47195.
- Federal Emergency Management Agency (FEMA). (2008f). *First Mississippi voluntary organizations active in disaster conference*. Retrieved February 20, 2008, from <u>www.fema.gov/news/newsrelease.fema?id=42661</u>.

- Federal Emergency Management Agency (FEMA). (2009a). *FEMA in focus: Where FEMA is now, and where FEMA is going* (Twitter news release). Retrieved February 20, 2009, from <u>www.fema.gov/news/newsrelease.fema?id=47256</u>.
- Federal Emergency Management Agency (FEMA). (2009b). *National disaster housing strategy*. Retrieved February 20, 2009, from <u>www.fema.gov</u>.
- Federal Heights. (2007). *Resident lock box program*. Retrieved January 31, 2009, from www.ci.federal-heights.co.us.index2.php?option=com_content&do_pdf=1&id=79.
- Federal News Service. (2008a). *First Mississippi Voluntary Organizations Active in Disaster conference*. Retrieved October 24, 2008, from <u>http://proquest.umi.com.argo.library.okstate.edu/pqdweb?did=1432292661&sid=</u> <u>7&Fmt=3&clientId=4653&RQT=309&VName=PQD</u>.
- Federal News Service. (2008b). *Rep. Graves issues statement from hearing on FEMA's predisaster mitigation program.* Retrieved August 20, 2008, from: <u>http://proquest.umi.com.argo.library.okstate.edu/pqdweb?did=1480413551&sid=</u> 2&Fmt=3&clientId=4653&RQT=309&VName=PQD.
- Federal News Service. (2008c). SBA disaster loans can include money for mitigation. Retrieved August 20, 2008, from <u>http://proquest.umi.com.argo.library.okstate.edu/pqdweb?did=1509450481&sid=</u> <u>2&Fmt=3&clientId=4653&RQT=309&VName=PQD</u>.
- Feeding America. (No date). *About us.* Retrieved October 16, 2008, from <u>http://feedingamerica.org/about-us.aspx</u>.
- Fernandez, L. S., Byard, D., Lin, C. C., Benson, S., & Barbera, J. A. (2002). Frail elderly as disaster victims: Emergency management strategies. *Prehospital and Disaster Medicine*, 17(2), 67–74.
- Fink, B., Windon, R., Beaulaurier, R., Contreras, G., Dilley, L., & Kissane, R. J. (2001). Social service organizations and welfare reform. Retrieved October 16, 2008, from www.mdrc.org/publications/83/workpaper.html.
- Fothergill, A. (2000). Knowledge transfer between researchers and practitioners. *Natural Hazards Review, 1*(2), 91–98.
- Fothergill, A., Maestas, E., & Darlington, J. (1999). Race, ethnicity, and disasters in the United States. *Disasters*, *23*(2), 156–173.
- Fox, M. H., White, G. W., Rooney, C., & Rowland, J. L. (2007). Disaster preparedness and response for persons with mobility impairments. *Journal of Disability Policy Studies*, *17*(4), 196–205.
- Frieden, L. (2009). Personal communication.

- Gardner, E., & Hollman, S. (2005). *Press release: Landmark settlement requires* accessible evacuation procedures at all Marshalls stores nationwide. Retrieved February 20, 2009, from <u>www.eadassociates.com/marshalls.html</u>.
- Graves, S. (2008). *Rep. Graves issues statement from hearing on FEMA's pre-disaster mitigation program.* Hearing date: April 30, 2008. Retrieved February 20, 2008, from <u>www.iaem.com/committees/GovernmentAffairs/documents/</u> <u>OpeningRankingMemberGraves043008.pdf.</u>
- Gerber, B. J. (2007). Disaster management in the United States: Examining key political and policy challenges. *The Policy Studies Journal, 35*(2), 227–238.
- Godschalk, D. R., & Brower, D. J. (1985). Mitigation strategies and integrated emergency management. *Public Administration Review, 45,* 64–71.
- Government Accountability Office (GAO). (2006a). *Preliminary observations on the evacuation of vulnerable populations due to hurricanes and other disasters.* Retrieved March 3, 2008, from www.gao.gov/new.items/d06790t.pdf.
- Government Accountability Office (GAO). (2006b). *Hurricane Katrina: Status of the health care system in New Orleans and difficult decisions related to efforts to rebuild it approximately 6 months after Hurricane Katrina*. Washington DC: GAO-06-576R.
- Government Accountability Office (GAO). (2007). *Hurricanes Katrina and Rita: Federal actions could enhance preparedness of certain state-administered federal support programs*. Retrieved January 6, 2009, from www.gao.gov/new.items/d07219.pdf.
- Government Accountability Office (GAO). (2008a). National disaster response: FEMA should take action to improve capacity and coordination between government and voluntary sectors. Retrieved December 15, 2008, from www.gao.gov/new.items/d08369.pdf.
- Government Accountability Office (GAO). (2008b). Voluntary organizations: FEMA should more fully assess organizations' mass care capabilities and update the Red Cross role in catastrophic events. Retrieved October 23, 2008, from http://gao.gov/products/GAO-08-823.
- Hammitt, J. (1994). Earthquake! Coping with the aftermath can be a disaster, too, for people with disabilities. *Mainstream*. Retrieved February 20, 2009, from www.accessiblesociety.org/topics/independentliving/quake.htm.

Harris Interactive. (2004). *Emergency Preparedness Survey*.

Heinz Center. (2002). Human links to coastal disaster. Washington, DC: Heinz Center.

- Hemingway, L., & Priestly, M. (2006). Natural hazards, human vulnerability and disabling societies: A disaster for disabled people? *Journal of Disability Policy Studies, 2*(3), 57–67.
- Heppner, C. (2005). *Cheryl Heppner's remarks, National Council on Disability press conference.* Northern Virginia Resource Center for Deaf and Hard of Hearing Persons. Retrieved July 4, 2008, from www.nvrc.org/content.aspx?page=6994§ion=8.
- Herr, R. (2007). *CERT training for the deaf and hard of hearing in Denver*. Retrieved October 30, 2008, from <u>http://denver.yourhub.com/Denver/Stories/</u> <u>Community/Community-happenings/Story~377813.aspx</u>.
- Holdeman, E. (2005). Destroying FEMA. *WashingtonPost.com*. Retrieved from <u>www.washingtonpost.com/wp-dyn/content/article/2005/08/29/</u> <u>AR2005082901445 pf.html</u>.
- Huebner, K.M., Joffee, E., Prickett, J. G., & Welch, T. R. (1995). *Hand in hand: Essentials of communication and orientation and mobility for your students who are deaf-blind*. New York: American Foundation for the Blind.
- Huerta, F., & Horton, R. (1978). Coping behavior of elderly flood victims. *Gerontologist*, *18*(6), 541–546.
- Hyer, K., Brown, L. M., Berman, A., & Polivka-West, L. (2006). GrantWatch: Report: Establishing and refining hurricane response systems for long-term care facilities. *Health Affairs-Web Exclusive* 25(5).
- Independent Living Resource Center San Francisco. *Earthquake tips for people with disabilities*. [Electronic version]. Retrieved April 9, 2008, from www.preparenow.org/eqtips.html.
- International Center for Disability Information. (2005). *Project Safe EV-AC*. Retrieved July 4, 2008, from <u>http://evac.icdi.wvu.edu</u>.
- International Code Council (ICC). (2008). *ICC 500-2008: ICC/NSSA standard for the design and construction of storm shelters, American national standard*. Washington, DC: ICC.
- Jenkins, P., & Phillips, B. D. (2008). Battered women, catastrophe and the context of safety. *NWSA Journal, 20*(3), 49–68.
- Johns Hopkins University Center for Civil Society. (2008). *Fact sheet.* Retrieved October 16, 2008, from www.jhu.edu/listeningpost/factsheet/listeningpostfactsheet_august2008.pdf.
- Kailes, J. (2005a). Disaster services and "special needs": Term of art or meaningless term? *IAEM Bulletin, 22*(4).

- Kailes, J. (2005b). Why and how to include people with disabilities in your emergency planning process? Retrieved from <u>http://www.nobodyleftbehind2.org/findings/pdfs/FinalWhyandHow.pdf</u>.
- Kailes, J., & Enders, A. (2007). Moving beyond "special needs": A function-based framework for emergency management and planning. *Journal of Disability Policy Studies*, *17*(4), 230–237.
- Kaiser Family Foundation and United Hospital Fund. (2002). *New York's disaster relief Medicaid: Insights and implications for covering low-income people*. Retrieved January 15, 2009, from <u>www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=</u> <u>14137</u>.
- Kaiser Family Foundation. (2005). *Survey of Hurricane Katrina evacuees. Washington Post*, Kaiser Family Foundation, Harvard University. Retrieved from www.kff.org/newsmedia/upload/7401.pdf.
- Kansas Association of Local Health Departments. (No date). *Special populations: Web-based GIS system to assist community emergency planning for vulnerable populations.* Retrieved May 15, 2009, from <u>www.kalhd.org/en/cms/210</u>.
- Katrina Disability Information. (2008). Katrina disability information. Retrieved January 15, 2009, from <u>http://katrinadisability.info</u>.
- Kessler, R. (2007). Hurricane Katrina's impact on the health care of survivors with chronic medical conditions *Journal of General Internal Medicine*, *22*(9), 1225–1230.
- King, R.O. (2005). *Hurricane Katrina: Insurance losses and national capacities for financing disaster risk.* CRS Report for Congress.
- Klein, K. R., & Nagel, N. E. (2007). Mass medical evacuation: Hurricane Katrina and nursing experiences at the New Orleans airport. *Disaster Management and Response*, *5*(2).
- Kruglanski, A., & Mayseless, O. (1987). Motivational effects in the social comparison of opinion. *Journal of Personality and Social Psychology*, *53*(5), 834–842.
- Labadie, J. R. (1984). Problems in local emergency management. *Environmental Management, 8*(6), 489–494.
- Landrigan, P. J., Lioy, P. J., Thurston, G., Berkowitz, G., Chen, L. C., Chillrud, S. N., et al. (2004). Health and environmental consequences of the World Trade Center disasters. *Environmental Health Perspectives*, 112(6), 731–739.
- Lin, S., Reibman, J., Bowers, J. A., Hwang, S.-A., Hoerning, A., Gomez, M. I., et al. (2005). Upper respiratory symptoms and other health effects among residents

living near the World Trade site after September 11, 2001. *American Journal of Epidemiology*, *162*(6), 499–507.

- Lindell, M., & Perry, R. (2004). *Communicating risk to multiethnic communities*. Thousand Oaks, CA: Sage.
- Litaker Group. (2006). The health and medical response to Hurricanes Katrina and Rita by the Texas Department of State Health Services: After-action report.
- Litman, T. (2006). Lessons from Katrina and Rita: What major disasters can teach transportation planners. *Journal of Transportation Engineering*, *132*(1), 11–18.
- Loy, B., & Batiste, L. C. (2004). Evacuation preparedness: Managing the safety of employees with disabilities. *Occupational Health and Safety*, *73*(9), 112–117.
- Malievskaya, E., Rosenberg, N., & Markowitz, S. (2002). Assessing the health of immigrant workers near Ground Zero: Preliminary results of the World Trade Center day laborer medical monitoring project. *American Journal of Industrial Medicine*, 42(6), 548–549.
- Mattaini, M.A., & Lowery, C. T. (2007). *Foundations of social work practice.* Washington, DC: National Association of Social Workers Press.
- May, P. J. (1985). *Recovering from catastrophes: Federal disaster relief policy and politics.* Westport, CT: Greenwood Press.
- McEntire, D. (1999). Issues in disaster relief: Progress, perpetual problems and prospective solutions. *Disaster Prevention and Management, 8*(5), 351–361.
- McEntire, D. (2001). Triggering agents, vulnerabilities and disaster reduction: Toward a holistic paradigm. *Disaster Prevention and Management, 1*(3), 189–196.
- McLoughlin, D. (1985). A framework for integrated emergency management. *Public Administration Review, 45* (special issue), 165–172.
- Medford. *If someone requests a lock box*. Retrieved January 31, 2009, from www.medford.org/Pages/MedfordMA_Diversity/lockreg.
- Metz, W. C., Hewett, P. L., Muzzarelli, J., & Tanzman, E. (2002). Identifying specialneeds households that need assistance for emergency planning. *International Journal of Mass Emergencies and Disasters, 20*(2), 255–281.
- Metz, W., Tanzman, E., Nieves, L., & Holt, V. (2006). Preparing people with special needs for emergencies: The Alabama chemical stockpile emergency preparedness program (CSEPP) model. *Journal of Emergency Management, 3*(4), 36–48.
- Mileti, D. (1999). *Disasters by design: A reassessment of natural disasters in the United States*. Washington DC: Joseph Henry Press.

- Mileti, D., & Peek-Gottschlich, L. (2001). Hazards and sustainable development in the United States. *Risk Management, 3*(1), 61–70.
- Mileti, D., & Sorenson, J. (1990). *Communication of emergency public warnings: A social science perspective and state-of-the-art assessment*. Oak Ridge, TN: Oak Ridge National Laboratory and U.S. Department of Energy.
- Mitchell, L. (2003). Guidelines for emergency managers working with culturally and linguistically diverse communities. *Australian Journal of Emergency Management, 18*(1), 13–18.
- Morris, M., & Blanck, P. (2006). *Disaster mitigation and persons with disabilities*. Retrieved February 21, 2009, from www.ilru.org/html/training/webcasts/handouts/2003/08-27-PB/Transcript.txt.
- Morrow, B. H. (1999). Identifying and mapping community vulnerability. *Disasters,* 23(1), 1–18.
- National Council on Disability (NCD). (2005). *Saving lives: Including people with disabilities in emergency planning*. Retrieved July 14, 2008, from www.ncd.gov/newsroom/publications/2005/saving_lives.htm.
- National Council on Disability (NCD). (2006). *The impact of hurricanes Katrina and Rita on people with disabilities: A look back and remaining challenges*. Retrieved from www.ncd.gov/newsroom/publications/2006/hurricanes_impact.htm.
- National Council on Disability (NCD). (2007). National Council on Disability Quarterly Meeting, July 2007.
- National Council on Disability (NCD). (2008a). *National Council on Disability Quarterly Meeting, January 2008*, New Orleans.
- National Council on Disability (NCD). (2008b). *National Council on Disability Quarterly Meeting, October 2008*, Kansas City, Missouri.
- National Council on Disability (NCD). (2008c). *National Council on Disability Quarterly Meeting, July 2008*, Seattle, Washington.
- National Emergency Number Association (NENA). (2008). *NENA video relay service* and *IP relay service PSAP interaction OID*. Retrieved January 2, 2009, from <u>http://www.nena.org/sites/default/files/NENA52-</u> <u>502VRSIPRelayOID02122008.pdf</u>.
- National Fire Protection Agency (NFPA). (2007). *NFPA 1600: Standard on disaster/emergency management and business continuity programs.*
- National Governors Association. (1979). *Comprehensive emergency management*. Washington, DC: National Governors Association.

- National Institute on Disability and Rehabilitation Research (NIDRR). (2001). *Assessing the impact of Hurricane Katrina on people with disabilities*. Retrieved December 18, 2008, from <u>www.rtcil.org/products/NIDRR_FinalKatrinaReport.pdf</u>.
- National Oceanic and Atmospheric Administration (NOAA) National Severe Storms Laboratory. (2008). *Questions and answers: OK-WARN: Weather alert remote notification for the deaf and hard-of-hearing*. Retrieved December 3, 2008, from <u>www.nssl.noaa.gov/edu/safety/pagers.html</u>.
- National Organization on Disability (NOD). (2005a). *Emergency preparedness initiative: Guide on the special needs of people with disabilities for emergency managers, planners, and responders*. Retrieved July 4, 2008, from <u>www.eadassociates.com/epiguide2005.pdf</u>.
- National Organization on Disability (NOD). (2005b). *Special Needs Assessment for Katrina Evacuees project*. Retrieved December 18, 2008, from <u>www.nod.org/emergency</u>.
- National Organization on Disability (NOD). (2007). *People with disabilities unprepared for terrorist, other crises at home or at work, new poll finds: Anxiety levels also run higher in this population segment.* Retrieved June 14, 2008, from www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=507.
- National Service Inclusion Project. (No date, a). *Emergency preparedness and people with disabilities*. Retrieved December 1, 2008, from <u>www.serviceandinclusion.org/index.php?page=emergency</u>.
- National Service Inclusion Project. (No date, b). *The benefits of inclusion.* Retrieved February 20, 2009, from <u>http://communityinclusion.org/surveys/nsip_story</u>.
- National Voluntary Organizations Active in Disaster (NVOAD). (2004). *Long-term* recovery manual. Retrieved October 30, 2008, from www.nvoad.org/Portals/0/LTRManualFinalApr232004a.doc.
- National Voluntary Organizations Active in Disaster (NVOAD). (2008). *National Voluntary Organizations Active in Disaster*. Retrieved October 20, 2008, from <u>www.nvoad.org</u>.
- Natural Hazards Center (NHRAIC). (2001). *Holistic disaster recovery*. Boulder, CO: NHRAIC and Public Entity Risk Institute.
- Natural Hazards Center (NHRAIC). (2005). *Holistic disaster recovery: Post-Katrina edition*. Boulder, CO: NHRAIC and Public Entity Risk Institute.

Neal, D. (2008). Personal communication.

Neal, D. M. (1997). Reconsidering the phases of disaster. *International Journal of Mass Emergencies and Disasters, 15*(2), 239–264.

- Nemery, B. (2003). Reactive fallout of World Trade Center dust. *American Journal of Respiratory and Critical Care Medicine, 168,* 2–3.
- Newport, J. K., & Jawahar, G. G. P. (2003). Community participation and public awareness in disaster mitigation. *Disaster Prevention and Management, 12*(1), 33–36.
- Nigg, J. M., Barnshaw, J., & Torres, M. (2006). Hurricane Katrina and the flooding of New Orleans: Emergent issues in shelter and temporary housing. *Annals of the Academy of Political and Social Science, 604*(1), 113–128.
- Norris, F. H., Friedman, M. J., & Watson, P. J. (2002). 60,000 disaster victims speak: Part II. Summary and implications of the disaster for mental health research. *Psychiatry* 65(3), 240–260.
- Norris, F. H., Friedman, M. J., Watson, P. J., Byrne, C. M., Diaz, E., & Kaniasty, K. (2002). 60,000 disaster victims speak: Part I. An empirical review of the empirical literature. *Psychiatry*, *65*(3), 207–239.
- Nosek, M. (2008). Riding out Ike on a vent, Testimony before Select Committee on Hurricane Ike Storm Devastation to the Texas Gulf Coast, November 10, 2008.
- Ocbbound (screen name). (2007). Emergency preparedness. Message posted to <u>www.afb.org/message_board_replies2.asp?TopicID=3124&FolderID=34&modes</u> <u>=sseniorsite</u>.
- Office of Emergency Preparedness and FEMA Federal Contractor. (2008). Overview of AMR/FEMA Federal National Ambulance Service support. Retrieved January 10, 2009, from <u>www.fema.gov</u>.
- Oklahoma ABLE Tech and Fire Protection Publications. (No date). Social etiquette: Tips for firefighters who work with people with disabilities.
- Oklahoma Office of Emergency Management. *OK-Weather Alert Remote Notification.* (No date). Retrieved January 14, 2009, from <u>http://www.ok.gov/OEM/Programs & Services/Preparedness/OK-</u> <u>Warn for the Deaf and Hard-of-Hearing/index.html</u>.

Oregon Partnership for Disaster Resilience. http://www.oregonshowcase.org.

- Parle, W., & Brown, A. (2005). *Educational Needs Survey Report*. Retrieved September 9, 2008, from <u>www.training.fema.gov/EMIWeb/edu/surveys.asp</u>.
- Parr, A. (1987). Disasters and disabled persons: An examination of the safety needs of a neglected minority. *Disasters, 11*(2), 148–159.

- Parr, A. (1997). Disasters and human rights of persons with disabilities: A case for ethical disaster mitigation policy. *Australian Journal of Emergency Management*, *12*(4), 2–4.
- Perilla, J. L., Norris, F. H., & Lavizzo, E. A. (2002). Ethnicity, culture, and disaster: Identifying and explaining ethnic differences in PTSD 6 months after Hurricane Andrew. *Journal of Social and Cultural Psychology, 21*(1), 20–45.
- Phillips, B. D., & Morrow, B. H. (2007). Social science research needs: Focus on vulnerable populations, forecasting, and warnings. *Natural Hazards Review*, 8(3), 61–68.
- Phillips, B. D., Metz, W. C., & Nieves, L. A. (2005). Disaster threat: Preparedness and potential response of the lowest income quartile. *Environmental Hazards, 6*(3), 123–133.
- Phillips, B. D., Thomas, D., Fothergill, A., & Blinn-Pike, L. (eds.). (2009). Social vulnerability to disasters. Boca Raton, FL: CRC Press.
- Pike, L., Phillips, B. D., & Reeves, P. (2008). Shelter life after Katrina: A visual analysis of evacuee perspectives. *International Journal of Mass Emergencies and Disasters*, *24*(3), 303–330.
- Platt, R. H. (1999). Disasters and democracy. Washington, DC: Island Press.
- Points of Light Foundation and Volunteer Center National Network. (2002). *Preventing a disaster within the disaster: The effective use and management of unaffiliated volunteers*. Retrieved November 20, 2008, from http://www.pointsoflight.org/downloads/pdf/programs/disaster/disasterbook.pdf.
- Powell, W. W., & Steinberg, R. (2006). *The nonprofit sector: A research handbook* (2nd edition). Westport, CT: Yale University Press.
- Prickett, B. (2005). *Louisiana school for the deaf*. Retrieved July 14, 2008, from www.audiologyonline.com/News/news_detail.asp?news_id=1842.
- Project Safe EV-AC. (No date). *Project Safe evacuation and accommodation for people with disabilities.* Retrieved May 14, 2009, from <u>http://evac.icdi.wvu.edu</u>.
- Public Entity Risk Institute. (2008). *Date resource library: Understanding the volunteer protection act*. Retrieved November 20, 2008, from www.riskinstitute.org/peri/index.php?option=com_bookmarks&task=detail&id=584.
- Public Health Agency of Canada. (2008). Second International Workshop on Seniors and Emergency Preparedness workshop report. Retrieved December 15, 2008, from www.policypointers.org/Page/View/8733.

- Public Safety Canada. (2008). *Canada's national disaster mitigation strategy*. Retrieved from <u>www.publicsafety.gc.ca/prg/em/ndms/strategy-eng.aspx</u>.
- Quarantelli, E. L. (1982). *Sheltering and housing after major community disasters*. Newark, DE: University of Delaware Disaster Research Center.
- Quarantelli, E. L. (1987). What should we study? Questions and suggestions for researchers about the concept of disasters. *International Journal of Mass Emergencies and Disasters, 5*, 7–32.
- Quarantelli, E. L. (1991). *Disaster assistance and recovery at the individual and household level*. Newark, DE: University of Delaware Disaster Research Center.
- Quarantelli, E. L. (1998). *The disaster recovery process: What do we know and not know?* Newark, DE: University of Delaware Disaster Research Center.
- Quillin, M. (2008). *Deaf get help on weather alerts*. Retrieved July 14, 2008, from www.newsobserver.com/news/story/1202935.html.
- Rahimi, M. (1993). An examination of behavior and hazards faced by physically disabled people during the Loma Prieta earthquake. *Natural Hazards Review*, *7*(1), 59–82.
- Rahimi, M. (1994). Behavior of mobility-disabled people in earthquakes: A simulation experiment. *Earthquake Spectra*, *10*(2), 381–401.
- Renne, J. L., Sanchez, T. W., & Litman, T. (2008). *National Study on Carless and Special Needs Evacuation Planning: A literature review*: New Orleans, LA: University of New Orleans Transportation Center.
- Rose, A. (2006). *Regional models and data to analyze disaster mitigation and resilience*. Los Angeles: University of Southern California, School of Policy, Planning, and Development and Center for Risk and Economic Analysis of Terrorism Events.
- Rubadiri, L., Ndumu, D. T., & Roberts, J. P. (1997). Predicting the evacuation capacity of mobility-impaired occupants. *Fire Technology*, *33*(1), 32–53.
- Rubin, C. B. (2007). *Emergency management: The American experience, 1900–2005*. Fairfax, VA: Public Entity Risk Institute.
- Saliba, D., Buchanan, J., & Kingston, R. S. (2004). Function and response of nursing facilities during community disaster. *American Journal of Public Health*, *94*(8), 1436–1441.
- San Mateo County California. (2005). *Emergency public health information and vulnerable populations in San Mateo County: After-action report community*

forums. Retrieved January 15, 2009, from www.pandemicpractices.org/files/14/14 after action report forum.pdf.

- Santrock, J. W. (2008). A topical approach to life-span development (4th edition). New York: McGraw-Hill.
- Schwab, J., Topping, K. C., Eadie, C. C., Deyle, R. E., & Smith, R. A. (1998). *Planning for post-disaster recovery and reconstruction*. Washington DC: FEMA.
- Shields, T. J., Boyce, K. E., & Silcock, G. W. H. (1997). *Client report, unannounced evacuation of Marks & Spencer, Sprucefield store*. Jordanstown, Northern Ireland: University of Ulster *Fire* Safety Engineering Research and Technology Centre.
- Shields, J. W., Boyce, K. E., & Silcock, G. W. H. (1999). Facilities management disability and emergency evacuation. *Facilities*, *17*(9/10), 345–351.
- Shields, T. J., Smyth, B., Boyce, K. E., & Silcock, G. W. H. (1999). Towards the prediction of evacuation behaviours for people with learning disabilities. *Facilities*, *17*(9/10), 336–344.
- Shinozuka, M., Rose, A., & Eguchi, R. (1998). *Engineering and socioeconomic impacts of earthquakes*. Buffalo, NY: Multidisciplinary Earthquake Engineering Research Center.
- Smith, P., Langa, K., Kabeto, M., & Ubel, P. (2005). Financial resources buffer subjective well-being after the onset of a disability. *Psychological Science*, *16*(9), 663–666.
- Snare Web Guide. (No date). U.S. National Civic Clubs and Organizations. Retrieved October 16, 2008, from www.thesnare.com/states/national/community/civic/civic.htm.
- Social Security Administration (SSA). (2008). *News release: Social Security checks again arriving in Gulf Coast states as Hurricane Ike approaches*. Retrieved January 7, 2009, from <u>www.ssa.gov/pressoffice/pr/hurricaneike-pr.htm</u>.
- Sorenson, J. (2000). Hazard warning systems: Review of 20 years of progress. *Natural Hazards Review, 1*(2), 119–125.

Springgate, B. (2007). Down in New Orleans. Health Affairs, 26(5), 1426–1430.

- State of Mississippi. (2007). *Special needs shelter general medical care guidelines*. Retrieved December 20, 2008, from <u>http://www.msdh.state.ms.us/msdhsite/_static/resources/1970.pdf</u>.
- State of Missouri. (2008). Special needs sheltering standard operating guide for local and county level emergency managers. Retrieved December 20, 2008, from http://www.msdh.state.ms.us/msdhsite/index.cfm/23,7057,288,html

State of New York. (2008). New York State medical and functional needs sheltering plan.

- Steinfeld, E. (2006). Evacuation of people with disabilities. *Journal of Security Education, 1*(4), 107–118.
- Stough, L., & Sharp, A. (2008). *An evaluation of the National Disability Rights Network participation in the Katrina Today project*. Washington, DC: The National Disability Rights Network.
- Styron, H. (2005). *Emergency management and people with disabilities: Before, during and after (congressional briefing, November 10)*. Retrieved July 10, 2008, from www.ncd.gov/newsroom/publications/2005/transcript_emergencymgt.htm.
- Swan, R. (2202). Overview of the nation's worst debris-generating disaster (World Trade Center). *Environmental Practice, 4*(2), 67–69.
- Szabo, L. (2006). A need for care in New Orleans. *USA Today* (online). Retrieved May 15, 2009, from <u>www.usatoday.com/news/health/2006-08-09-doc-shortage x.htm</u>.
- Szema, A., Khedkar, M., Maloney, P. F., Takach, P. A., Nickels, M. S., Patel, H., et al. (2004). Clinical deterioration in pediatric asthmatic patients after September 11, 2001. *Journal of Allergy and Clinical Immunology*, *113*(3), 420–426.
- Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Informatics Association*, 13(2), 121–126.
- Taylor, A. J., & Frazer, A. G. (1981). The stress of post-disaster body handling and victim identification work. *Journal of Human Stress, 8*, 4–12.
- Tierney, K. (1996). *Business impacts of the Northridge earthquake*. Newark, DE: University of Delaware Disaster Research Center.
- Tierney, K., Petak, W., & Harlan, H. (1988). *Disabled persons and earthquake hazards*. Los Angeles: University of Southern California.
- Tierney, K. J., Lindell, M. K., & Perry, R. W. (2001). *Facing the unexpected: Disaster preparedness and response in the United States.* Washington, DC: Joseph Henry Press.
- Tierney, K., Nigg, J. M., & Dahlhamer, J. M. (1996). The impact of the 1993 Midwest floods: Business vulnerability and disruption in Des Moines. In R. T. Sylves & W. L. Waugh (eds.), *Cities and Disaster: North American Studies in Emergency Management*. Springfield, MA: Charles C. Thomas.

- Trout, D., Nimgade, A., Mueller. C., Hall, R., & Earnest, G. S. (2002). Health effects and occupational exposure among office workers near the World Trade Center disaster. *Journal of Occupational and Environmental Medicine*, *44*(7), 601–605.
- United States Access Board. *Rehabilitation Act Amendments*. (1998). Retrieved June 7, 2008, from <u>www.access-board.gov/sec508/guide/act.htm</u>.
- United States Fire Administration and Federal Emergency Management Agency. (No date). *Emergency procedures for employees with disabilities in office occupancies*. Retrieved May 14, 2008, from <u>www.eadassociates.com/fa-154.pdf</u>.
- United States Fire Administration and Federal Emergency Management Agency. (2002). *FA-235: Orientation manual for first responders on the evacuation of people with disabilities*. Retrieved May 14, 2008, from www.usfa.dhs.gov/downloads/pdf/publications/FA-235-508.pdf.
- University of Minnesota. (No date). *Promising practices: Pandemic preparedness tools, Kansas*. Retrieved February 23, 2009, from <u>www.pandemicpractices.org/practices/list.do?state-id=20</u>.
- Ursano, R. J., & McCarroll, J. E. (1990). The nature of a traumatic stressor: Handling dead bodies. *Journal of Nervous and Mental Disease*, *178*(6), 396–398.
- van Willigen, M., Edwards, T., Edwards, B., & Hessee, S. (2002). Riding out the storm: Experiences of the physically disabled during hurricanes Bonnie, Dennis, and Floyd. *Natural Hazards Review, 3*(3), 98–106.
- Wagner, C. G. (2006). Disaster planning for the disabled. The Futurist (March 1).
- Washington State Military Department. (2007). *Disaster preparedness handbook: An emergency planning and response guide*. Retrieved May 14, 2008, from www.doh.wa.gov/phepr/handbook.htm.
- Waugh, W. (1988). Current policy and implementation issues in disaster preparedness. In L. K. Comfort (ed.), *Managing Disaster: Strategies and Policy Perspectives* (pp. 111–125). Durham, NC: Duke University Press.
- Webb, G., Tierney, K., & Dahlhamer, J. M. (2000). Businesses and disasters: Empirical patterns and unanswered questions. *Natural Hazards Review*, *1*(3), 83–90.
- Wenger, D., Quarantelli, E. L., & Dynes, R. (1987). *Disaster analysis: Emergency management offices and arrangements*. Final report. Disaster Research Center, University of Delaware.
- Western Illinois Agency on Aging. (2008). *RSVP Program.* Retrieved February 20, 2009, from <u>www.wiaaa.org/rsvp/about_rsvp.htm</u>.

- WGBH National Center for Accessible Media. (2005). *Press release: Access alerts: Making emergency information accessible to people with disabilities, September 15, 2005.* Retrieved June 14, 2008, from <u>http://ncam.wghb.org/news/pr_20050915.html</u>.
- White, G. W., Fox, M. H., & Rooney, C. (2007). Nobody left behind: Report on exemplary and best practices in disaster preparedness and emergency response for people with disabilities. Retrieved June 14, 2008, from www.nobodyleftbehind2.org/findings/pdfs/bestpractices 3-21-072.pdf.
- Wilson, J., & Oyola-Yemaiel, A. (2001). The evolution of emergency management and the advancement toward a profession in the United States and Florida. *Safety Science*, *39*, 117–131.
- Wilson, R. (1991). *The Loma Prieta earthquake: What one city learned*. Washington, DC: International City Management Association.
- Wisner, B. (2002). Disability and disaster: Victimhood and agency in earthquake risk reduction. In C. Rodrigue & E. Rovai (eds.), *Earthquakes*. London: Routledge.
- Women's Commission on Refugee Women and Children (WCRWC). (2008). *Disabilities among refugees and conflict-affected populations*. Retrieved October 17, 2008. from www.womenscommission.org/pdf/disab_fulll_report.pdf.
- Wood, V. T., & Weisman, R. A. (2003). A hole in the weather warning system. *Bulletin* of the American Meteorological Society, 84(2), 187–194.
- Yelvington, K. (1997). Coping in a temporary way: The tent cities. In W. Peacock (ed.), *Hurricane Andrew* (pp. 92–115). London: Routledge.
- Young, J. R. (2008). Emergency alerts via Facebook and MySpace are new ways to reach students. *Chronicle of Higher Education* (August 22).
- Zuckerman, S., & Coughlin, T. (2006). *After Katrina: Initial health policy responses to Hurricane Katrina and possible next steps*. Retrieved from <u>www.urban.org/publications/900929.html</u>.

APPENDIX A: Resources

This appendix lists resources for emergency managers and other professionals. It includes links to content from relevant conferences as well as reviews of materials of interest.

• Conferences and Meetings

- Disability and Special Needs Technical Assistance Conference, January 2008. The National Organization on Disability's Emergency Preparedness Initiative, in cooperation with the *Homeland Defense Journal*, hosted this conference in Washington, D.C. The conference brought together federal, state, local, and private sector experts to discuss day-to-day challenges in emergency planning and response for people with disabilities and special needs. To view presentations from the conference, go to <u>www.datacenterconference.com/SpNeedsConf</u> and enter the password spneeds08.
- Working Conference on Emergency Management and Individuals with Disabilities and the Elderly, June 2006. The Department of Health and Human Services and the Department of Homeland Security organized this three-day working conference to address issues of persons with a disability, the elderly, and other vulnerable populations in emergency management. The website provides the conference report, transcripts of each session, PowerPoint presentations, and links to resources on the topics addressed. Go to <u>www.add-em-conf.com</u>.
- NCD quarterly meeting minutes include information and reports on current events and emerging practices. They can be found at <u>www.ncd.gov/newsroom/quarterly/quarterly.htm</u>. The January 2008 quarterly meeting in New Orleans is particularly recommended for its content on Hurricane Katrina.

- Emergency Preparedness: Addressing the Needs of People with Disabilities, A National Consensus Conference, March 2007. This conference, hosted by the National Center for Disaster and the Mailman School of Public Health at Columbia University, brought together leading experts on the topic from around the country to gather information and best practices. The report is available at www.ncdp.mailman.columbia.edu/files/disability2.pdf.
- Increasingly, the topic of disability and emergency management is being added to conference agendas; for example, Citizen Corps, Voluntary Organizations Active in Disaster, National Hurricane Conference, and International Association of Emergency Managers. Usually such content is added as a subtopic or breakout session. Often the topic of disability is combined with broader special needs topics.
- Federal Guidance
 - Comprehensive Preparedness Guide (CPG) 301: Special Needs Planning: <u>www.fema.gov/news/newsrelease.fema?id=45436</u>. (Also see the draft of CPG 302, which is to include content on service animals.)
 - ADA Best Practices Tool Kit for State and Local Governments (DOJ): www.ada.gov/pcatoolkit/toolkitmain.htm.
 - FEMA's Orientation Manual for First Responders on the Evacuation of People with Disabilities: <u>www.usfa.dhs.gov/downloads/pdf/publications/FA-235-</u> <u>508.pdf</u>.
- Tools
 - Safe Evac is an off-the-shelf training tool kit. Information is at http://evac.icdi.wvu.edu/library/training.htm.
 - The Carl and Ruth Shapiro Family National Center for Accessible Media at WGBH led a four-year grant—Access to Emergency Alerts for People with Disabilities—funded by the Department of Commerce, and has published a set of recommendations for accessible notification. The recommendations

were developed by representatives from emergency management, industry, and consumers, with the participation of the project's national working group and advisory board. The recommendations are directed to specific audiences, including consumers, federal and state government, emergency management, and the media. Materials can be viewed at http://ncam.wgbh.org/alerts/articles/AccessAlertsFinalRecs.pdf

- Nobody Left Behind. A series of posters, papers, and PowerPoints on emergency preparedness and disabilities: <u>www2.ku.edu/~rrtcpbs/powerpoint</u>.
- Tips for Emergency Responders cards were created by the University of New Mexico: <u>http://cdd.unm.edu/products/tips_web020205.pdf (description</u> http://cdd.unm.edu/products/tipsforfirstresponders.htm).
- Journals, Overviews, and Publications
 - The *IAEM Bulletin* dedicated two issues to special needs: March and April 2005 (volume 22, issues 3 and 4).
 - Emergency Management Research and People with Disabilities, a Resource Guide: www.ed.gov/rschstat/research/pubs/index.html#emergencyguide
 - The National Organization on Disabilities offers a downloadable guide for emergency managers and a complete set of downloadable, disability-specific brochures at its Emergency Preparedness Initiative website. Materials can be found at <u>www.nod.org</u>.

Visual Resources

The following section offers overviews of visual resources of interest to emergency managers, voluntary organizations, caregivers, disability organizations, and individuals with disabilities. Each listing includes a summary. Quoted material is directly excerpted from the resource.

"Planning Ahead for Special Needs During a Disaster," produced by the Rogue Valley Council of Governments. This video, offered in both English and Spanish, presents a method to plan ahead for a disaster, whether the viewer is an individual with a disability or a caregiver. The video includes the following:

- An explanation of how to prepare, presented by host Gayle Wilson.
 - o "The plan you create should be easy to carry out in a disaster."
 - "The concept of 'Get a buddy, be a buddy." Have someone in the neighborhood who is a buddy, someone who will check up on you during a disaster. And be that sort of person for someone else.
- An explanation of the need to have a health information card ready for rescuers.
 - "Keep a copy on the refrigerator, in your wallet, and in your portable disaster kit."
 - Include the following information on your health care:
 - "Medications that you are taking (including dosages)
 - Medical and special equipment needs
 - Allergies and sensitivities
 - Possible communication difficulties
 - Preferred treatment and doctors
 - Who to contact (with phone numbers)"
- A discussion of disaster preparedness kits.
 - "One is a 72-hour disaster kit that will help you get by in your home for 72 hours."
 - "The other is a smaller, portable disaster kit (fits in a backpack) that you can take with you if you have to leave your home and go to a shelter."
- An in-depth discussion of the 72-hour disaster kit.
 - What to include in this kit.

- "Enough blankets for everyone
- Water supply (two gallons per person, per day)
- Nonperishable food supply for three days
- Manual can opener
- Something to eat with
- Flashlight
- Battery-powered radio
- Extra batteries
- Extra pet food/pet supplies"
- A discussion about when you might want to leave your home.
 - o "Be alert to weather conditions and changing conditions."
 - "Prepare your home for a disaster."
 - "Make sure you have a buddy in your neighborhood, and be a buddy to your neighbors."
- An in-depth discussion of the portable disaster kit.
 - "The kit should include special items you must take with you if you evacuate your home in a disaster."
 - What to include:
 - "Personal hygiene items
 - Change of clothing
 - Extra set of keys to your house and car
 - Cash
 - Insurance agent's name and phone number
 - Eyeglasses
 - Copy of health information card

- Medication(s)"
- "Keep it simple enough to carry."
- A discussion of considerations if you have a physical disability, or if you are caring for someone who does.
 - Example: "If you use oxygen, have spare bottles on hand."
- A discussion of considerations if you have cognitive needs, or if you are caring for someone who does.
 - Example: "Plan strategies for coping with disaster(s)."
- A discussion of considerations if you have a service animal, or if you are caring for someone who does.
 - Example: "Owners should make sure that dogs are licensed and have current ID tags in case of emergency."
 - "Have an animal care plan in place."
 - "Also have a plan in place for non-service animals/pets
 - o "See if a friend could take care of your pet if you were forced to leave."
 - "Discuss this before an event."
- A brief discussion of personal networks.
 - Personal networks—those individuals who would assist you during a disaster: family, friends, and neighbors.
- Overview
 - "Prearrange as much as possible.
 - Think ahead.
 - Be prepared to evacuate.
 - Have a plan in place.
 - Involve your family, friends, and neighbors."

For information on obtaining this video, contact the Rogue Valley Council of Governments at 541-664-6674.

"Working with People with Disabilities: A Guide for Responders," produced by the Baltimore County Fire Department and sponsored by the Baltimore County Commission on Disabilities.

- Video can be viewed in standard format or with closed captioning
 - The video is intended to help firefighters/EMS (first responders) during an event involving people with: permanent disabilities, persons with visual impairment, the deaf and hard of hearing, people with mobility impairment, people with mental illness, and people with cognitive impairments.
 - "This video will help responders communicate with people who may be living with any of these conditions."
- A discussion of including perspectives from people with disabilities.
 - "Most say that they don't know whom to contact about an emergency plan and that they haven't done much to prepare themselves."
- A list of what first responders should do to prepare for emergencies involving people with disabilities.
 - "Familiarize yourself with your response area, paying special attention to buildings that house persons with disabilities.
 - Participate in emergency planning for people with disabilities before they occur.
 - During a crisis, try to make accommodations that emphasize the disabled person's abilities.

- Include citizens with disabilities in the decision-making process, including during the emergency itself. These citizens want to be treated as people, not as objects."
- The presentation then moves on to commentaries by professionals who work with the disability community and have a disability themselves.
 - They talk about what they want first responders to know/realize when it comes to a person with special needs.
 - For example, asking "What's the best way for me to pick you up?" when a person has fallen out of his or her wheelchair.
- Discussion: "Don't try to treat everybody with a disability the same."
 - People are different; for example, there are varying levels of blindness.
- Discussion of responding to those who are blind or have a visual impairment: the right and wrong things to do.
- Discussion of the importance of service animals and the fact that they need to be rescued, too.
- Discussion of working with people who are deaf—the key is to be patient.
- Discussion of working with those who may have a cognitive disability.
 - Again, the key is to be patient.
 - \circ Don't talk down to them. If they are adults, treat them like adults.
 - Offer simple directions.
- Discussion of working with those who may have a mental illness.
 - "First responders need to have a basic understanding of these sorts of conditions."
- Discussion of the different types of mental illness.
- Discussion of working with those who have mobility disabilities.
 - o "Ask me, 'What is the best way for me [the responder] to help you move?"

- Communication with people with disabilities is crucial.
 - Video concludes with a list of additional resources on the topics discussed (websites and telephone numbers).

A copy of this DVD is available free of charge from the Baltimore County Fire Department. To request a copy, email Fire Director James Korn at <u>jkorn@baltimorecountymd.gov</u>; or call 410-887-4860.

"Emergency Responders and the Deaf and Hard of Hearing Community: Taking the First Steps to Disaster Preparedness. Live Response with Al Ruechel" (aired on October 29, 2007). Live Response is an interactive program in which people can call in and ask questions. The video includes the following:

- A discussion of the Community Emergency Preparedness Information Network (CEPIN) course, "Emergency Responders and the Deaf and Hard of Hearing Community: Taking the First Steps to Disaster Preparedness."
 - "With 28 million Americans coping with the challenges of hearing loss, emergency responders need to be aware of the challenges these people may face in a disaster event."
- A discussion of "If we have a disaster, how can we protect the deaf and hard of hearing community?"
 - "Training courses must be offered to those who are deaf. Accommodations must be made so that those that are deaf can get the training they need to prepare for a disaster."
 - "You must have a disaster plan that includes considerations for the deaf."
- A question and answer period—questions posed by the host and callers, answers from two experts in the field.
 - Questions like these:

- "How big is the deaf/hearing impaired community in this country?"
- "What have we done in the past with regard to communicating with the deaf during a disaster?"
- A discussion of CEPIN: what it is, when and why it was established, etc.
- Discussion: Myths about those who are deaf:
 - "Every deaf person can sing.
 - Every deaf person can read lips.
 - Sign language is all the same/universal."
- Discussion about the differences between an emergency and a disaster in terms of the right way to respond to someone who is deaf or hard of hearing.
- Discussion of the importance of planning.
- Discussion of the importance of learning from past events and events that have taken place in other locations.
- In-depth discussion of the four phases of the disaster management process and what should be done during each phase.
 - Preparedness
 - Response
 - Recovery
 - Mitigation
- Other discussion topics:
 - An overview of the National Incident Management System (NIMS) and the Incident Command System (ICS).
 - How to get the deaf community motivated to participate in meetings and the planning process in general.
 - The different scenarios that are used in this training course and how they apply to the deaf community.

- What should people who are deaf do to prepare themselves for a disaster?
- What are the legal responsibilities of the community toward this population?
- What should people do in their communities after taking the training course ("What can or should I do in my community?").

More information is available on the CEPIN website: <u>www.cepintdi.org</u>.

• To view the video or request a copy, visit the Live Response website: <u>http://terrorism.spcollege.edu</u>.

"After the Storm: Remember and Recovering," produced by the Louisiana School for the Deaf: the story of Hurricane Katrina, from the perspective of the superintendent and students of LSD. The video includes the following:

- Discussion by Superintendent Bill Prickett of the days following Hurricane Katrina.
 - How they made an effort to locate their students, most of whom had evacuated to locations throughout the southern United States.
 - How they encouraged parents to bring their children back to the school, which reopened just three days after the event.
 - How they provided shelter to students and their parents who did not have a home to go back to.
 - How they supported the shelter financially. They had to rely on donations,
 which they received from people in all 50 states and from around the globe.
- The video shows TV coverage broadcast during the days before and after the hurricane, then turns to stories told by LSD students about their experiences with the hurricane.

- Living through it.
- Evacuating before it hit.
- Not knowing what was happening at home.
- To obtain a copy of this video, contact: Louisiana School for the Deaf Post Office Box 3074
 2888 Brightside Lane Baton Rouge, LA 70821/70820
 (225) 769-8160

"Voices of Wisdom: Seniors Cope with Disaster," U.S. Fire Administration, Emergency Management Institute, and FEMA. This video includes the following:

- Discussion of earthquakes on June 28, 1992.
 - o 7.2 quake in the Mohave Desert
 - 6.6 quake in the Big Bear area
- Interviews of seniors who experienced the earthquakes
 - Discussion of the loss of control experienced in events like this—the feeling of helplessness.
- What people lost: personal/material goods as well as necessities (water, electricity, telephone, etc.).
- Discussion of the healing process
 - Conditions that may be present after a disaster: problems with concentration, short-term memory, sleeping, etc.
- Discussion of coping:
 - What can/should people do?
- "Use your support network.
- Caregivers themselves need to find support in the community. You may be charged with caring for others, but do not neglect your own needs.
- Put your own needs first.
- Focus on your strengths.
- Take time to relax.
- Don't be embarrassed to ask for financial support."
- Discussion of the changes people have experienced since the quakes.
 - o "There is no right or wrong way to cope with a trauma in your life."
 - It's important to talk to others about your experience.
- This video can be ordered by writing to FEMA, PO Box 2012, Jessup, MD 20794-2012, or by calling 1-800-480-2520. A PDF Version of the FEMA Publication Catalog is available at www.fema.gov/library/file?type=publishedFile&file=femapubcatalog.pdf&fileid=49
 e2a5f0-476d-11dc-bda9-000bdba87d5b.

"EENT: Disabled and Elderly Persons in Disasters: Key Issues for Emergency Managers." This video includes the following:

- Discussion of the impact of the Americans with Disabilities Act of 1990 on emergency management.
 - Discussion of Title I, II, III, IV; Rehabilitation Act of 1973.
- In-depth discussion of ADA requirements for emergency management.
 - Introduction to the topic by former FEMA Director James Lee Witt: "We will not forget about those people who have special needs."
- In-depth overview of ADA and Title I.

- Questions that the EEOC may ask if a complaint arises:
 - "Is the employer covered under the law?"
 - "Is the person who lodged the complaint covered under ADA?"
 - "Is the person qualified to do the job?"
- Discussion of reasonable accommodations:
 - What employers should/must do and what they do not have to do.
 - Example: "They do not have to provide personal use items."
 - Example: "Employer does not need to lower real production standards."
 - Discussion of other important provisions of ADA.
 - "No segregation.
 - No contracts that discriminate.
 - No discrimination because of relationship with someone with a disability."
 - Discussion of ADA restrictions on questions about medical history:
 - Pre-offer stage
 - Employers may not:
 - "Ask any disability-related questions."
 - "Require medial examinations."
 - Employers may:
 - "Ask about the applicant's ability to do job functions."
 - "Ask applicants to describe how they would perform a task."
 - "Administer physical agility tests."
 - Post-offer stage
 - Employers may:
 - "Require any medical examinations."

- "Withdraw an offer on the basis of disability if the reason is job-related and consistent with business necessity."
- "Ask questions."
- Medical information must be kept confidential (exceptions are noted).
- A list of resources, with telephone numbers, to obtain more information about this subject (Title I, ADA requirements, etc.).
- A discussion of the emergency management perspective on the questions posed above. What effect has ADA had on emergency management?
- Discussion of being an emergency manager/first responder who has a disability.
- In-depth overview of ADA and Title II and III.
- What they are; what they apply to.
- When they took effect.
 - What emergency managers should consider regarding the requirements of Title II of ADA.
- A list of resources, with telephone numbers to call to get more information about Title II and Title III.
- A question-and-answer period, with questions posed by the moderator and by the public calling in, and answers provided by a panel of experts.
- Discussion of the difference between handicap and disability.
- An in-depth discussion on how to interview individuals that may have a disability; for example, through an interview simulation.
- Emergency Education Network (EENET) videotapes are "not available through EENET. Most (including this one) are only available to borrow from some State Emergency Management/FEMA Regional Offices"
 (www.emforum.org/pub/eiip/EENETIst.doc). Contact your local State Emergency Management or FEMA Regional Office for more information.

"Get Ready San Mateo County," San Mateo County Sheriff's Office of Emergency Services. The video includes the following:

- Description of San Mateo County, California.
- Overview of disaster risks that San Mateo County faces, including earthquakes, tsunamis, wildfires, and terrorism.
- Why it is important for San Mateo residents to prepare themselves.
- Getting started
 - Discussion of a communication plan—a plan a person/family puts together that includes names and phone numbers of friends and family members to call after an event, to tell them that something has happened and that they are all right.
 - Discussion of making copies of driver's license, social security card, and other important documents.
 - Discussion of documenting household items; taking pictures or video of the rooms in your home.
- Preparing your home
 - Discussion of predetermining exits, and knowing where the exits are and which ones to use.
 - Discussion of the importance of things such as flexible gas lines, which allow hot water heaters to move/flex without breaking.
 - Discussion of other items that can be used to prepare a house before an event; a fire extinguisher, for example
 - Discussion of the importance of knowing your child's school emergency plan.
- Earthquake procedures
 - o "What should you do if you are at home?"

- "What should you do if you are in your car?"
- Utilities
 - Importance of knowing where outside utilities are located, and where the shut-off mechanisms are.
 - Knowing when and how to shut off gas lines/the flow of gas into your home.
 - Knowing when and how to shut off the water to your home.
 - Knowing when and how to shut off the electricity to your home.
- Supply kit
 - Knowing what to include in your emergency supply kit.
 - One gallon of water per person per day for at least seven days.
 - Canned food.
 - Manual can opener.
 - Extra medication.
 - Flashlight, extra batteries.
 - Pet supplies.
 - Knowing what to include in your first aid kit.

The SMC Ready website is <u>www.smcready.org</u>.

To view the video or request a copy, go to <u>www.smcready.org</u> or call 650-363-4790.

"Existing Facility Checklist," Meeting the Challenge, Inc., Colorado Springs, CO. The Americans with Disabilities Act – ADA.

• Available in both a standard CD-ROM and an accessible version for people with visual impairments.

- This is an interactive, computer-based training that does the following:
 - Offers an introduction/overview of accessibility and ADA requirements.
 - Talks about small business tax credits for "eligible access expenditures....The max tax credit each year is \$5,000."
 - o Gives an overview of the checklist and defines "existing facility."
 - "[T]hose that were built prior to January 26, 1992, as defined under Title III of the ADA."
 - Explains the four priorities that this material is based on (as required under Title III of the ADA):
 - Accessible approach and entrance.
 - Access to goods and services.
 - Access to restrooms.
 - Any other measures necessary.
- Chapter/Priority 1: Approach and Entrance
 - Overview
 - Discussion of parking requirements, including the required number of accessible spaces a facility should have.
 - "One in every eight accessible spaces must be van-accessible, with a minimum of one van-accessible space."
 - Solutions for incorporating parking in existing lots.
 - Overview of proper walkway access.
 - Overview of signage (the new required height for accessibility sign (handicapped parking sign).
 - Discussion of accessible routes, such as sidewalks.
 - "Is at least one entrance accessible into the establishment?"
 - "Is the route at least 36 inches wide?"

- Discussion and solutions for barriers that might not be detected by those who are visually impaired.
- Discussion of accessible ramp requirements.
- "Slope no greater than 1:12 (8.33%).
- Width at least 36 inches."
- Discussion of entrance requirements.
- "Doors have at least 32 inches of clear opening.
- Threshold height.
- Door handle no higher than 48 inches."
- Chapter/Priority 2: Goods and Services
 - \circ Overview
 - "Is the accessible route to all public spaces at least 36 inches wide?"
 - Discussion of indoor signage.
 - Proper height
 - Braille requirements
 - Discussion of reach ranges (the range that a person can reach while in a wheelchair).
 - Discussion of service counter height.
 - Discussion of stair requirements.
 - Discussion of elevator requirements.
- Chapter/Priority 3: Restrooms
 - Discussion of restroom entrances.
 - Discussion of toilet seat height.
 - Discussion of stall requirements.
 - Space requirements.

- Grab bar.
- Discussion of lavatory requirements.
 - Height of lavatory.
 - Height of mirror.
- Soap and hand dryer height requirements.
- Chapter/Priority 4: Additional Access Features
 - Drinking fountain height requirements.
 - Pay/public phone requirements.
 - Alarm system requirements.
- List of Resources
 - Resources/contact information/websites.
 - Publications/websites.
- To request a copy of the CD-ROM, contact: Meeting the Challenge, Inc.
 3630 Sinton Road, Suite 103
 Colorado Springs, CO 80907
 719-444-0252

"Building Toward a Disaster." The Florida Department of Elderly Affairs organized a Hurricane Conference in March 1993, following Hurricane Andrew in 1992. The purpose of the conference was to discuss the issue of responding to special needs populations during disasters (focusing on hurricanes). Hurricane Andrew illustrated that society needs to do better in responding to those with special needs. This video is an excerpt from a speech by Dr. Neil Frank (former director of the National Hurricane Center), delivered on April 1, 1993, at "Food, Water, and Ice: Caring for Frail Elders Before, During, and After a Hurricane," a national conference sponsored by the Florida Department of Elder Affairs in Tampa. The video include the following:

- Explanation of hurricanes:
 - "If you move to California and locate your home on one of those fault lines, don't complain about earthquakes."
 - "If you move to Florida, and live on one of those islands, don't complain about hurricanes."
- Explanation of storm surge:
 - An explanation of what damage can be caused by a storm surge.
- How do you motivate people to evacuate?
 - Behavior factors in response:
 - Confirmation
 - Past experience
 - Misunderstanding
 - Peer pressure
 - Demographics
- Explanation of storm damage.
- Explanation of the importance of building codes.

For information on obtaining a copy of this video, contact one of the Florida Area Agencies on Aging (a list of the agencies is at <u>www.agingcarefl.org/network/aaalist</u>) or the Florida Department of Elder Affairs (<u>http://elderaffairs.state.fl.us/index.php</u>).

"Katrina's Lesson." A conference titled Katrina's Lesson was held October 24–25, 2006, in King County, Washington. The purpose was to focus on vulnerable populations. The DVD includes:

- Chapter 1: Support Materials
 - Each chapter has a list of downloadable materials to enhance learning and expand people's knowledge about this topic.
- Chapter 2: Introduction
 - A materials list is provided at the beginning of this section.
 - The presentation is based on the preparedness phase in disaster management.
 - Discussion of vulnerable populations.
 - Discussion of the vision of King County:
 - Cultural competency.
 - Collaboration.
 - Essential service access for all.
 - Business continuity after an emergency.
 - Discussion of the importance of knowing who might be vulnerable and where they live.
 - "Do they have needs?
 - What sorts of needs do they have on a daily basis?
 - How will these need increase/change after a disaster?"
- A PowerPoint presentation on preparedness and the history of CARD (Collaborating Agencies Responding to Disasters).
 - History of CARD.
 - Discussion of Loma Prieta earthquake and its aftermath.

- Discussion of preparedness problems:
 - "No money for implementation.
 - No emergency managers to implement planning."
- Discussion of the CARD approach.
 - Discussion of CARD core trainings.
- Discussion of people with special needs:
 - Emphasis on those we may not think about; for example,
 - Those with language barriers.
 - Ex-convicts and registered offenders.
 - Those who are socially isolated.
- Nonprofits as preparedness partners.
- Other sections:
 - Impediments to preparedness.
 - Messages to the public.
 - "We have to include the most vulnerable in these messages."
 - Actions to take.
- Chapter 3: Getting Your Agency Ready
 - List of materials.
 - Developing agency emergency plans.
 - "We cannot recover without the strength/help of our nonprofits."
 - Discussion about educating the community.
 - Disaster mission statement:
 - "Who are we going to be for each other?"
 - Discussion of personal preparedness.

- Discussion of onsite supplies.
 - A list of the basic disaster supply items that you should have on hand.
 - Importance of key personal documents.
 - Making copies of important papers.
 - Saving them to a disk.
 - Giving copies to someone you know outside the immediate area in which you live.
- Overview of facility preparedness.
- Discussion of mapping resources.
 - Knowing where key resources are at all times.
 - Key facilities, transportation routes, etc.
- Evacuation/transportation.
- Ensuring service continuation.
 - Make sure you are clear on your service priorities.
- Chapter 4: Overview of the Incident Command System (ICS)
 - Detailed discussion of ICS, its history and use.
 - Discussion of CARD and ICS training.
- Section 5: Preparing for Pandemic Flu
 - Solutions.
 - Supplies needed.
 - Definitions: epidemic and pandemic.
 - Why we care.
 - Why are we talking about pandemic influenza?
 - Potential impacts of pandemic influenza.

- Key steps for preparedness.
- Discussion of pandemic influenza preparedness.

For information about this video, as well as the documents (PDF versions) and PowerPoint presentations from the video, go to www.kingcounty.gov/healthservices/health/preparedness/VPAT/katrina.aspx.

"Project Safe EV-AC" is a CD-ROM that contains a number of different resources, as well as a train-the-trainer PowerPoint presentation. The disc includes the following:

- Resource #1: "In a Pinch"
 - Introduction.
 - "In a Pinch is a guide covering the techniques for evacuating people with disabilities from various sites and situations. The manual is a quick reference guide to assist with managing evacuations in minutes or seconds."
 - The idea is that it can be used easily and quickly.
 - Breakdown of how to evacuate people with vision, speech, respiratory, motor, cognitive, and psychiatric impairments.
 - List of additional resources.
- Resource #2: "Information for Individuals with Disabilities"
 - Explanation of Project Safe EV-AC.
 - Discussion of what to tell your employers about your disability, so they know in case of an emergency.
 - Questions:
 - "Does my accommodation request have to be in writing?

- Are there specific forms I should use to make my accommodation request?
- How can I find information on accommodations for people with disabilities?
- How can I locate resources for advocacy and legal assistance?"
- Sample accommodation request letter.
- Contact information for Project Safe EV-AC.
- List of additional resources (with websites).
- Resource #3: "Train the Trainer"
 - An explanation of the importance of emergency planning and inclusive evacuation plans.
 - Some discussion on awareness and etiquette in interacting with people who may have disabilities.
 - Discussion on learning how to develop, implement, and maintain inclusive emergency evacuation plans.
 - The "Three-Step EV-AC Accommodation Process" and the "EV-AC Accommodation Process Flow Chart."
 - A collection of charts, forms, and checklists, including these:
 - "Emergency Evacuation Planning: Accommodation Form for Employees and Residents."
 - "Emergency Evacuation Planning: Accommodation Form for Visitors."
 - "Sample Checklist for Establishing a Corporate Culture of Safety."
 - "Sample Checklist for Establishing Community Links."
 - "Sample Checklist for Establishing a Personal Network."
 - "EV-AC Accommodation Process Flow Chart."
 - A checklist for employers: "Activities to Help Overcome Fear and Anxiety."

- An extensive list of resources, including names, addresses, phone numbers, and websites.
- Contact information for Project Safe.
- Resource #4: "In Advance"
 - A history of the topic: evacuating people with disabilities.
 - An explanation of how to overcome fear—at home, at work, etc.
 - An overview of the EV-AC accommodation process, with many useful charts (many of which are included in the train-the-trainer section).
 - A list of options to be considered with regard to this topic.
 - "Specific Disaster Fact Sheet," covering the before, during, and after of disaster events, which include earthquakes, floods, and hurricanes.
 - It tells you what to do and what not to do if you find yourself in one of these situations—very helpful and informative.
 - Evacuation by setting, including day care centers, nursing homes, medical facilities, and prisons.
 - An extensive section on resources and additional materials.
- PowerPoint Presentation: "Train the Trainer"
 - This PowerPoint presentation includes the following:
 - An introduction.
 - An overview of Project Safe.
 - The importance of inclusive plans.
 - Disability awareness and etiquette.
 - An explanation of different impairments that people might have.
 - Developing an inclusive evacuation plan.
 - EV-AC accommodation process.

- Plan development.
- Plan implementation.
- Plan maintenance.
 - With extensive explanations of each phase.
- A section on overcoming fear and inertia.

For information on this CD-ROM, contact: International Center for Disability Information P.O. Box 6080 Morgantown, WV 26506-6080 Direct: (304) 293-7186 Fax: (304) 293-6080 EVAC@icdi.wvu.edu http://evac.icdi.wvu.edu

"Discover How to Make Your Emergency Plan Accessible to Everyone" is part of the TARGET Discovery Series, an online training resource produced by the Department of Agriculture TARGET Center. This session includes:

- An introduction to the USDA TARGET Center and to the TARGET Discovery Series.
- Discussion of priorities for emergency planning.
- Discussion of the importance of communication.
 - "Focus on your message."
 - "Focus on your audience."
- "Why should you include persons with disabilities in your planning? What is the benefit?"

- The keys to inclusion.
- Incident command.
- Overview of the steps in the communication process.
 - o Step 1
 - "Let people know that the plan exists.
 - Invite people to think about how they fit into the plan.
 - Provide ways for people to make their needs known."
 - o Step 2
 - Self-identification: the highest hurdle of all
 - Confidentially
 - Trust
 - Initial considerations
 - Ongoing considerations
 - Step 3
 - "Do it again.
 - Do it again, but do it differently,
 - Do it again, but use another method,
 - Do it again, but focus on another crowd."
- Discussion of various communication modes.
 - Fire alarm
 - Public address (PA) system
 - Text messaging
- Importance of inclusion in planning.

This training session, as well as other sessions, is available to the public at www.da.usda.gov/oo/target/discovery.

"Planning for Emergencies for Floridians with Disabilities" is a collection of short Internet video presentations. All five videos have voiceover commentary as well as a person signing. These presentations include the following:

- Video 1—"Emergencies for Floridians with Disabilities and Special Health Care Needs"
 - Overview of what people can and should do before a disaster.
 - Brief discussion of hurricane season.
 - A resource list:
 - Learn more about planning for people with disabilities and special health care needs and medical resources at:
 - <u>www.floridahealthfinder.gov</u>
 - <u>www.floridadisaster.org</u>
 - o Overview of what to do during hurricane season.
 - Discussion of other considerations before a disaster.
 - "Create a support network."
 - "Identify your resources."
 - "Create a communication plan (get a plan to be a survivor!)."
- Video 2—"Learn the Difference Between a Hurricane Watch and a Hurricane Warning"
 - Discussion of what triggers a hurricane watch to be issued by the National Hurricane Center.

- What your family should do if a hurricane watch is issued.
- Discussion of what triggers a hurricane warning to be issued by the National Hurricane Center.
 - What your family should do if a hurricane warning is issued.
- Video 3— "Evacuation Checklist"
 - A discussion of the importance of creating a checklist:
 - Examples of what might be included on that checklist.
 - "Put up shutters or plywood on all windows and openings in your home."
 - "Move patio furniture, hanging plants, grills, and other outdoor items inside."
 - "Secure any items that are too large to be brought inside."
- Video 4—"Emergency Supply Kit"
 - Importance of an emergency supply kit.
 - Items to include:
 - Credit cards
 - Cash
 - Road maps
 - A battery-operated radio, flashlight, and extra batteries
 - A NOAA weather radio
 - Tools
 - Medications
 - First aid kit
 - Food
 - Water (1 gallon/person/day)
 - Manual can opener

- Toilet paper
- Extra clothing
- Copies of important papers
- Special items for babies, the elderly, people with special needs, and pets.
- Video 5—"Special Needs Registry"
 - Discussion of the importance of special needs registries.
 - "Know in advance which locations are designated as special needs shelters and plan to go to the nearest one when directed by local officials."
 - "Don't forget to take any special items you may need, and plan to be there for at least three days."

You can view these videos at www.floridadisaster.org/disability/video/index.htm.

APPENDIX B: Voluntary Organizations

Examples of faith-based organizations active in disaster relief.

- Ananda Marga Universal Relief Team
- Catholic Charities
- Church World Services
- Hadassah
- Interfaith Alliance
- Jewish Community Relations Council
- Lutheran Disaster Response
- Mennonite Disaster Assistance
- Presbyterian Disaster Assistance
- Salvation Army
- Taiwan Buddhist Tzu Chi Foundation USA
- Unitarian Universalists for a Just Economic Community
- Unitarian Universalist Social Committee on International Relief
- United Methodist Committee on Relief (UMCOR)

Community-based organizations with experience in disaster relief.

- American Radio Relay League
- American Red Cross
- CARE International
- Disaster Psychiatry Outreach
- Feeding America (formerly America's Second Harvest)
- Habitat for Humanity

- International Relief and Development
- International Rescue Committee
- National Organization for Victim Assistance
- Points of Light Institute and the Hands On Network
- Save the Children
- United Way
- Volunteers of America

Examples of civic organizations with a history of contributing resources.

- Elks Club of America
- Feeding America
- Kiwanis International
- Lions Clubs International
- Masonic Clubs of Michigan
- Rotary International

Examples of social service organizations with links to people with disabilities.

- AIDS advocacy organizations
- Area Agency on Aging
- American Council of the Blind
- Centers for Independent Living
- Local health clinics
- Local mental health clinics
- Meals on Wheels
- Senior centers/programs

To learn more about voluntary organizations, visit the National Voluntary Organizations Active in Disaster website at <u>www.nvoad.org</u>.

The FEMA Independent Study free course on volunteers (IS-288 The Role of Voluntary Agencies in Emergency Management) can be found at http://training.fema.gov/IS/crslist.asp.

APPENDIX C: Annotated Bibliography

This appendix offers annotations of selected references and provides additional information on promising studies, technical reports, and guidance materials used in this report. Information offered in quotation marks indicates verbatim excerpts from abstracts or references. A complete set of references for this report can be found in the References section that follows Appendix C.

American Foundation for the Blind. (2005). Carl Augusto blog: Access to Emergency Information. Retrieved from <u>www.afb.org/blog/blog_posts.asp?FolderID=19</u>.

Carl Augusto posted this blog post in the wake of Hurricane Katrina. The post discusses the need for better access to sources of emergency information. Television is not the most accessible source, especially for people with vision and hearing impairments.

American Legion. (No date). *American Legion National Emergency Fund.* Retrieved October 16, 2008, from <u>www.legion.org/veterans/assisstance/nef</u>.

The American Legion National Emergency Fund helps members meet temporary needs such as access to temporary housing, food, water, diapers, and clothing. Eligibility requirements, application forms, and information about how to donate to the fund are available on the fund's Web site.

American Legion. (No date). *American Legion.* Retrieved October 16, 2008, from <u>www.legion.org/homepage.php</u>.

The American Legion homepage is a starting point for researching the organization's programs related to disaster relief or people with disabilities.

American Red Cross. (No date). *Disaster preparedness for people with disabilities.* Retrieved March 5, 2008, from www.redcross.org/services/disaster/beprepared/disability.pdf.

This guide is meant to help people with disabilities prepare themselves for an emergency or a disaster. The caregiver or parent of a person with a disability can also use the guide. The booklet contains narrative suggestions as well as preparedness checklists and space for other information, such as the kinds of assistance that will be needed during an event.

American Veterinary Medical Association. (2008). *Emergency preparedness and response guide*. Retrieved January 10, 2008, from <u>www.avma.org/disaster/emerg_prep_resp_guide.pdf</u>.

The American Veterinary Medical Association guide outlines its program to prepare for disaster and emergencies involving animals. The program and guide take an all-hazards, all-species approach to animals in disasters. The guide also provides fact sheets, animal handling and care guidelines, and sample forms.

Andrews, J. (2001). Safe in the 'hood: Earthquake preparedness in midcity Los Angeles. *Natural Hazards Review, 2*(1), 2–11.

The article describes a pilot earthquake preparedness and mitigation program in Los Angeles. The program included presentations by earthquake experts, the creation of a neighborhood earthquake response and recovery plan, and the organization of an earthquake safety fair that was open to the entire community.

Australian Council for International Development (ACFID). (2006). *Tsunami disability issues*. Retrieved October 17, 2008, from <u>www.acfid.asn.au/what-we-do/issues/disability-and-development</u>.

ACFID's disability and development working group includes more than 40 agencies that work on disability issues. Their report on tsunamis and people with disabilities provides information on why it is important to include people with disabilities in disaster plans and how to do so. The report includes general guidelines, as well as guidelines on water and sanitation, food and nutrition, shelter, and health services.

Baptist Child and Family Services. (2008). Retrieved November 20, 2008, from <u>www.bcfs.net</u>.

This webpage provides information about emergency services provided by Baptist Child and Family Services, with sections devoted to special needs, feeding, sheltering, training, applications and documents, and preparedness.

Bascetta, C. A. (2006). *Disaster preparedness: Limitations in federal evacuation assistance for health facilities should be addressed*. DIANE Publishing.

In this Government Accountability Office report to congressional committees, the author evaluated the evacuation of hospital patients and nursing home residents. The study looked at the challenges faced by staff, the limitations in the design of the National Disaster Medical System, and the federal requirements for hospital and nursing home disaster and evacuation plans.

Berggen, R., & Curiel, T. (2006). After the storm: Health care infrastructure in post-Katrina New Orleans. *New England Journal of Medicine, 354*(15), 1549–1552.

This article describes the difficulties of rebuilding the health care systems in post-Katrina New Orleans. In April 2006, almost 8 months after Hurricane Katrina, the New Orleans hospital system was at around half of its pre-hurricane capacity. The city faces a shortage of nurses, doctors, and other staff to work at the hospitals. The article also discusses the problems facing the medical schools and students in the state.

Best Buddies. (No date). *About us.* Retrieved October 16, 2008, from www.bestbuddies.org/best-buddies.

Best Buddies International provides one-on-one friendships and employment to people with intellectual disabilities. The group's vision is to end the social isolation of this group. Ultimately, the organization would like to fully integrate this group into every part of mainstream society worldwide.

Blanchard, W. (No date). *FEMA Higher Education Project manager discusses the generation of emergency managers*. Retrieved from www.training.fema.gov/EMIWeb/edu/highpapers.asp.

In an interview with the *IAEM Bulletin*, Wayne Blanchard, the manager of the Federal Emergency Management Agency's Higher Education Project, discussed the emergency manager position and how it has changed and continues to change. The interview includes a discussion of emergency manager stereotypes and what direction the position must take in the future.

Block, M., & Siegel, R. (2005). Gulf Coast rebuild to include levees, wetlands. *NPR's All Things Considered*. Retrieved from <u>www.npr.org/templates/story/story.php?storyID=4851768</u>.

In this National Public Radio story, oceanographer Robert Twilley and engineer Hassan Mashriqui speak to two reporters about how to make the coastal areas around New Orleans more resilient to flooding and hurricanes. They offered two solutions, both involving rebuilding the wetlands and upgrading protections such as levees and canals.

Bourque, L., Siegel, J., Kano, M., & Wood, M. (2006). Weathering the storm: The impact of hurricanes on physical and mental health. *The Annals of the Academy of Political and Social Science, 604*(1), 129–151.

This study reports on death, injuries, and diseases caused by pre-Katrina hurricanes. Deaths from salt water drowning have decreased; deaths caused by inland flooding and wind have not changed. Katrina deaths indicate an overrepresented elderly population, which was subject to long-term problems caused by exposure, lack of resources, and a failed government response.

Brookings Institution & Greater New Orleans Community Data Center. (2008). *The New Orleans Index anniversary edition: Three years after Katrina*. Retrieved August 31, 2008, from <u>www.brookings.edu/reports/2007/08neworleansindex.aspx</u>.

This report offers detailed charts and summaries of all dimensions of Hurricane Katrina recovery and presents an important, useful set of information that can help recovery planners with their efforts to understand how a catastrophic event can affect every element in the community. The report is from the three-year mark after the storm.

Burnside, R., Miller, D. S., & Rivera, J. D. (2007). The impact of information and risk perception on the hurricane evacuation decision-making of Greater New Orleans residents. *Sociological Spectrum*, *27*(6), 727–740.

The authors find that information sources are vital to the evacuation process. In most cases, people use a variety of information sources when deciding whether to evacuate. They do not rely just on television or radio; they also take into account the information provided by family and friends. The article also discusses how information is disseminated, and why that is and should be important to the media and policymakers.

Byrne, M., & Davis, E. A. (2005). Preparedness for All, why including people with disabilities in drills is a learning tool: Interagency Chemical Exercise (ICE). *IAEM Bulletin* (April).

The article reports the findings of the Interagency Chemical Exercise (ICE), in which they included people with disabilities. To test the responders' reaction to people with disabilities, four participants were briefed and given the role of a person with disabilities—two were blind and two were in wheelchairs. Each of the four experienced similar treatment by the responders: they were ignored. Other participants (but not responders) helped them through the exercise. The authors have included disability-specific findings as well.

Cahill, A. (2006). *Planning tools you can use to meet the needs of people with disabilities in an emergency: What to do, what not to do, and what difference does it make?* Paper presented at the Working Conference on Emergency Management and Individuals with Disabilities and the Elderly, Washington, DC.

This presentation looks at the different ways in which jurisdictions have collected and dispersed information to emergency personnel on people with special needs within their jurisdiction. It makes recommendations on how states and local governments can implement the different techniques or develop their own. The presentation also looks at how state governments can support local efforts in this area.

California State Independent Living Council. (2004). *The impact of southern California wildfires on people with disabilities.* Retrieved March 3, 2008, from <u>www.calsilc.org/impactCAWildfires.pdf</u>.

The report discusses how people with disabilities were impacted by the 2003 California wildfires. It indicates that the areas affecting the disabled community the most were preparation, notification, evacuation, sheltering and interim services, and recovery. The report discusses each of these areas, and includes recommendations relating to each of the them.

Cashen, K. M. (2006). A compilation of necessary elements for a local government continuity of operations plan. Monterey, CA: Naval Postgraduate School.

The article provides a list of best practice elements that should be contained in a continuity of operations plan. It also contains templates for continuity of operations plans. The author suggests that academics should research continuity of operations plans in order to gain more information about their effectiveness.

Catholic Charities. (2008). *HHS Case Management Pilot Update*. Retrieved October 23, 2008, from www.nvoad.org/Portals/0/Catholic%20Charities%20Update%20HHS%20Pilot.doc.

The update provides information about the progress of developing a model for disaster case management. Catholic Charities is progressing toward a pilot

disaster case management. Catholic Charities is progressing toward a pilot program, possibly in the form of a tabletop exercise. After the tabletop exercise, participants would provide feedback about how the model can be improved.

The Center for an Accessible Society. (No date.) *Supreme Court upholds ADA "integration mandate" in Olmstead decision*. Retrieved September 19, 2008. from <u>www.accessiblesociety.org/topics/ada/olmsteadoverview.htm</u>.

This article announces the Supreme Court's ruling to uphold the 'integration mandate' of the ADA. The Court stated that "states are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." The page also provides information about the legislative history of the ADA and some additional information that led to the Court's decision.

Center for Independence of the Disabled in New York (CID-NY). (2004). Lessons learned from the World Trade Center disaster: Emergency preparedness for people with disabilities in New York, September 2004. Retrieved October 16, 2008, from www.closerware.net/content/cidnyweb/Files/CIDNY_Views/Reports/2004/WTCpa

www.closerware.net/content/cidnyweb/Files/CIDNY_Views/Reports/2004/WTCpa per.doc.

CID-NY uses the experiences of September 11 to better understand preparedness for people with disabilities in New York. The report sets forth four recommendations to give people with disabilities the same chance to prepare for, respond to, and recover from a disaster:

- 1. Emergency responders, as well as relief and other service agencies, must incorporate into their planning and operations an appropriate strategy for ensuring equitable access to response and recovery services for people with disabilities.
- 2. Emergency responders, as well as relief and other service agencies, must incorporate into their planning and operations an appropriate strategy for ensuring equitable access to response and recovery services for people with disabilities.
- 3. The day after a disaster is too late for agencies to start doing outreach to make their services known to people with disabilities.
- 4. During the recovery phase, there must be a priority to restore or address those services and needs most critical to people with disabilities, especially related to access to home attendants, assistive equipment, medication, accessible transportation and temporary shelter, and food delivery." (p. 1)

Centers for Disease Control and Prevention (CDC). (2002). Self-reported increase in asthma severity after the September 11 attacks on the World Trade Center— Manhattan, New York, 2001. Retrieved January 15, 2008, from www.cdc.gov/mmwr/preview/mmwrhtml/mm5135a1.htm.

"This report summarizes the results of a telephone survey conducted among Manhattan residents 5–9 weeks following the September 11, 2001, terrorist attacks on the World Trade Center in lower Manhattan in New York City. The findings indicate that among the 13% of adult respondents with asthma, 27% reported experiencing more severe asthma symptoms after September 11." The report also includes a table showing the results of their analysis. Christensen, K. M., Blair, M., & Holt, J. M. (2007). The built environment, evacuations, and individuals with disabilities. *Journal of Disability Policy Studies, 17*(4), 249–254.

According to the abstract, "This article proposes a framework perspective on 4 forms of emergency evacuation according to the timing and duration of the evacuation (protective, preventive, rescue, and reconstructive), as well as 3 overlying factors that affect all emergency evacuations: the behavior of the individual, the planned systems active in the event, and the environment in which the event occurs. Recent catastrophic events have demonstrated a disproportionate effect of emergency evacuations on individuals with disabilities. Policy and planning discussions for the evacuation of individuals with disabilities would benefit from a more informed and accepted understanding of the complexity of evacuation issues. This article attempts to explain the complexity by proposing a framework that emphasizes the conditions associated with various forms of emergency evacuations and factors that affect an individual's response to these conditions."

Christensen, K. M., Collins, S. D., & Holt, J. M., N. (2006). The relationship between the design of the build environment and the ability of egress to individuals with disabilities. *Review of Disability Studies 2*(3), 24–34.

The article focuses on the relationship between the built environment, the egress of decentralized groups of people, and the ability of people with disabilities to find a means of egress from the built environment during an emergency event. The authors state that most designers of the built environment do not consider people with disabilities at any significant level. These designers also assume that government-imposed regulatory standards are best practices, which the authors state are questionable during disasters.

Citizen Corps. (No date). Retrieved July 14, 2008, from www.citizencorps.gov.

The Citizen Corps website describes the government-funded group as being vital to making our communities stronger, safer, and better prepared for any emergency situation. According to the website, "Citizen Corps asks you to embrace the personal responsibility to be prepared; to get training in first aid and emergency skills; and to volunteer to support local emergency responders, disaster relief, and community safety."

City Cares. (2002). The effective practices guide to creating inclusive and accessible days of services. Retrieved October 30, 2008, from http://nationalserviceresources.org/files/legacy/filemanager/download/711/ InclusiveAccessibleService.pdf.

This document provides guidelines on how to include people with disabilities in volunteer organizations or activities. The document suggests asking three questions while planning an inclusive event: what should we do, who should we

ask to volunteer, and where should we do our service? The guide then provides help answering these questions.

Coker, A. L., Hanks, J. S., Eggleston, K. S., Risser, J., Tee, P. G., Chronister, K. J., et al. (2006). Social and mental health needs assessment of Katrina evacuees. *Disaster Management & Response, 4*(3), 88–94.

The effects of Hurricane Katrina included elevated rates of post-traumatic stress disorder (PTSD). In addition, evacuees experienced significant disruption from health care providers. The social and psychological effects of loss from deaths, injuries, and dissolved social networks are expected to last for a considerable time.

Comerio, M. (1998). *Disaster hits home*. Berkeley, CA: University of California Press.

This is one of the few available books that describes the impact of disaster on various communities, and offers recovery models and perspectives that discuss damage assessment, reconstruction, and efforts to restore housing.

Cornell University Law School. *OLMSTEAD V. L. C. (98-536) 527 U.S. 581 (1999).* Legal Information Institute. Retrieved July 14, 2008, from <u>http://supct.law.cornell.edu/supct/html/98-536.ZS.html</u>.

"The court concluded that, under Title II of the ADA [Americans with Disabilities Act], States are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

Crandall, W., Bentzen, B., Meyers, L., & Easton, R. *Emergency information for people with visual impairments: evaluation of five accessible formats: Part III.* Smith-Kettlewell Rehabilitation Engineering Research Center.

The article describes the purpose and a few activities of the California State Fire Marshal's Emergency Evacuation Information Task Force for People Who Are Blind or Visually Impaired. The main purpose of the task force is to ensure that information on fire-related emergency evacuation and procedures for the visually impaired is provided in an accessible format. The task force has discovered that there is scant research on how people with visual impairments use the different types of accessible evacuation communication. They performed their own research, of which the report provides the results and implications.

Cutter, S. (2005). *The geography of social vulnerability: Race, class, and catastrophe*. Retrieved September 18, 2008, from <u>http://understandingkatrina.ssrc.org/Cutter</u>.

Cutter's essay describes how segregation and similar patterns can marginalize a group so that they are more vulnerable to disaster and take longer to recover.

Daley, W. R., Brown, S., Archer, P., Kruger, E., Jordan, F., Batts, D., et al. (2005). Risk of tornado-related death and injury in Oklahoma, May 3, 1999. *American Journal of Epidemiology*, *161*(2), 1144–1150.

The article looks at all of the deaths, hospital admissions, and emergency room visits related to a particular tornado in Oklahoma to determine which risk factors were most important. The researchers found that people living in mobile homes or those who were outdoors at the time of the tornado were more likely to die or be injured than other groups.

Dash, N., Morrow, B. H., Mainster, J., & Cunningham, L. (2007). Lasting effects of Hurricane Andrew on a working class community. *Natural Hazards Review*, *8*(1), 13–21.

In the only 10-year examination of a disaster recovery process, these authors spell out the lingering socioeconomic effects that stall recovery, sometimes permanently, for those affected.

Deaf and Hard of Hearing Consumer Advocacy Network (DHHCAN). (2004). *Emergency preparedness and emergency access: Lessons learned since 9/11 and recommendations*. Retrieved May 10, 2008, from <u>www.nad.org/atf/cf/{A2A94BC9-2744-4E84-852F-D8C3380D0B12}/</u> DHHCANEmergencyReport.pdf.

The report discusses the weaknesses in the emergency preparedness infrastructure, especially the lack of accessible emergency communications. The report recommends improving the emergency warning and communications systems to make them more accessible to people who have visual and hearing impairments. Another recommendation is to increase the involvement and integration of people with communication impairments in the planning process. The report gives specific recommendations for specific actors in and parts of the emergency management process.

Department of Education. (2005). *Emergency evacuation of people with physical disabilities from buildings: 2004 conference proceedings.* Retrieved December 20, 2008, from www.ncddr.org/new/announcements/pwd-emergency-evac.html.

The conference on Emergency Evacuation of People with Physical Disabilities from Buildings provided a forum to discuss the following issues:

1. "The impact of building and life safety codes on the evacuation of people with physical disabilities from buildings;

- 2. The current evacuation procedures for people with physical disabilities from the first responder perspective;
- 3. The experiences of people with physical disabilities during emergency evacuations from buildings;
- 4. The design and development of different types of evacuation devices; and
- 5. The current state of research on mobility equipment, human factors and egress modeling." (p. 1)

Department of Health and Human Services. (2005). *Hurricane Katrina Bulletin: HIPAA privacy and disclosures in emergency situations*. Retrieved September 5, 2008, from <u>http://privacyruleandresearch.nih.gov/pdf/HurricaneKatrina.pdf</u>.

Providers and health plans covered by the *Health Insurance Portability and Accountability Act* (HIPAA) Privacy Rule can share patient information in the following ways:

- 1. "Treatment: Health care providers can share patient information as necessary to provide treatment.
- 2. Notification: Health care providers can share patient information as necessary to identify, locate and notify family members, guardians, or anyone else responsible for the individual's care or the individual's location, general condition, or death.
- 3. Imminent Danger: Providers can share patient information with anyone as necessary to prevent or lessen a serious and imminent threat to the health and safety of a person or the public—consistent with applicable law and the provider's standards of ethical conduct.
- 4. Facility Director: Health care facilities maintaining a directory of patients can tell people who call or ask about individuals whether the individual is at the facility, their location in the facility, and general condition."

Department of Health and Human Services. (2008). *HIPAA Privacy Rule: Disclosures* for Emergency Preparedness—a decision tool. Retrieved from: www.hhs.gov/ocr/privacy/hipaa/understanding/special/emergency/source1n.html.

The site states, "The [HIPAA] Privacy Rule does not apply to all persons or entities that regularly use, disclose, or store individually identifiable health information."

Department of Health and Human Services. (2008). *HIPAA Privacy Rule: Disclosures* for emergency preparedness—a decision tool. Retrieved September 5, 2008,

from www.hhs.gov/ocr/privacy/hipaa/understanding/special/emergency/source1n.html.

The report assesses the progress made in including people with disabilities in the emergency management process, as mandated in Executive Order 13347. The report specifically looks at how the executive order is being implemented and what results have been achieved in the different programs; it provides recommendations for further progress.

Department of Homeland Security. (2007). *Lessons learned information sharing newsletter (March 2007)*. Retrieved July 10, 2008, from www.llis.gov/displayContent?contentID=23748.

This Department of Homeland Security newsletter includes information on the Homeland Security Exercise and Evaluation Program Resource Page, Critical Infrastructure/Key Resource protection, the Fusion Process Technical Assistance Resource Center, the new LLIS.gov external site and unique documents of interest on LLIS.gov, new original content (seven lessons learned, 14 Practice Notes, and three good stories), and upcoming LLIS.gov Conference participation.

Department of Homeland Security. (No date). *Disabilities and other special needs: Massachusetts Emergency Management Agency's emergency information compact discs for residents who are visually impaired*. Retrieved July 1, 2008, from www.llis.gov.

According to the abstract, "The Massachusetts Emergency Management Agency (MEMA) created compact discs (CDs) with emergency information for visually impaired individuals. MEMA distributed the CDs in communities near three New England nuclear power plants."

Department of Housing and Urban Development. (2001). *Faith-based organizations in community development*. Retrieved November 10, 2008, from www.huduser.org/publications/pdf/faithbased.pdf.

One key finding of this research is that few faith-based organizations are involved in community development activities. The report discusses why so few faithbased organizations are involved in community development, and lists the implications of the findings. The authors also remind readers that much is still unknown or uncertain about the topic, and more research and inquiry is needed.

Department of Justice. (2006). Americans with Disabilities Act: Chapter 1: ADA basics: Statute and regulations. Retrieved December 20, 2008, from www.ada.gov/pcatoolkit/chap1toolkit.htm.

Chapter one of the ADA lays out the fundamentals of the act, including information such as who is covered (i.e., a definition of "disabled"), what is covered, the differences between pre-ADA buildings and post-ADA buildings, and enforcement and remedies.

Department of Justice. (2006). *An ADA guide for local governments.* Retrieved April 16, 2008, from <u>www.ada.gov/emergencyprepguide.htm</u>.

This guide provides action steps that local government officials can take to make preparedness and response programs more accessible to people with disabilities. The guide provides information on every stage of preparedness and response from notification to returning home, and includes pictures that demonstrate many of the action steps.

Department of Justice. (2007). *Americans with Disabilities Act: Chapter 3: General effective communication requirements under Title II of the ADA*. Retrieved December 20, 2008, from <u>www.ada.gov/pcatoolkit/chap3toolkit.htm</u>.

Chapter three of the ADA provides guidance on effective and equal communication. Questions answered by this chapter include:

- 1. What is effective communication?
- 2. What are auxiliary aids and services?
- 3. When is a state or local government required to provide auxiliary aids and services?
- 4. Who chooses the auxiliary aid or service that will be provided?

Department of Justice. (2007). *Americans with Disabilities Act: Chapter 4:9-1-1 and Emergency communications services*. Retrieved September 15, 2008, from <u>www.usdoj.gov</u>.

Chapter four of the ADA discusses the basic requirements for 911 and other communications services that are operated by state and local governments. Questions answered by this chapter include:

- 1. What types of emergency communications services are covered?
- 2. How does a teletypewriter (TTY) work?
- 3. What are voice carryover and hearing carryover?
- 4. How must a call taker handle silent, open line calls?
- 5. What training should call takers receive?
- 6. How are technological changes affecting the way deaf people communicate, and what impact does this have on emergency communication services?
- 7. How can direct emergency communications services be provided to individuals with hearing disabilities who do not have TTYs?
Department of Justice. (2007). *Enforcing the ADA: A status report from the Department of Justice*. Retrieved April 16, 2008, from <u>www.ada.gov/julsep07.htm</u>.

This status report includes information about the Department of Justice's ADA activities in the third quarter of 2007. These activities include ADA litigation, formal settlement agreements, other settlements, and mediation. The report also includes information about technical assistance, other sources of ADA information, and how to file complaints.

Department of Justice. (2008). *ADA best practices toolkit for state and local governments*. Retrieved December 20, 2008, from <u>www.ada.gov/pcatoolkit/toolkitmain.htm</u>.

The ADA Best Practices Toolkit provides information and guidance on all aspects of the ADA. It is organized by chapter and provides all addendums and appendices. The Department of Justice encourages state and local governments to use the toolkit in order to comply with the ADA, but use is not required.

Department of Labor, Office of Disability Employment Policy. (2008). *Part III: Breakout* sessions: Individualizing emergency plans. Retrieved July 3, 2008, from www.dol.gov/odep/pubs/ep/part3g.htm.

The breakout session discussed how to individualize emergency plans for people with disabilities. The discussion topics included how to involve people with disabilities in preparedness and planning, how employers and employees can collaborate on individualized plans in conjunction with the overall agency plans and procedure, and tips and tools for specific areas of concern. Other topics included the legal requirements of employers, and determining whether an individual will require assistance.

Department of Transportation. (2006). *Catastrophic hurricane evacuation plan evaluation: A report to Congress*. Retrieved July 3, 2008, from <u>www.fhwa.dot.gov/reports/hurricanevacuation/rtc_chep_eval.pdf</u>.

This report details the findings of a Department of Transportation review and assessment of federal and state evacuation plans for catastrophic hurricanes and other catastrophic events impacting the Gulf Coast region. This review was requested by Congress and was produced with the cooperation of the Department of Homeland Security. The report includes major findings in the following areas: decision-making and management, planning, public communication and preparedness, evacuation of people with special needs, evacuation operations, sheltering, and training and exercises. The report also includes seven recommendations to improve mass evacuation planning and implementation capabilities.

Disabilityinfo.gov. (No date). *DisabilityInfo.gov*. Retrieved November 8, 2008, from www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=203.

DisabilityInfo.gov provides information and online resources for people with disabilities. The link above provides information about voluntary and community service groups. This includes links to the group's website and a brief description of the group.

The Disaster Center. (No date.) *The Disaster Center (1997–2007)*. Retrieved November 1, 2008, from <u>www.disastercenter.com/agency.htm</u>.

The Disaster Center website provides a list of disaster relief agencies. The list also includes a brief description of the agency.

Drabek, T. E. (1985). Managing the emergency response. *Public Administration Review, 45* (special issue), 85–92.

This article describes the landscape of American emergency management through four structural qualities: localism, lack of standardization, unit diversity, and fragmentation. The author also discusses who responds to emergencies, suggests six strategies for enhancing intergovernmental coordination, and lays out the implications for managing emergency responses.

Drabek, T. E., & McEntire, D. A. (2003). Emergent phenomena and the sociology of disasters: Lessons, trends, and opportunities from the research literature. *Disaster Prevention and Management, 12*(2).

According to the abstract, "Research on emergent behavior has been a significant topic within disaster studies. Through a detailed review of the literature we provide background information about this particular branch of disaster sociology. Following a brief discussion of the process by which literature was selected, important trends and areas of debate are discussed. These include the validation of previous findings, an expansion of the discussion on emergent phenomena and a critique of the bureaucratic approach. We conclude with implications for the theory and practice of emergency management."

Edward, F. L. (2007). Recovering from Katrina: A work in progress—2007. *The Public Manager, 36*(4), 67–72.

According to the abstract, "The American Society for Public Administration's (ASPA) Hurricane Katrina Task Force continued its multiyear study of the disaster and its management, providing its second report at the 2007 ASPA annual conference. The task force examined areas that have improved and those that still need to, as the Gulf Coast states struggle to recover from the disastrous storm season of 2005. The task force discussion was joined by a highly engaged audience, which included members of the Hurricane Katrina Advisory Commission. This article offers public agency leaders information to improve local emergency mitigation, preparedness, response, and recovery planning. The rebuilding plan focuses on the restoration of key landmarks and improvements in facilities for the community. Post-disaster rebuilding requires a vibrant economic base to generate the taxes needed to support local government. Much is left to be done to improve

the US emergency management system, as the federal government refocuses its efforts toward mitigation for natural disasters."

Elder, K., Xirasagar, S., Miller, N., Bowen, S. A., Glover, S., & Piper, C. (2007). African Americans' decisions not to evacuate New Orleans before Hurricane Katrina: A qualitative study. *American Journal of Public Health* 97(Supplement 1), S124–S129.

"The major themes identified related to participants' decisions to not evacuate were as follows: (1) perceived susceptibility, including optimism about the outcome because of riding out past hurricanes at home and religious faith; (2) perceived severity of the hurricane because of inconsistent evacuation orders; (3) barriers because of financial constraints and neighborhood crime; and (4) perceived racism and inequities."

 Enarson, E., & Morrow, B. H. (1997). A gendered perspective: The voices of women. In
 W. Peacock, B. H. Morrow, & H. Gladwin (Eds.), *Hurricane Andrew: Ethnicity,* gender, and the sociology of disasters (pp. 116–140). London: Routledge.

This volume and this chapter offer insights into the experiences of people surviving disaster as they are impacted by the differential and discriminatory effects of racism, sexism and class issues. The chapter provides insight into the realities of low income issues in a disaster context.

Enos, E. (2008). Custom frame. *Fire Chief.* Retrieved, from <u>http://firechief.com/leadership/public-education/custom_frames_0501</u>.

The author discusses how a frame analysis has shown some of the weaknesses of the emergency operations plan in the city of Petersburg, VA. The author provides a description of each of the six stages of frame analysis, which is based on the book *Strategic Decision Making: A Best Practice Blueprint* by George Wright. Enos suggests using scenario planning after the frame analysis to further emphasize the importance of hazard mitigation.

Environmental Protection Agency. (1995). *Planning for disaster debris*. Retrieved January 15, 2008, from <u>www.epa.gov/osw/conserve/rrr/imr/cdm/pubs/disaster.htm</u>.

This guide, based on the experiences of other communities, suggests some helpful planning considerations. It describes "[s]teps a community can take to prepare for dealing with the waste created by natural disasters and to speed recovery after such disasters" and "[w]ays communities can reduce the burden on their municipal solid waste management systems in the event of a natural disaster." Federal Communications Commission (FCC). (2001). *Public notice: Reminder to video* programming distributors of obligation to make emergency information accessible to persons with hearing or vision disabilities. Retrieved January 8, 2009, from www.fcc.gov/cgb/dro/reminder.pdf.

Because the FCC had received complaints from several states that the original rule mandating video programmers to provide audio emergency information in other accessible forms was not being met, the FCC published this reminder of the rule. The reminder includes a fact sheet with information about rules requiring access and how to file a complaint.

Federal Communications Commission. (2006). *Public notice: Reminder to video* programming distributors of obligation to make emergency information accessible to persons with hearing or vision disabilities. Retrieved January 8, 2009, from <u>http://hraunfoss.fcc.gov/edocs_public/attachmatch/DA-06-1483A1.pdf</u>.

This public notice reminds video programming distributors of their obligation to provide emergency information in accessible forms. The notice also provides information on the impact of the 100 percent closed-captioning benchmark on the provision, as well as information about consumer complaints and enforcement.

Federal Emergency Management Agency. (No date). *FEMA's Project Impact making a difference*. Retrieved February 20, 2009, from <u>www.hurricaneville.com/project_impact.html</u>.

The webpage provides information on how Project Impact has been used to help mitigate the effects of hurricanes. The town most discussed on the page is Freeport, which is on Long Island in New York. The page chronicles how Freeport used Project Impact successfully, and then passed that knowledge to other communities in the area.

Federal Emergency Management Agency. (No date). *FEMA listing of disability needs*. Retrieved November 8, 2008, from www.fema.gov/plan/prepare/specialplans.shtm#resources.

The webpage provides information about the additional steps that people with disabilities will have to take in the event of a disaster. Each general type of disability is addressed separately, but there are some general statements on how to check for hazards in the home and on how to be ready to evacuate.

Federal Emergency Management Agency. (1995). *Emergency procedures for people with disabilities in office occupancy.* Retrieved April 19, 2008, from www.usfa.dhs.gov/downloads/pdf/publications/fa-154.pdf.

This guide published by FEMA and the U.S. Fire Administration provides information to employers of people with disabilities. The guide is meant to help employers provide these employees with safe egress during an event. This includes help with detection, notification, and movement.

Federal Emergency Management Agency. (1999). *Project Impact: Building a disasterresistant community*. Retrieved, from <u>www.fema.gov/news/newsrelease.fema?id=8895</u>.

The news release describes Project Impact, a four-pronged program meant to build safe communities. Individuals, businesses, and community leaders will take the following steps: Identify and recruit Project Impact partners in the community, such as local government leaders, civic and volunteer groups, businesses, and individual citizens; determine the community's risk for falling victim to natural disasters; set priorities and target resources to reduce the impact of future disasters; and keep the entire community informed and focused on Project Impact's ability to reduce damage and costs of future disasters.

Federal Emergency Management Agency. (2002). Orientation manual for first responders on the evacuation of people with disabilities. Retrieved April 19, 2008, from <u>www.eadassociates.com/fa-235-508.pdf</u>.

The guide is meant to give first responders information on working with people with disabilities. It is meant to make first responders more aware of the unique issues surrounding the evacuation of people with disabilities. The guide is organized into sections on emergency preparedness, categories of impairments, and mobility.

Federal Emergency Management Agency. (2003). *FEMA and the national voluntary* organizations active in disaster partner in Citizen Corps. Retrieved October 22, 2008, from www.fema.gov/news/newsrelease.fema?id=3060.

The news release announced the official affiliation between the National Voluntary Organizations Active in Disaster (NVOAD) and the Citizen Corps initiative. The purpose of the partnership is to raise public awareness about emergency preparedness, first aid and disaster response training, and disaster-related volunteer service activities of NVOAD member organizations through the national, state, and local Citizen Corps Councils.

Federal Emergency Management Agency. (2003). *G197: Emergency planning and special needs populations—student manual.*

Available at the FEMA website as an independent study course or through special offerings by qualified instructors.

Federal Emergency Management Agency. (2004). *Preparing for disaster for people with disabilities and other special needs*. Retrieved February 25, 2008, from www.redcross.org/images/pdfs/preparedness/A4497.pdf.

The guide provides information for people with disabilities and their caregivers about what to do to prepare for a disaster. It also provides information about what to do when disaster strikes, including a list of items for a disaster supply kit. Federal Emergency Management Agency. (2005). *Louisiana unmet needs committees bring help to Katrina survivors.* Retrieved October 22, 2008, from <u>www.fema.gov/news/newsrelease.fema?id=21498</u>.

The news release describes the convening of unmet needs committees. These unmet needs committees are organized at the parish level and focus on individuals and families who have significant unmet needs after receiving the maximum allowed assistance from government disaster programs. The committees bring together local community representatives from private agencies, institutions, churches, and not-for-profit organizations, as well as individuals, to develop reasonable solutions for individuals in crisis.

Federal Emergency Management Agency. (2007). *IS-1: Emergency Manager: An orientation to the position*. Retrieved January 15, 2009, from http://training.fema.gov/EMIweb/IS/is1Ist.asp.

The course covers the basics of emergency management, and is an introduction to the principles and tasks involved in emergency management.

Federal Emergency Management Agency. (2008). *FEMA history.* Retrieved, from <u>www.fema.gov/about/history.shtm</u>.

The webpage provides a brief history of FEMA. The first section discusses the period of time leading up to the formation of FEMA. The second section describes Executive Order 12127 that established FEMA. The last section discusses FEMA and the new homeland security mission.

Federal Emergency Management Agency. (2008). *Interim emergency management planning guide for special needs populations*. Retrieved September 2008, from www.fema.gov/pdf/media/2008/301.pdf.

According to the guide, "This guide is intended as a tool for State, Territorial, Tribal, and Local emergency managers in the development of emergency operations plans (EOPs) that are inclusive of the entire population of a jurisdiction of any size. It provides recommendations for planning for special needs populations" (p. 1).

Federal Emergency Management Agency. (2008). *IS 632: Debris operations* Retrieved January 15, 2008, from <u>http://training.fema.gov/EMIWeb/IS/is632.asp</u>.

From the course description: "The course is divided into two major topic areas: General Debris Removal Operations and Critical Issues in Debris Operations. There is also a resource center, which includes Public Assistance documents, test resources (exam), sample forms, key content, and a link to the FEMA Web site." Federal Emergency Management Agency. (2008). *Press Release: FEMA launches consolidated website for disaster applicants*. Retrieved January 7, 2009, from www.fema.gov/news/newsrelease.fema?id=47195.

The press release announces the launch of <u>www.disasterassistance.gov</u>, which "provides a central location for information about forms of disaster assistance. At the time of launch, users can: apply for FEMA assistance and U.S. Small Business Administration loans through a single online application; check the status of their online application(s); choose to have their Social Security benefits redirected to a new address; have access to their federal student loan account information."

Federal Emergency Management Agency. (2008). *Rock Springs to host town meeting on flood recovery*. Retrieved September 27, 2008, from www.fema.gov/news/newsrelease.fema?i=45784.

The press release discusses public meetings in Rock Springs, WI. The meetings were held to gather information that will be used to establish a framework for a plan to strengthen flood prevention defenses and remove obstacles to flood mitigation.

Federal Emergency Management Agency. (2009). *FEMA in Focus: Where FEMA is now, and where FEMA is going* (Twitter news release). Retrieved February 20, 2009, from www.fema.gov/news/newsrelease.fema?id=47256.

The press release provides information on an all-access media press conference held by FEMA Administrator using the agency's Twitter account (<u>www.twitter.com/femainfocus</u>). The purpose of the press conference is to show the usefulness of social networking sites in emergency management. During the press conference, any person with a Twitter account who follows FEMA could ask questions and receive a reply from the Administrator or a FEMA representative.

Federal Emergency Management Agency. (2009). *National disaster housing strategy*. Retrieved February 20, 2009, from <u>www.fema.gov</u>.

Released January 19, 2009, this strategy directs states to establish housing task forces that include disability representatives. The detailed guidance materials also include an annex on special needs issues.

Federal Heights. (2007). *Resident lock box program*. Retrieved January 31, 2009, from www.ci.federal-heights.co.us/index2.php?option=com_content&do_pdf=1&id=79.

The site describes a resident lock box program in the city of Federal Heights, CO. The lock box program provides a safe, sturdy, and secure lock box on the outside of a residence that contains an access key for emergency personnel to use when necessary. This allows emergency personnel to enter a residence without damaging the windows or doors. The lock box program is open to the entire community but will be especially beneficial to the elderly and to people with disabilities who might be unable to answer the door.

Feeding America. (No date). *About us.* Retrieved October 16, 2008, from www.feedingamerica.org/about us/%20feeding america.html.

"Feeding America is the largest domestic hunger-relief charity in America. It provides assistance to about 25 million low-income people every year. On the About Us page, you can find information or links to information on Feeding America's statement of values, staff, board of directors, and their network of food banks."

Fernandez, L. S., Byard, D., Lin, C. C., Benson, S., & Barbera, J. A. (2002). Frail elderly as disaster victims: Emergency management strategies. *Prehospital and Disaster Medicine*, *17*(2), 67–74.

The purpose of the study was to identify the vulnerabilities of the elderly during disasters and develop strategies to address them. The researchers concluded that because the number of elderly in the United States is rapidly growing, the elderly should be included as a special population in emergency plans. The authors also provide strategies and recommendations.

Fink, B., Windon, R., Beaulaurier, R., Contreras, G., Dilley, L., & Kissane, R. J. (2001). Social service organizations and welfare reform. Retrieved October 16, 2008, from www.mdrc.org/publications/83/workpaper.html.

This report looks at how agency staff members view welfare reform, including general knowledge, the impact of welfare reform, and expectations. The findings show preliminary insights on how new government policies affect existing agencies and policies. The findings include:

- 1. "Agency staff was generally aware that major changes in welfare policy had occurred, but few expressed detailed knowledge of the policies.
- 2. The overwhelming majority of respondents expressed negative or mixed views of welfare reform.
- 3. Changes attributed to welfare reform began soon after the policies were implemented, but these changes have not yet been as dramatic as the critics of reform have predicted.
- 4. Changes in the demand for education and training services have been the biggest effect of welfare reform so far. Agencies' experiences—whether demand increased or decreased depended partly on the state and local welfare policies and how they were implemented.

- 5. Most basic needs organizations have not yet seen an increase in demand. Nor, however, have they seen increases in private donations as predicted by supporters of welfare reform. Moreover, the experiences of a few Cleveland agencies suggest that time limits or sanctioning policies that cause many people to lose benefits will significantly affect the demand faced by these private charities.
- 6. Despite the limited impact that the first year of welfare reform had on community organizations, respondents anticipate that the new policies will appreciably increase the demand for their services in the future. Many, however, have no plans for meeting the new needs or the possible rise in demand."
- Fothergill, A. (2000). Knowledge transfer between researchers and practitioners. *Natural Hazards Review, 1*(2), 91–98.

According to the abstract, "This study assesses the knowledge transfer process in the natural hazards and disasters field. The study includes 78 interviews with a diverse sample of hazards professionals. How information travels—or does not travel—from academic researchers to practitioners in the field is analyzed using these interview data, and four conceptual categories emerged concerning factors affecting the knowledge transfer process. These categories are (1) culture; (2) institutions; (3) links; and (4) interaction. This article discusses each of these factors and concludes with several recommendations to improve knowledge transfer in the hazards field."

Fothergill, A., Maestas, E., & Darlington, J. (1999). Race, ethnicity, and disasters in the United States. *Disasters*, *23*(2), 156–173.

This is a thorough literature review of what is known from scientific studies about issues of race and ethnicity in disaster situations. It is considered a landmark effort to assess what is known and identify needed research.

Fox, M. H., White, G. W., Rooney, C., & Rowland, J. L. (2007). Disaster preparedness and response for persons with mobility impairments. *Journal of Disability Policy Studies, 17*(4), 196–205.

This article discusses the impact of disasters on county-level preparedness for people with disabilities. The researchers looked at disability surveillance capacity, the extent to which the disaster experience influenced changes in policies and practices, whether persons with disabilities were involved in the planning process, what factors appeared to drive the planning process, and whether current policies and procedures could be best practices. The authors suggest improving training, awareness, and surveillance in order to improve response to people with disabilities.

Gardner, E., & Hollman, S. (2005). *Press Release: Landmark settlement requires* accessible evacuation procedures at all Marshalls stores nationwide. Retrieved February 20, 2009, from <u>www.eadassociates.com/marshalls.html</u>.

The settlement discussed in the press release will require Marshalls, a major discount retailer, to provide accessible evacuation routes for shoppers with disabilities in all of its stores nationwide. The settlement was made possible by an earlier decision which stated that the Americans with Disabilities Act requires public accommodations such as malls, restaurants, and movie theaters to consider people with disabilities when developing emergency evacuation plans.

Gerber, B. J. (2007). Disaster management in the United States: Examining key political and policy challenges. *The Policy Studies Journal, 35*(2), 227–238.

This article focuses on four key issues: the concept of disaster vulnerability, how individuals respond to hazard risks, challenges associated with effective hazard mitigation, and the idea of policy learning in the area of disasters. The discussion on each issue is centered around a recent book on the subject. After discussing each issue, the authors provide a discussion section that ties each issue to the others.

Government Accountability Office. (2006). *Preliminary observations on the evacuation of vulnerable populations due to hurricanes and other disasters.* Retrieved March 3, 2008, from www.gao.gov/new.items/d06790t.pdf.

This report provides preliminary observations on:

- 1. "Challenges faced by hospital and nursing home administrators that are related to hurricane evacuations;
- 2. The federal program that supports the evacuation of patients needing hospital care and nursing home residents; and
- 3. Challenges states and localities face in preparing for and carrying out the evacuation of transportation-disadvantaged populations and efforts to address evacuation needs."

Government Accountability Office. (2007). *Hurricanes Katrina and Rita: Federal actions could enhance preparedness of certain state-administered federal support programs.* Retrieved January 6, 2009, from <u>www.gao.gov/new.items/d07219.pdf</u>.

GAO assessed (Highlights Page):

- 1. "Challenges the hurricanes created for programs to take applications and pay benefits,
- 2. Factors that helped or hindered programs' efforts, and

3. Areas that warrant further attention and actions being taken to improve programs' disaster response."

GAO recommends (Highlights Page):

- "That HHS take steps, such as disseminating information on promising practices and further study of case management approaches as part of its efforts to improve delivery of human services during disasters;
- 2. That HHS works with states to collect information on the need for TANF disaster planning."
- 3. HHS agreed with the recommendations on actions to strengthen its recent efforts, but did not agree to address TANF planning specifically.

Government Accountability Office. (2008). *National disaster response: FEMA should take action to improve capacity and coordination between government and voluntary sectors.* Retrieved December 15, 2008, from <u>www.gao.gov/new.items/d08369.pdf</u>.

This report examines (Highlights Page):

- "Why the primary role for mass care in the NRF shifted from the Red Cross to the Federal Emergency Management Agency (FEMA), and potential issues with implementation,
- 2. Whether National Voluntary Organizations Active in Disasters (NVOAD)—an umbrella organization of 49 voluntary agencies—is equipped to fulfill its NRF role,
- 3. The extent to which FEMA has addressed issues with mass care for the disabled since the hurricanes,
- 4. The extent to which major voluntary agencies have prepared to better serve the disabled since the hurricanes, and
- 5. The extent to which FEMA has addressed issues voluntary agencies faced in receiving Public Assistance reimbursement."

GAO recommends that (Highlights Page):

- 1. "FEMA improve coordination with voluntary agencies, such as by enhancing capabilities of its specialized staff,
- 2. NVOAD improve information-sharing during the response to disasters, and

3. FEMA increase coordination with the National Council on Disability. Agency officials agreed with the recommendations."

Government Accountability Office. (2008). Voluntary organizations: FEMA should more fully assess organizations' mass care capabilities and update the Red Cross role in catastrophic events. Retrieved October 23, 2008, from http://gao.gov/products/GAO-08-823.

This report examines (Highlights Page):

- 1. "The roles of five voluntary organizations in providing mass care and other services,
- 2. The steps they have taken to improve service delivery,
- 3. Their current capabilities for responding to mass care needs, and
- 4. The challenges they face in preparing for large-scale disasters."

GAO recommends (Highlights Page):

- 1. "That FEMA update and document the Red Cross's role in a catastrophic event,
- 2. Take steps to incorporate voluntary organizations' capabilities in its assessments, and
- 3. Clarify funding guidance for certain disaster preparedness grants."
- 4. FEMA agreed with two recommendations, but disagreed with the recommendation to better incorporate voluntary organizations in assessments.
- Hammitt, J. (1994). Earthquake! Coping with the aftermath can be a disaster, too, for people with disabilities. *Mainstream*. Retrieved February 20, 2009, from www.accessiblesociety.org/topics/independentliving/quake.htm.

This article discusses the experience of people with disabilities during the Northridge earthquake of 1994. It showed how a disaster may sever the link between people with disabilities and the way they receive assistance—in this case through the Office of Disabled Student Services at California State University–Northridge. The author discusses the issues that arise when people with disabilities are not included in emergency plans.

Harris Interactive. (2004). Emergency Preparedness Survey.

The Emergency Preparedness Survey was commissioned by the National Organization on Disability to study how emergency management at the state and

local levels has incorporated people with disabilities into emergency plans. The methodology involved interviewing 197 emergency management officials. The survey generally concluded that steps are being taken to incorporate the needs of people with disabilities, but more can and should be done.

Heinz Center. (2002). Human links to coastal disaster. Washington, DC: Heinz Center.

This report focuses on how to build more disaster-resistant coastal communities. The report advocates starting this process at the lowest levels: individual households and neighborhoods. The report discusses these areas of concern (p. 1): human vulnerability of coastal communities, with emphasis on identification of high-risk populations; human impacts of disasters, including the mental and physical health effects on individuals; and the impacts of natural disasters on the social institutions that make up coastal communities. The report also makes recommendations in three general categories: human vulnerability, human impacts, and community and institutional impacts.

Hemingway, L., & Priestly, M. (2006). Natural hazards, human vulnerability and disabling societies: A disaster for disabled people? *Journal of Disability Policy Studies, 2*(3), 57–67.

This article looks at the assumption that people with disabilities are included as a vulnerable population. The authors look at both Hurricane Katrina and the Asian tsunami of 2004 to assess the vulnerability. They conclude that the vulnerability of people with disabilities arises from socially created forms of disadvantage and exclusion, not from their physical or cognitive impairments. The authors suggest that strengthening the community and organizations that link people with disabilities with the larger community will make them more resilient during an event.

Heppner, C. (2005). *Cheryl Heppner's remarks, National Council on Disability press conference.* Northern Virginia Resource Center for Deaf and Hard of Hearing Persons. Retrieved July 4, 2008, from www.nvrc.org/content.aspx?page=6994§ion=8.

The remarks presented at this press conference reiterate the fact that people with disabilities should be included in the emergency management and homeland security planning process from the beginning. The speaker states that if this does not occur, "no system will be effective and it will always be costly to fix it later."

Herr, R. (2007). *CERT training for the deaf and hard of hearing in Denver*. Retrieved October 30, 2008, from <u>http://denver.yourhub.com/Denver/Stories/Community/Community-happenings/Story~377813.aspx</u>.

The article describes the first CERT training in Colorado that was devoted specifically to hearing impairments. The training was accessible to all participants through the use of sign interpreters and captioning. There were problems with some of the videos not being captioned. The participants and

instructors also discussed how to adapt the training and CERT program as a whole for people with hearing impairments. Overall, participants felt empowered by their CERT training.

Holdeman, E. (2005). Destroying FEMA. *WashingtonPost.com.* Retrieved from <u>www.washingtonpost.com/wp-</u> dyn/content/article/2005/08/29/AR2005082901445 pf.html.

In this article written just one day after Hurricane Katrina made landfall, the author—an emergency manager—discusses the effect of moving FEMA under the direction of the Department of Homeland Security and the new homeland security mission on the function and effectiveness of FEMA. The author also praises Project Impact and James Lee Witt for helping to mitigate the effects of disaster. The final sections of the article highlight the disastrous effects of taking disaster preparedness out of the hands of FEMA.

Hyer, K., Brown, L. M., Berman, A., & Polivka-West, L. (2006). GrantWatch: Report: Establishing and refining hurricane response systems for long-term care facilities. *Health Affairs-Web Exclusive* 25(5).

The authors discuss the 2006 Hurricane Summit. Representatives from five Gulf Coast states that sustained damage during the 2005 hurricane season and Georgia (which received hurricane evacuees) attended the summit. The summit participants created a list of five lessons learned and associated grant opportunities. They include (pp. w409–w410):

- 1. "Coordinating emergency management structures with long-term care services.
- 2. Establishing decision-making criteria and guidelines for resident evacuation.
- 3. Developing effective communication systems.
- 4. Establishing resident tracking and case management systems.
- 5. Development and refinement of disaster preparedness guides."

This checklist is to be used in conjunction with the American Red Cross preparedness guide, the Independent Living Resource Center San Francisco's Earthquake Tips for People with a Specific Disability, Tips for Collecting Emergency Documents, and Tips for Creating an Emergency Health information Card. The sections discuss establishing a personal network, traveling, health cards, emergency contact lists, emergency documents, conducting an ability self-

Independent Living Resource Center San Francisco. *Earthquake tips for people with disabilities.* [Electronic version]. Retrieved April 9, 2008, from www.preparenow.org/eqtips.html.

assessment, communication, supplies to always carry, disaster kits, medication, and assistive devices and equipment.

International Center for Disability Information. (2005). *Project Safe EV-AC.* Retrieved July 4, 2008, from <u>http://evac.icdi.wvu.edu</u>.

"Project Safe EV-AC seeks to improve the evacuation of people with disabilities during emergencies by providing training on the evacuation and accommodation (EV-AC) of this group. They state that all of their training materials are sound, accessible, free, and effective (S.A.F.E.). The project aims to address the problems surrounding evacuation by developing an effective training program for overcoming avoidance behavior and integrating available best safety evacuation practices into easy-to-use training materials."

International Code Council. (2008). *ICC 500-2008: ICC/NSSA Standard for the design and construction of storm shelters, American national standard*. Washington, DC: International Code Council.

From <u>www.iccsafe.org/e/prodshow.html?prodid=7026S08</u>: "This standard provides minimum design and construction requirements for storm shelters that provide a safe refuge from storms that produce high winds, hurricanes, and tornadoes. The magnitude of wind speeds associated with these events require building occupants and residents to evacuate the area or seek protection in a shelter designed for resistance to extraordinary loads and flying debris. This standard provides design requirements for the main wind resisting structural system and components and cladding of these shelters, and provides basic occupant life safety and health requirements for these shelters including means of egress, lighting, sanitation, ventilation, fire safety, and minimum required floor space for occupants."

Jenkins, P., & Phillips, B. D. (2008). Battered women, catastrophe and the context of safety. *NWSA Journal, 20*(3), 49–68.

This article seeks to add to the understanding of how disasters affect women who are the survivors or victims of domestic violence. The authors used data from focus groups with survivors, interviews with advocates, secondary data on the incidence of domestic violence, and observations at community meetings (p. 55). The article includes a discussion of both evacuating and returning to New Orleans. The authors recommend that emergency managers and planners consider the special needs of victims of domestic abuse and the programs that serve them during the preparedness process.

Johns Hopkins University Center for Civil Society. (2008). *Fact sheet*. Retrieved October 16, 2008, from www.jhu.edu/listeningpost/factsheet/listeningpostfactsheet_august2008.pdf.

The fact sheet provides information about the Center for Civil Society's Listening Post Project. The Listening Post Project seeks to identify how nonprofit

organizations are being affected by the major developments confronting them and to explore promising approaches that organizations have tried in response (p. 1). The goal of the project is to provide practical knowledge and to integrate knowledge into teaching and research (p. 1). Issues discussed and researched by the participants have included advocacy and lobbying, personnel issues, governance, and accountability (p. 2).

Kailes, J. (2005). Disaster services and "special needs": Term of art or meaningless term. *IAEM Bulletin, 22*(4).

Kailes argues that the use of "special needs" does a disservice to the people who are lumped into the broad category. She states that if the term "special needs" is replaced by terms that refer to the specific disability or situation, emergency managers and planners would have a much more accurate view of how to plan for and respond to these groups. Her suggestions include using the more specific "medical needs shelter" instead of "special needs" shelter, providing shelter and other disaster services to non-English speakers in their own language, estimating or anticipating the number of citizens in a jurisdiction with memory or understanding limitations, and remembering that not all elderly people need to be included in this category (p. 4).

Kailes, J. (2005). Why and how to include people with disabilities in your emergency planning process? Retrieved from www.nobodyleftbehind2.org/findings/pdfs/FinalWhyandHow.pdf.

Kailes argues that including people with disabilities or qualified advisors will help an organization: take advantage of the wealth, depth, and breadth of information available from the disability community, and effectively plan to include people with disabilities and activity limitations as well as prevent making a variety of sometimes costly mistakes (p. 3). The author also provides information on what makes a person a qualified advisor, how to recruit people with disabilities to help, and how to accommodate people with disabilities during the process.

Kailes, J., & Enders, A. (2006). Moving beyond "special needs": A function-based framework for emergency management and planning. *Journal of Disability Policy Studies, 17*(4), 230–237.

The authors argue that using a framework based on essential functional needs, such as maintaining functional independence, communication, supervision, medical care, and transportation, will provide greater capacity for disaster preparation and response. They argue that this framework is more flexible, accurate, and effective (p. 18). This type of framework is needed to build appropriate levels of capacity for disaster preparation, and emergency response processes, procedures, and systems; adopt appropriate guidelines and protocols for resource management; strengthen service delivery and training; improve response successes; prevent secondary conditions; reduce institutionalization and the use of scarce, expensive, and intensive emergency medical services and

the use of "downstream" services; allow disaster services to integrate the value that everyone should have the chance to survive; and translate lessons documented into lessons applied (p. 19).

Kaiser Family Foundation, & United Hospital Fund. (2002). New York's disaster relief Medicaid: Insights and implications for covering low-income people. Retrieved January 15, 2009, from <u>www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=</u> 14137.

The study was commissioned to observe New Yorkers' experience with the Disaster Relief Program. The key findings of the study include (pp. iii–v): Enrollees are diverse and previously lacked access to care, enrollees had positive views of the program, enrollees praise the enrollment process, enrollment leads to use of primary and preventive services, and enrollees are confused about the transition process. The policy implications of the study include (pp. vi–vii): Higher income eligibility levels and no asset test made a difference, an easier enrollment process paved the way, enrollees benefited from assistance completing applications and the in-language forms and workers, and the encouragement of positive word of mouth was key.

Kaiser Family Foundation. (2005). *Survey of Hurricane Katrina evacuees*. The Washington Post, Kaiser Family Foundation, Harvard University. Retrieved from www.kff.org/newsmedia/upload/7401.pdf.

This report is the result of a three-way partnership and an experiment in combining survey research and reporting to better inform the public (p. 1). The Kaiser Family Foundation, *Washington Post*, and Harvard School of Public Health jointly design and analyze surveys on major issues. The *Washington Post* then reports the result in order to dismiss misperceptions and poor information. This report details the results of their survey of Hurricane Katrina evacuees. The report includes a detailed methodology and the resulting data collected.

Katrina Disability Information. (2008). Katrina disability information. Retrieved January 15, 2009, from <u>http://katrinadisability.info</u>.

The website provides a wide variety of information about disasters and emergency events for people with disabilities. The main page includes sections entitled "Breaking News," "Be Prepared," and "Important Disaster Preparedness Articles and Guides."

Klein, K. R., & Nagel, N. E. (2007). Mass medical evacuation: Hurricane Katrina and nursing experiences at the New Orleans airport. *Disaster Management and Response*, *5*(2).

From the abstract: "This article describes the experiences and solutions of nurses and other personnel from 3 Disaster Medical Assistance Teams assigned to the New Orleans airport responsible for perhaps the most massive patient assessment, stabilization, and evacuation operation in U.S. history. As the frequency of disasters continues to rise, it is imperative that the nursing profession realizes its value in the disaster arena and continually take leadership roles."

Labadie, J. R. (1984). Problems in local emergency management. *Environmental Management, 8*(6), 489–494.

This article focuses on the role of the emergency manager. It includes discussions on stereotypical organizational roles and the constraints placed on the emergency manager. The article also includes suggestions for solving the problems surrounding the role and topics for further research.

Landrigan, P. J., Lioy, P. J., Thurston, G., Berkowitz, G., Chen, L. C., Chillrud, S. N., et al. (2004). Health and environmental consequences of the World Trade Center disasters. *Environmental Health Perspectives*, 112(6), 731–739.

The authors of this study researched the effects of exposure to the World Trade Center (WTC) destruction. The researchers used methods such as ambient air sampling; analyses of outdoor and indoor settled dust; high-altitude imaging and modeling of the atmospheric plume; inhalation studies of WTC dust in mice; and clinical examinations, community surveys, and prospective epidemiologic studies of exposed populations (p. 731). They found that exposure to the WTC site was associated with adverse health effects (p. 731). They outline their methods and results in detail in the article.

Lin, S., Reibman, J., Bowers, J. A., Hwang, S.-A., Hoerning, A., Gomez, M. I., et al. (2005). Upper respiratory symptoms and other health effects among residents living near the World Trade site after September 11, 2001. *American Journal of Epidemiology*, 162(6), 499–507.

This article reports the results of the author's research on changes in respiratory health after 9/11 in residents near the World Trade Center. To determine if any changes occurred, the authors compared the group living near the site to a control group. The results of the study showed that residents living near the site reported higher rates of new respiratory symptoms than residents in the control group (p. 499).

Lindell, M., & Perry, R. (2004). *Communicating risk to multiethnic communities*. Thousand Oaks, CA: Sage.

This book covers models and research on the dissemination of warnings in a community context. The text includes thoroughly developed applications that are based on scientific research.

Litaker Group. (2006). The health and medical response to Hurricanes Katrina and Rita by the Texas Department of State Health Services: After-action report.

The purpose of this report was to identify strengths and weaknesses of the health and medical response to hurricanes Katrina and Rita by the Texas Department of State Health. That information would then be used to improve operational performance in the next storm. The major findings of the report fall into the following categories: information flow, roles and responsibilities, preparedness, and continuity of operations.

Litman, T. (2006). Lessons from Katrina and Rita: What major disasters can teach transportation planners. *Journal of Transportation Engineering*, *132*(1), 11–18.

The article discusses ways to improve transportation services during the response phase. These improvements are based on the problems that arose during the response to hurricanes Katrina and Rita. The best practices section of the article states that emergency transportation plans should include (p. 16):

- 1. "Communication and support networks to serve the most vulnerable people;
- 2. Planning to allow quick deployment of buses, vans, and trains;
- 3. A system to prioritize evacuations based on factors such as geographic location (evacuate the highest risk areas first), and individual need and ability;
- 4. Emergency evacuation information should regularly be distributed to at-risk populations and all officials;
- 5. Coordination of fuel, emergency repair, and other support services;
- 6. Priority for buses and other high occupancy vehicles where critical resources are limited."
- Loy, B., & Batiste, L. C. (2004). Evacuation preparedness: Managing the safety of employees with disabilities. *Occupational Health & Safety*, *73*(9), 112–117.

The article discusses how employers can manage the safety of employees with disabilities during evacuation (p. 112). The first section of the article describes the laws and guidelines that dictate planning for the evacuation of people with disabilities, which is limited. The bulk of the article discusses in detail the steps in designing an emergency evacuation plan for people with disabilities.

Malievskaya, E., Rosenberg, N., & Markowitz, S. (2002). Assessing the health of immigrant workers near Ground Zero: Preliminary results of the World Trade Center day laborer medical monitory project. *American Journal of Industrial Medicine*, 42(6), 548–549.

The authors report four lessons learned from their study of the health effects of Ground Zero (p. 549):

- 1. "Respiratory illness among fire fighters demonstrated that some Ground Zero workers have become ill as a result of exposures at the site.
- 2. Systematic and appropriate occupational medical screenings for workers at or near Ground Zero has not occurred in a timely and coordinated fashion.
- 3. Humane occupational safety practices are not universally engrained in American industry.
- 4. Immigrant occupational health problems are generally considered among the most difficult to address, much less to resolve, in occupational health."

McEntire, D. (1999). Issues in disaster relief: Progress, perpetual problems and prospective solutions. *Disaster Prevention and Management, 8*(5), 351–361.

The author of this article is trying to investigate the present state of international disaster responses. He interviewed disaster victims, government leaders, and officials from local disaster research and prevention institutions, foreign embassies, the United Nations, the U.S. Agency for International Development and the Pan American Health Organization who were involved in the relief effort after Hurricane Georges in the Dominican Republic. He also analyzed reports from the United Nations and other nongovernmental organizations. The bulk of the article is dedicated to a summary of the findings of these interviews.

McLoughlin, D. (1985). A framework for integrated emergency management. *Public Administration Review, 45* (special issue), 165–172.

The author argues for the use of integrated emergency management. First, he describes the role of governments in emergency management, followed by a discussion of the components of emergency management, including the four phases. Then the author fully describes the integrated emergency management framework. This discussion includes descriptions of each element.

Medford. *If someone requests a lock box*. Retrieved January 31, 2009, from www.medford.org/Pages/MedfordMA_Diversity/lockreg.

This webpage provides information on the process of obtaining a lock box in the city of Medford, MA.

Metz, W. C., Hewett, P. L., Muzzarelli, J., & Tanzman, E. (2002). Identifying specialneeds households that need assistance for emergency planning. *International Journal of Mass Emergencies and Disasters, 20*(2), 255–281.

From the abstract: "This study characterizes special needs households that are located in the vicinity of a chemical weapons storage site in Alabama. Attitudes

toward specific protective actions and an assessment of the ability of the specialneeds household to take those actions were also sought out. Recommendations are made to the emergency planning community for addressing the support needs of special populations."

Mileti, D. (1999). *Disasters by design: A reassessment of natural disasters in the United States*. Washington DC: Joseph Henry Press.

This book is an important summary of scientific literature to date on the full range of topics in emergency management. It was compiled by Mileti but based on the reports of more than 100 of the nation's top practitioners and researchers, and is on the top ten list of required readings.

Mileti, D., & Peek-Gottschlich, L. (2001). Hazards and sustainable development in the United States. *Risk Management, 3*(1), 61–70.

From the abstract: "The major thesis of the findings from this national project is that hazard losses, and the fact that there seems to be an inability in the US to reduce those losses, are the consequences of narrow and short-sighted development patterns, cultural premises, and attitudes toward the natural environment, science, and technology. A way is proposed for people and the US to take responsibility for disaster losses, to design future hazard losses, and to link hazard mitigation to sustainable development."

Mitchell, L. (2003). Guidelines for emergency managers working with culturally and linguistically diverse communities. *Australian Journal of Emergency Management, 18*(1), 13–18.

The author highlights the importance of planning with and preparing for working with culturally and linguistically diverse communities, using several examples from Australia. Each example provides lessons for working with culturally and linguistically diverse communities. The paper shows that the new guidelines are applicable in many different situations. The guidelines are based on inclusiveness, a local approach, and the development of ongoing relationships involving trust, credibility, respect for diversity, and a willingness to connect (p. 15).

Morris, M., & Blanck, P. (2006). Disaster mitigation and persons with disabilities. Retrieved February 21, 2009, from www.ilru.org/html/training/webcasts/handouts/2003/08-27-PB/Transcript.txt.

"This webcast is designed to stimulate discussion, to be interactive, and really to continue the dialogue about using accessible communications technology and disability policy to save lives and reduce human suffering in the face of disasters throughout the world and to engage people with disabilities in this dialogue."

Morrow, B. H. (1999). Identifying and mapping community vulnerability. *Disasters*, 23(1), 1–18.

The article extends the argument that disaster vulnerability is a social construct to American demographic trends (p. 1). The author uses Hurricane Andrew as an example that many groups, such as the poor, elderly, woman-headed households, and recent residents are at a higher risk than other populations. Emergency managers and planners can use community vulnerability maps to identify and locate these populations in order to mitigate the increased risk. The author also argues that these groups must be involved in planning, response, and mitigation efforts.

National Council on Disability. (2006). *The impact of hurricanes Katrina and Rita on people with disabilities: A look back and remaining challenges*. Retrieved from www.ncd.gov/newsroom/publications/2006/hurricanes_impact.htm.

In this report, published one year after Hurricane Katrina, the National Council on Disability describes how people with disabilities were affected by the hurricane more than the general population. Generally, this was because their needs were overlooked or disregarded prior to, during, and after the event. The report also argues that in order to avoid another situation like Katrina, people with disabilities must be included in the rebuilding efforts and also in planning for future events.

National Council on Disability (NCD). Quarterly Meeting Reports.

These reports can be found at <u>www.ncd.gov</u> and provide important, practical insights into the problems and potential solutions of people with disabilities facing disaster situations. The quarterly meeting from New Orleans in January 2008 is particularly useful, as it addresses Hurricane Katrina.

National Council on Disability. (2005). *Saving lives: Including people with disabilities in emergency planning*. Retrieved July 14, 2008, from www.ncd.gov/newsroom/publications/2005/saving_lives.htm.

The purpose of this report is to describe the steps the federal government should take to build an infrastructure that will allow the government to include people with disabilities in emergency management and homeland security programs. The report examines 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, and how an effective disability-related homeland security and emergency preparedness infrastructure could be developed. The report also provides several key findings and recommendations.

National Emergency Number Association (NENA). (2008). *NENA video relay service and IP relay service PSAP interaction OID*. Retrieved January 2, 2009, from www.nena.org/media/File/NENA52-502VRSIPRelayOID02122008.pdf.

This document provides guidelines for PSAPs and recommendations to the FCC for (p. 6): "Emergency calling to 9-1-1 using Video Relay and IP Relay services; Relay of such calls to the appropriate Public Safety Answering Point (PSAP);

Interaction between the caller, the video relay interpreter or communications assistant and tele-communicator."

National Fire Protection Agency (NFPA). (2007). *NFPA 1600: Standard on disaster/emergency management and business continuity programs*.

This document provides disaster and emergency management and business continuity programs the criteria to assess current programs or to develop and implement new programs (p. 4). The standards apply to both public and private entities.

National Institute on Disability and Rehabilitation Research. (2001). *Assessing the impact of Hurricane Katrina on people with disabilities*. Retrieved December 18, 2008, from www.rtcil.org/products/NIDRR_FinalKatrinaReport.pdf.

The purpose of this research and report is to identify major barriers faced during Hurricane Katrina by centers for independent living (CILs) and emergency managers in responding to the needs of people with disabilities (p. 3). The research shows gaps in three areas: Pre-disaster planning by CILs, individuals with disabilities, and local emergency management agencies; pre- and post-disaster communication and information sharing within CILs, between CILs and consumers, and between local emergency management agencies; and pre- and post-disaster coordination between CILs and other disability agencies, local and regional emergency management organizations, and community supports. The report also describes in detail nine recommendations to close those gaps.

National Organization on Disability. (2005). *Emergency preparedness initiative: Guide* on the special needs of people with disabilities for emergency managers, planners, and responders. Retrieved July 4, 2008, from www.eadassociates.com/epiguide2005.pdf.

"This guide was developed to aid emergency managers and planners write plans that include the needs of people with disabilities in every phase of emergency management. The guide summarizes key issues and provides steps for emergency managers to take to make sure people with disabilities are integrated into the jurisdictions' emergency plans" (p. 4).

National Organization on Disability. (2005). *Special Needs Assessment for Katrina Evacuees project*. Retrieved December 18, 2008, from <u>www.nod.org/emergency</u>.

The purpose of the SNAKE Project was to "capture a snapshot in time through a representative sampling of experience and observation on the ground" (p. 3). NOD used four rapid assessment teams to gather time-sensitive data on the impact of the hurricane on those with disabilities, seniors, and medically managed persons (p. 4). The report can be used as a starting point for addressing challenges, further research, and developing corrective action (p. 4).

National Organization on Disability. (2007). *People with disabilities unprepared for terrorist, other crises at home or at work, new poll finds: Anxiety levels also run higher in this population segment.* Retrieved June 14, 2008, from <u>www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=507</u>.

The article highlights the fact that larger percentages of people with disabilities are unprepared for terrorist events than people without disabilities. The poll shows:

- "58 percent of people with disabilities say they do not know whom to contact about emergency plans for their community in the event of a terrorist attack or other crisis.
- 61 percent say that they have not made plans to quickly and safely evacuate their home.
- Among those who are employed full or part time, 50 percent say no plans have been made to safely evacuate their workplace."

National Service Inclusion Project. (No date). *Emergency preparedness and people with disabilities*. Retrieved December 1, 2008, from www.serviceandinclusion.org/index.php?page=emergency.

The webpage provides information about preparation, notification and evacuation, sheltering and interim services, and recovery. Additional information is provided about reverse 911 and paratransit.

National Service Inclusion Project. (No date). *The benefits of inclusion.* Retrieved February 20, 2009, from <u>http://communityinclusion.org/surveys/nsip_story</u>.

This article offers practical and useful information on the benefits of including people with disabilities and how to do so.

National Voluntary Organizations Active in Disaster. (2004). *Long-term recovery manual.* Retrieved October 30, 2008, from www.nvoad.org/Portals/0/LTRManualFinalApr232004a.doc.

The *Long-term Recovery Manual* is meant for people who have experienced a disaster in their community and are thinking about recovery. It can be used as a planning guide (p. 1). It provides an overview of actors involved in response and recovery, some models of successful long-term recovery, and tools and samples that can be adapted to fit individual circumstances.

National Voluntary Organizations Active in Disaster. (2008). *National Voluntary Organizations Active in Disaster*. Retrieved October 20, 2008, from <u>www.nvoad.org</u>. This webpage is a portal to information gathered by NVOAD and its members. The news and information section provides information about planning documents, case management, donations management, and summaries of meetings.

Natural Hazards Center. (2001, 2005). *Holistic disaster recovery*. Boulder, CO: NHRAIC and Public Entity Risk Institute

This volume was originally published in 2001 and reissued with updated content in 2005 after Hurricane Katrina. The volume offers a holistic and practical approach to recovery efforts including planning, participatory processes, economic recovery, environmental concerns, vulnerable populations, and more. This is a useful volume to purchase from the Public Entity Risk Institute or download for free (2001 edition only) from www.colorado.edu/hazards.

Neal, D. M. (1997). Reconsidering the phases of disaster. *International Journal of Mass Emergencies and Disasters, 15*(2), 239–264.

From the abstract: "Many problems exist with the current use of disaster periods. In summary, I find that the current uses of disaster periods lack conceptual clarity for improving scientific and practical use. As a result, I suggest ways the field can recast the use of disaster phases to improve the theoretical and applied dimensions of the field."

Nemery, B. (2003). Reactive fallout of World Trade Center dust. *American Journal of Respiratory and Critical Care Medicine, 168,* 2–3.

This article discusses the merits of a study researching reactive airways dysfunction syndrome (RADS) in rescue workers after the World Trade Center attacks. It also discusses the general problems faced in diagnosing RADS, and wonders why the incidence of RADS and other respiratory ailments are not being studied in rescue workers in other disasters or in workers who regularly work dirty jobs.

Newport, J. K., & Jawahar, G. G. P. (2003). Community participation and public awareness in disaster mitigation. *Disaster Prevention and Management, 12*(1), 33–36.

The authors argue that community involvement in resource identification, capabilities, coping mechanisms, and vulnerability assessment makes mitigation and planning more effective. The authors discuss contingency planning, community preparedness, task forces (comprising active youths in the ratio of one youth for 10 families) and response mechanisms as methods of community involvement. They also discuss an approach used by the Society for National Integration through Rural Development.

NOAA National Severe Storms Laboratory. (2008). *Questions and answers: OK-WARN: Weather alert remote notification for the deaf and hard-of-hearing*. Retrieved December 3, 2008, from <u>www.nssl.noaa.gov/edu/safety/pagers.html</u>. This webpage provides information about OK-WARN, which gives people with hearing impairments better access to weather information. The page includes basic information such as equipment needed and how the system works, along with links to more information.

Norris, F. H., Friedman, M. J., & Watson, P. J. (2002). 60,000 Disaster Victims Speak: Part II. Summary and Implications of the Disaster Mental Health Research. *Psychiatry 65*(3), 240–260. And: Norris, F. H., Friedman, M. J., Watson, P. J., Byrne, C. M., Diaz, E., & Kaniasty, K. (2002). 60,000 disaster victims speak: Part I. An empirical review of the empirical literature. *Psychiatry, 65*(3), 207–239.

These two seminal articles collate and explain psychological research on the disaster experience. The meta-analysis offered here describes the effects of disasters for various populations and is considered a critical piece to consult prior to conducting research and attempting to construct a program of psychological recovery services.

Nosek, M. (2008). Riding out Ike on a vent, Testimony before Select Committee on Hurricane Ike Storm Devastation to the Texas Gulf Coast, November 10, 2008.

In her testimony, Margaret Nosek provides five lessons learned from her experience as a person with a disability during Hurricane Ike. She also makes six recommendations that could make coping with the aftermath of a disaster better for people with disabilities.

Ocbbound (screen name). (2007). Emergency preparedness. Message posted to <u>www.afb.org/message_board_replies2.asp?TopicID=3124&FolderID=34&modes</u> <u>=sseniorsite</u>.

The response discusses the use of lockboxes. It also mentions a voluntary special needs registry.

Oklahoma ABLE Tech and Fire Protection Publications. Social etiquette: Tips for firefighters who work with people with disabilities.

The guide provides information on how to effectively communicate with people with disabilities. It also provides information on how to react to situations that might arise while interacting with people with disabilities. It provides general etiquette tips as well as tips specific to different types of disabilities.

Oklahoma Weather Alert Remote Notification. (No date). Retrieved January 14, 2009, from <u>http://www.ok.gov/OEM/Programs & Services/Preparedness/OK-</u> <u>Warn for the Deaf and Hard-of-Hearing/index.html</u>.

This webpage is the homepage for the Oklahoma Weather Alert Remote Notification (OK-WARN) program. The site provides information about what the program is, how to sign up, and assistance.

Oregon Partnership for Disaster Resilience. <u>www.oregonshowcase.org</u>

"The Oregon Partnership for Disaster Resilience is a coalition of public, private, and professional organizations working collectively toward the mission of creating a disaster resilient and sustainable state" (para. 1). The partnership website includes information on their current projects and links to other reports and overviews.

Parle, W., & Brown, A. (2005). *Educational Needs Survey Report*. Retrieved September 9, 2008, from <u>www.training.fema.gov/EMIWeb/edu/surveys.asp</u>.

The purpose of this study was to determine the types of technical and theoretical knowledge that emergency managers at the local level of government considered to be most helpful in their professional work (p. 1). The report outlines the results and findings of the survey. The authors also include a list of implications and conclusions.

Parr, A. (1987). Disasters and disabled persons: An examination of the safety needs of a neglected minority. *Disasters*, *11*(2), 148–159.

The purpose of this article is to report the finding of a one-year exploratory research project on the effect of disasters on people with disabilities in New Zealand (p. 148). The data was gathered through interviews with people with disabilities, emergency personnel, and officials from the private and public sector. The author found that the needs of people with disabilities have been neglected in terms of disasters.

Parr, A. (1997). Disasters and human rights of persons with disabilities: A case for ethical disaster mitigation policy. *The Australian Journal of Emergency Management, 12*(4), 2–4.

From the abstract: "Disaster management for persons with disabilities is a neglected topic that requires urgent attention. As a start it can be best addressed by focusing on an ethical approach in the formulation of disaster mitigation policy. The formulation of disaster mitigation policy and its implementation through emergency management involves making basic ethical choices. Value dilemmas need to be confronted and moral positions worked out. Ethical philosophies need to be formulated and put forward to justify and guide emergency management especially for persons with disabilities and other groups with enhanced vulnerability. What is needed urgently is a philosophy of disaster mitigation that is solidly grounded morally."

Phillips, B. D., & Morrow, B. H. (2007). Social science research needs: Focus on vulnerable populations, forecasting, and warnings. *Natural Hazards Review*, 8(3), 61–68.

From the abstract: "This paper assesses the state of social science research specific to populations at risk vis-à-vis weather forecasting and warnings. At-risk populations are defined as groups historically disadvantaged by socioeconomic

status; patterns of discrimination and exclusion, or both; a lack of political representation; or cultural distancing. These contexts marginalize some groups, leaving them less likely to receive, interpret, and respond appropriately to forecasts and warnings. We give an overview of key concepts from vulnerability research and suggest research topics emanating from the social science literature relevant to forecasting and warnings."

Phillips, B. D., Metz, W. C., & Nieves, L. A. (2005). Disaster threat: Preparedness and potential response of the lowest income quartile. *Environmental Hazards, 6*(3), 123–133.

This article describes the findings of a study looking at the preparedness and potential response activities of people living near an army depot that could be the source of a chemical release (p. 1). The authors found that respondents at the lowest income levels were more vulnerable to the potential hazard than other groups of respondents. The authors also provide implications for future research and emergency management practice.

Phillips, B. D., Thomas, D., Fothergill, A., & Blinn-Pike, L. (Eds.). (2009). Social vulnerability to disasters. Boca Raton, FL: CRC Press.

This edited book offers a review of existing research coupled with practical strategies for a variety of populations including people with disabilities, women, low-income groups, families, and racial and ethnic minorities. Several concluding chapters offer practical advice for emergency managers to empower and work with their communities in an effort to transform vulnerability into capacity.

Pike, L., Phillips, B. D., & Reeves, P. (2008). Shelter life after Katrina: A visual analysis of evacuee perspectives. *International Journal of Mass Emergencies and Disasters*, *24*(3), 303–330.

This study offers a unique examination of shelter life that put cameras into the hands of shelter residents, including people with disabilities.

Points of Light Foundation, & Volunteer Center National Network. (2002). *Preventing a disaster within the disaster: The effective use and management of unaffiliated volunteers*. Retrieved November 20, 2008, from www.community.ups.com/downloads/pdfs/disasterbook.pdf.

The purpose of this guide is to ensure that volunteers are utilized as best they can be during an emergency or disaster. To do so, the recommendations made in the guide are organized by phase of emergency management: mitigation, preparedness, response, and recovery. There is also a section devoted to organization-specific recommendations, as well as a list of possible volunteer activities according to phase.

Prickett, B. (2005). *Louisiana school for the deaf.* Retrieved July 14, 2008, from www.audiologyonline.com/News/news_detail.asp?news_id=1842.

The letter, by the superintendant of the Louisiana School for the Deaf, describes how the school aided the deaf community in the wake of Hurricane Katrina. The letter also provides information on the delivery of relief service and how to donate money or goods to the relief effort.

Public Entity Risk Institute. (2008). *Date resource library: Understanding the volunteer protection act.* Retrieved November 20, 2008, from www.riskinstitute.org/peri/index.php?option=com_bookmarks&task=detail&id=584.

The webpage describes the Volunteer Protection Act, which is meant to protect volunteers from liability. A description of the final bill and its exemptions and limitations are included as well. The final section of the webpage includes frequently asked questions about the Volunteer Protection Act.

Public Health Agency of Canada. (2008). Second International Workshop on Seniors and Emergency Preparedness workshop report. Retrieved December 15, 2008, from <u>www.policypointers.org/Page/View/8733</u>.

The report provides an overview of the conference proceedings, including presentations, discussions, and priorities. The workshop goals were to (p. 2):

- "Share tools and resources;
- Identify gaps and prioritize development of practical tools and resources;
- Find ways to integrate seniors into existing models and promising practices;
- Identify effective messages and communication strategies;
- Set in motion specific activities for ongoing collaborative work;
- Strengthen networks/partnerships; and
- Determine best ways to influence policy at national and international levels."

Public Safety Canada. (2008). *Canada's national disaster mitigation strategy*. Retrieved from <u>www.publicsafety.gc.ca/prg/em/ndms/strategy-eng.aspx</u>.

The document's purpose is to:

1. "Set out a common vision for disaster mitigation activities in Canada.

- 2. Promote mitigation through transparent National Strategy that integrates disaster mitigation into Canada's evolving emergency management framework.
- Identify primary actions that will be undertaken by Federal, Provincial and Territorial partners to support implementation of the National Strategy. It is recognized that full implementation of the National Strategy will require a long-term effort."

Quarantelli, E. L. (1982). *Sheltering and housing after major community disasters*. Newark, DE: University of Delaware Disaster Research Center.

This classic work outlines the processes and phases of sheltering and housing.

Quarantelli, E. L. (1987). What should we study? Questions and suggestions for researchers about the concept of disasters. *International Journal of Mass Emergencies and Disasters, 5*, 7–32.

This article discusses what should be studied as a disaster. The author begins with a discussion of the historical use of the term "disaster," then proceeds to discuss how the term is used at the time of writing. The author then calls for a reformulation of the term and suggests some starting points for the process. Once the term has been reformulated the author states that there must be two typologies: one that puts disasters in a larger framework and another within the term disaster (a threshold). The author argues that disaster researchers should focus on the long-term payoff of research.

Quarantelli, E. L. (1991). *Disaster assistance and recovery at the individual and household level*. Newark, DE: University of Delaware Disaster Research Center.

Theoretical insights are offered into the recovery process.

Quarantelli, E. L. (1998). *The disaster recovery process: What do we know and not know*. Newark, DE: University of Delaware Disaster Research Center.

A useful article for researchers and people interested in thinking through the implications of various kinds of recovery approaches. A state of the art article on what is known through empirical research at the time of its publication.

Quillin, M. (2008). *Deaf get help on weather alerts*. Retrieved July 14, 2008, from <u>www.newsobserver.com/news/story/1202935.html</u>.

The newspaper article describes a program in North Carolina that distributes weather radios equipped with strobe lights and pillow vibrators to the deaf community. The impetus of the program was the sight of deaf residents swimming from a mobile home park following Hurricane Floyd. The device allows the hearing impaired to be alerted in case of emergency weather.

Rahimi, M. (1993). An examination of behavior and hazards faced by physically disabled people during Loma Prieta earthquake. *Natural Hazards Review*, 7(1), 59–82.

The author used a questionnaire to study the responses of disabled residents who experienced the Loma Prieta earthquake. The study found that the physical limitations of the residents did not increase their vulnerability. Many of the residents did not feel vulnerable and those who did took actions to limit their vulnerabilities.

Rahimi, M. (1994). Behavior of mobility-disabled people in earthquakes: A simulation experiment. *Earthquake Spectra*, *10*(2), 381–401.

From the abstract: "A simulation experiment was conducted to assess the behavior of disabled occupants in earthquakes. A living room was set-up to show the after-effects of two simulated California earthquakes (low intensity R4.0 and high intensity R6.5) to a building's contents. Seventy-two participants were selected: 24 users of manual wheelchairs, 24 users of powered wheelchairs, and 24 able-bodied persons as a comparison base-line. It was found that the users of manual wheelchairs performed the instructed tasks significantly faster than the users of powered wheelchairs under both low and high intensity simulations. Using a pathway analysis, the disabled groups faced a significantly greater number of obstacles and maneuvered around the objects more than the control group only in the high intensity damage scenario. The feasibility and weaknesses of this type of experimental approach is elaborated."

Renne, J. L., Sanchez, T. W., & Litman, T. (2008). *National Study on Carless and Special Needs Evacuation Planning: A literature review*: New Orleans, LA: University of New Orleans Transportation Center.

The authors of the literature review used a wide range of publications to identify the best practices and weaknesses in carless and special needs evacuation. They conclude that an integrated, multimodal approach would provide the most efficient evacuation of the groups, and also state that the evacuation must be a coordinated effort between the government (at all levels) and nonprofit groups (p, v).

Rose, A. (2006). *Regional models and data to analyze disaster mitigation and resilience*. Los Angeles: University of Southern California, School of Policy, Planning, and Development and Center for Risk and Economic Analysis of Terrorism Events.

The author uses models of economic interaction and responsiveness to gain knowledge about infrastructure independence and resilience (p. 2). He focuses on a disaster's impact on a regional economy rather than the local or national economy. He does this by studying the interruption to business by damaged

infrastructure, because small changes in infrastructure can have a great effect on an economic system.

Saliba, D., Buchanan, J., & Kingston, R. S. (2004). Function and response of nursing facilities during community disaster. *American Journal of Public Health*, *94*(8), 1436–1441.

The researchers describe the roles and functions of nursing facilities following disasters (p. 1436). They gathered data by surveying administrators at nursing facilities following the Northridge earthquake. The study found that nursing facilities met important needs, but that in order to optimize response, disaster plans should include nursing facilities (p. 1436).

San Mateo County California. (2005). *Emergency public health information and vulnerable populations in San Mateo County: After action report community forums*. Retrieved January 15, 2009, from www.pandemicpractices.org/files/14/14 after action report forum.pdf.

This report details how the San Mateo County Health Department determined how to best distribute emergency public health information to vulnerable populations within its jurisdiction. The department decided that community-based organizations (CBOs) provided critical links to these populations, and that the department should partner with these CBOs to distribute information. The document provides information about each of the different vulnerable populations and the CBOs that might be best suited for distributing information within that population, and also includes information gathered during community forums on the subject.

Schwab, J., Topping, K. C., Eadie, C. C., Deyle, R. E., & Smith, R. A. (1998). *Planning for post-disaster recovery and reconstruction*. Washington DC: FEMA.

This is the single best existing guide to conducting recovery planning: a comprehensive guide to the parts of a recovery plan and strategies to put them into place. A PDF file of key chapters can be downloaded from the FEMA website. The entire volume is now available for purchase from the American Planning Association.

Shields, J. W., Boyce, K. E., & Silcock, G. W. H. (1999). Facilities management disability and emergency evacuation. *Facilities*, *17*(9/10), 345–351.

The burden of making sure facilities are safe for occupants is now on the owners and operators of facilities; this includes proper and accessible evacuation routes. Facility managers have a duty to maintain these routes and to know the profile of their occupants. If there are people with mobility disabilities, they must provide safe evacuation routes for them as well. Shields, T. J., Smyth, B., Boyce, K. E., & Silcock, G. W. H. (1999). Towards the prediction of evacuation behaviours for people with learning disabilities. *Facilities*, 17(9/10), 336–344.

Because facilities that cater to people with learning disabilities are housed in many different types of buildings, there is a need for a wide range of plans and programs to ensure that the occupants are safe in case of an emergency event. This is especially true for facilities where people with learning disabilities sleep or reside. The authors also discuss an evacuation capability assessment.

Smith, P., Langa, K., Kabeto, M., & Ubel, P. (2005). Financial resources buffer subjective well-being after the onset of a disability. *Psychological Science*, *16*(9), 663–666.

From the abstract: "We examined the hypothesis that the relationship between financial status and subjective well-being, typically found to be very small in cross-sectional studies, is moderated by health status. Specifically, we predicted that wealth would buffer well-being after the onset of a disability. Using data from the Health and Retirement Study, a longitudinal study of people at and approaching retirement age, we employed within-subjects analyses to test whether wealth measured prior to the onset of a disability protected participants' well-being from some of the negative effects of a new disability. We found support for this hypothesis: Participants who were above the median in total net worth reported a much smaller decline in well-being after a new disability than did participants who were below the median. We also found some evidence that the buffering effect of wealth faded with time, as below-median participants recovered some of their well-being."

Snare Web Guide. (No date). U.S. National Civic Clubs and Organizations. Retrieved October 16, 2008, from www.thesnare.com/states/national/community/civic/civic.htm.

The Snare Web Guide is a portal to U.S. national civic clubs and organizations. Organizations are organized by state and divided into three subcategories: civic, youth, and veteran organizations.

Social Security Administration. (2008). *News release: Social Security checks again arriving in Gulf Coast states as Hurricane Ike approaches*. Retrieved January 7, 2009, from <u>www.ssa.gov/pressoffice/pr/hurricaneike-pr.htm</u>.

The press release announces that the Social Security Administration will be distributing payments one day early in preparation for Hurricane Ike. Officials urge people to evacuate regardless of whether they receive their checks. The federal government also urged banks to make direct deposit funds available early as well, but the decision is up to the individual banks.

Sorenson, J. (2000). Hazard warning systems: Review of 20 years of progress. *Natural Hazards Review, 1*(2), 119–125.

This is a useful literature review of what was known about warning systems at the time of its publication.

State of Mississippi. (2007). *Special need shelter general medical care guidelines*. Retrieved December 20, 2008, from http://www.msdh.state.ms.us/msdhsite/ static/resources/1970.pdf.

This document provides information and protocols on a wide variety of medical conditions. The document is divided into general medical needs and emergency medical needs.

State of Missouri. (2008). Special needs sheltering standard operating guide for local and county level emergency managers. Retrieved December 20, 2008, from www.msdh.state.ms.us.msdhsite.

The State of Missouri's special needs sheltering guide provides information on all aspects of sheltering. The appendices include many helpful forms, figures, signs, and logs.

State of New York. (2008). New York State medical and functional needs sheltering plan.

The State of New York's medical and functional needs sheltering guide provides information on all phases of the sheltering process, from planning through deactivation. The guide also includes descriptions of the roles of the different agencies and organizations involved in sheltering.

Steinfeld, E. (2006). Evacuation of people with disabilities. *Journal of Security Education, 1*(4), 107–118.

Because of the problems experienced by people with disabilities during evacuation, the author argues for universal design approaches that take into account the needs of people with disabilities during evacuation. He also argues that these design approaches would benefit all people, not just people with disabilities.

Stough, L., & Sharp, A. (2008). *An evaluation of the National Disability Rights Network participation in the Katrina Today project*. Washington, DC: The National Disability Rights Network.

The report evaluates the quality of case management provided to people with disabilities and the impact of case management on the Protection and Advocacy Centers as legal service organizations (p. 3). The report provides detailed quantitative and qualitative results. The survey instruments and interview questions are provided in the appendices.

Styron, H. (2005). *Emergency management and people with disabilities: Before, during and after (congressional briefing, November 10)*. Retrieved July 10, 2008, from www.ncd.gov/newsroom/publications/2005/transcript_emergencymgt.htm.

Hilary Styron, director of the Emergency Preparedness Initiative, provides testimony regarding the impact of disasters on people with disabilities, provides information about her experiences in Louisiana after Hurricane Katrina, and discusses the SNAKE project.

Swan, R. (2202). Overview of the nation's worst debris-generating disaster (World Trade Center). *Environmental Practice, 4*(2), 67–69.

This article briefly describes the process used to remove debris from Ground Zero. It discusses how the special circumstances that surround Ground Zero have affected the removal of the debris—the special circumstances being that every piece of debris is part of a crime scene; Building 7 contained ammunition, weapons, and evidence from ongoing criminal cases, and the victims were entombed in the debris.

Szema, A., Khedkar, M., Maloney, P. F., Takach, P. A., Nickels, M. S., Patel, H., et al. (2004). Clinical deterioration in pediatric asthmatic patients after September 11, 2001. *Journal of Allergy and Clinical Immunology*, *113*(3), 420–426.

The purpose of this article is to assess the effect of the World Trade Center on local pediatric asthmatic patients (p. 420). To do so, the authors reviewed the medical charts of pediatric patients with asthma from a clinic in lower Manhattan (p. 420). They found that asthma in children living closer to Ground Zero worsened after the attacks (p. 420).

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: Definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Informatics Association*, 13(2), 121–126.

From the abstract: "In a 2005 working symposium, the American Medical Informatics Association's College of Medical Informatics discussed the issues surrounding personal health record systems and developed recommendations for PHR-promoting activities. Personal health record systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care. When PHRs are integrated with electronic health record systems, they provide greater benefits than would stand-alone systems for consumers. This paper summarizes the College Symposium discussions on PHR systems and provides definitions, system characteristics, technical architectures, benefits, barriers to adoption, and strategies for increasing adoption."

Tierney, K. (1996). *Business impacts of the Northridge Earthquake*. Newark, DE: University of Delaware Disaster Research Center. See also: Tierney, K. J., Lindell, M. K., & Perry, R. W. (2001). *Facing the unexpected: Disaster* preparedness and response in the United States. Washington, DC: Joseph Henry Press; and Tierney, K., Nigg, J. M., & Dahlhamer, J. M. (1996). The impact of the 1993 Midwest floods: Business vulnerability and disruption in Des Moines. In R. T. Sylves & W. L. Waugh (Eds.), *Cities and Disaster: North American Studies in Emergency Management*. Springfield, MA: Charles C. Thomas.

These articles pull from several studies to demonstrate that there are both direct and indirect effects of disasters; a business does not have to be directly impacted to sustain damage, including loss of a customer base and disruption to power lines and other utilities that prevent business losses.

Trout, D., Nimgade, A., Mueller. C., Hall, R., & Earnest, G. S. (2002). Health effects and occupational exposure among office workers near the World Trade Center disaster. *Journal of Occupational and Environmental Medicine*, *44*(7), 601–605.

From the abstract: "The objective of this study was to evaluate concerns related to health effects and occupational exposures three months after the WTC [World Trade Center] disaster among a population of employees working in a building close to the disaster site. A cross-sectional questionnaire survey was performed of Federal employees working near the WTC site in New York City (NYC) and a comparison group of Federal employees in Dallas, Texas. An industrial hygiene evaluation of the NYC workplace was conducted. Constitutional and mental health symptoms were reported more frequently among workers in NYC compared to those in Dallas; level of social support was inversely related to prevalence of mental health symptoms. Post-September 11th counseling services were utilized to a greater degree among workers in NYC, while utilization of other types of medical services did not differ significantly between the groups. No occupational exposures to substances at concentrations that would explain the reported constitutional symptoms were found; however, we were unable to assess potential occupational exposures in the time immediately after the WTC disaster. There is no evidence of ongoing hazardous exposure to airborne contaminants among the workers surveyed. Specific causes of reported constitutional health symptoms have not been determined. Health care providers and management and employee groups should be aware of the need to address mental health issues as well as constitutional symptoms among the large number of workers in the NYC area who have been indirectly affected by the WTC disaster."

United States Access Board. *The Rehabilitation Act Amendments*. (1998). Retrieved June 7, 2008, from <u>www.access-board.gov/sec508/guide/act.htm</u>.

The Rehabilitation Act Amendments requires access to electronic and information technology provided by the federal government. The act applies to all federal agencies. The agencies must make sure that technology is accessible to employees and members of the public.

United States Fire Administration & Federal Emergency Management Agency. (2002). FA-235: Orientation manual for first responders on the evacuation of people with *disabilities*. Retrieved May 14, 2008, from www.usfa.dhs.gov/downloads/pdf/publications/FA-235-508.pdf.

This manual provides valuable information to first responders on issues surrounding the evacuation of people with disabilities. The guide emphasizes preparedness as the starting point of successful evacuation, and includes information about different categories of impairment. The final section of the guide discusses issues surrounding mobility.

van Willigen, M., Edwards, T., Edwards, B., & Hessee, S. (2002). Riding out the storm: Experiences of the physically disabled during hurricanes Bonnie, Dennis, and Floyd. *Natural Hazards Review, 3*(3), 98–106.

This article compares the experiences during three hurricanes of households with and without a member with a disability. The research was based on phone surveys and interviews with relevant actors. The authors found that households with a member with a disability were less likely to evacuate, owing to a lack of or perceived lack of access to services (p. 98). The authors also provide implications of the research.

Wagner, C. G. (2006). Disaster planning for the disabled. The Futurist (March 1).

This article argues that more planning needs to occur with respect to the evacuation of people with disabilities from public buildings. The article discusses the research of Judith Holt and Keith Christensen, who are looking at the effectiveness of accommodations for people with disabilities.

Washington State Military Department. (2007). *Disaster preparedness handbook: An emergency planning and response guide*. Retrieved May 14, 2008, from: <u>www.doh.wa.gov/phepr/handbook.htm</u>.

The Washington State Military Department provides this guide for personal preparedness. The guide includes information about many types of situations, from natural disasters to terrorism to household risks. This information is provided in the form of fact sheets.

Webb, G., Tierney, K., & Dahlhamer, J. M. (2000). Businesses and disasters: Empirical patterns and unanswered questions. *Natural Hazards Review*, *1*(3), 83–90.

This is an insightful article regarding businesses and losses after disaster impact, and is considered an important piece in the existing minimal research on businesses and disasters. Wenger, D., Quarantelli, E. L., & Dynes, R. (1987). *Disaster analysis: Emergency management offices and arrangements.* Disaster Research Center, University of Delaware. Retrieved from <u>www.udel.edu/DRC</u>.

The report chronicles the findings of the author's research on the responses of local emergency management systems in six community disasters. The research produced an eight-fold categorization of emergency management systems (p. 3): offices, by-passed agencies, emergent agencies, established agencies, embedded agencies, by-passed community agencies, emergent community agencies, and established community agencies. They also provide policy implications for response, planning, and structure of local emergency management systems.

WGBH National Center for Accessible Media. (2005). *Press release: Access alerts: Making emergency information accessible to people with disabilities, September 15, 2005.* Retrieved June 14, 2008, from <u>http://ncam.wgbh.org/news/pr_20050915.html.</u>

The press release announces a project that is a collaborative effort to unite emergency alert providers, local information resources, the telecom industry and public broadcasting representatives, and consumers. This project is meant to develop and encourage the adoption of standard methods, systems, and services to deliver emergency information to people with disabilities. The press release also includes information on activities that will seek to meet the goals of the program.

White, G. W., Fox, M. H., & Rooney, C. (2007). Nobody left behind: Report on exemplary and best practices in disaster preparedness and emergency response for people with disabilities. Retrieved June 14, 2008, from www.nobodyleftbehind2.org/findings/pdfs/bestpractices_3-21-072.pdf.

This report outlines some preparedness and response best practices for people with disabilities. It is part of a larger project to assess the ability of emergency management sites to assist people with mobility disabilities. The report includes not only the best practices but also information about resources required for guidelines.

Wilson, J., & Oyola-Yemaiel, A. (2001). The evolution of emergency management and the advancement toward a profession in the United States and Florida. *Safety Science*, *3*9, 117–131.

The authors explore the process of professionalization that is occurring in emergency management, a process that generally includes certification and accreditation. The authors also provide information on the history of and changes to emergency management in the United States. Wisner, B. (2002). Disability and disaster: Victimhood and agency in earthquake risk reduction. In C. Rodrigue & E. Rovai (Eds.), *Earthquakes*. London: Routledge.

This book chapter discusses the relationship between disability and disaster. The author argues that people with disabilities and the organizations that represent them should be involved in every phase of the emergency management cycle. The author calls for more research and discussion on the relationship between disability and disaster, and argues that without further information, the issues will reemerge.

Women's Commission on Refugee Women and Children. (2008). *Disabilities among refugees and conflict-affected populations*. Retrieved October 17, 2008. from <u>www.womenscommission.org/pdf/disab_fulll_report.pdf</u>.

This report summarizes the findings of a six-month project to address the rights and needs of displaced persons with disabilities, with a particular focus on women (including older women), children, and youth (p. 2). The purpose of the project is to eventually produce a resource kit for the United Nations and nongovernmental organizations that work with displaced people with disabilities. The findings suggest that services are better in refugee camps than in urban settings (p. 2). The report also includes a list of recommendations for all humanitarian actors (p. 5).

Wood, V. T., & Weisman, R. A. (2003). A hole in the weather warning system. *Bulletin* of the American Meteorological Society, 84(2), 187–194.

From the abstract: "This article documents the problems people with hearing impairments experience when attempting to access weather warning systems in Oklahoma and Minnesota. The traditional methods of warning and sources of information—sirens, radio, and television—are generally not accessible to this group. New technology, new FCC rules, and the Internet have helped to fill the gap in weather warning and notification for people with hearing impairments but there is still room for improvement. The author has included a list of possible solutions to these problems."

Yelvington, K. (1997). Coping in a temporary way: The tent cities. In W. Peacock (Ed.), *Hurricane Andrew* (pp. 92–115). London: Routledge.

This is an informative chapter on the experience of living in a tent city from the perspective of the residents displaced from their homes.

Young, J. R. (2008). Emergency alerts via Facebook and MySpace are new ways to reach students. *The Chronicle of Higher Education* (August 22).

This article describes a program at the University of Maryland at College Park that provides emergency alerts and information via Facebook. The author notes that students do not receive information in traditional ways anymore, and discusses the possible limitations of providing information this way. The article also includes information about a prototype social network being built by researchers at the university that would disperse emergency information exclusively.

Zuckerman, S., & Coughlin, T. (2006). *After Katrina: Initial health policy responses to Hurricane Katrina and possible next steps*. Retrieved from www.urban.org/publications/900929.html.

The Urban Institute looked at the early response to the health care issues caused by Hurricane Katrina. The authors also discuss the issues that will continue to emerge. The document concludes with a discussion of how to rebuild New Orleans' health care infrastructure.

APPENDIX D: Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency, composed of 15 members appointed by the President, by and with the consent of the U.S. Senate.

The purpose of the NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, and that empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

To carry out this mandate we gather public and stakeholder input, including that received at our public meetings held around the country; review and evaluate federal programs and legislation; and provide the President, Congress and federal agencies with advice and recommendations.

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.*

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.