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

Effective Emergency Management (PDF, 1774K)

National Council on Disability

August 12, 2009

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,

 Figure representing Signature of John R. Vaughn

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 disability-related 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.

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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.

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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.

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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 super-cell 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 (www.nod.org, 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.

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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 (www.disabilityinfor.gov), 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

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.

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 self-assessment 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.

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.

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.

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.

Available @ 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.

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

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).

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

The Department of Homeland Security website, www.ready.gov, 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 three-step process: Get a Kit, Make a Plan, Get Informed.

Organizations and Communities

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.

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.

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.

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

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.

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.

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.

- *Prepare in a Year*
- *Emergency Preparedness:Taking Responsibility for Your Own Safety: Tips for People with Disabilities and Activity Limitations*
- *Emergency Readiness Wheels*
- *Preparing for Disaster for People with Disabilities and Other Special Needs*
- *OK-WARN for the Deaf and Hard-of-Hearing*
- *Safe Escape*
- *Emergency Preparedness and People Who Are Blind and Visually Impaired*
- www.acb.org/washington/emergency-preparedness-final.doc.

- *State Agency Created CDs (Massachusetts EMA)*
- *Ready America*
- Project Safe EV-AC
- *An ADA Guide for Local Governments*
- *Emergency Planning and Special Needs Populations (G197)*
- *Emergency Procedures for Employees with Disabilities in Offices Occupancies*
- *Orientation Manual for First Responders on the Evacuation of People with Disabilities*
- *Sign Language Booklet for Emergency Medical Situations*
- *Social Etiquette—"Tips for Firefighters*

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 towww.ok.gov/OEM/OK-WARN/index.html). 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" (www.section508.gov, 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).

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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 aging-specific 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-ã-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 real-time 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 real-time 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.
3. 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 6â€"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. 42 U.S.C. Â§ 12101(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. Â§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). 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 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 out 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 (http://evac.icdi.wvu.edu, 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 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 self-identify 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 notes–

> Various 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 evacuation becomes a necessity. However, it is clear that some conditions prompt 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 traffic-related 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, www.vtpi.org/tdm/tdm88.htm).

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 (http://fems.dc.gov/fems/site/default.asp) 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 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 (www.audiologyonline.com), 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 closed-captioned 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 HUD-subsidized 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.

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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 retrofitting 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 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 (www.ncd.gov/newsroom/publications/2006/hurricanes_impact.htm):

> "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 www.nvoad.org). 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 faith-based 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 self-appointed 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.

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