

Consumer Perspective

Narrative Analysis of a Disaster Preparedness and Emergency Response Survey From Persons With Mobility Impairments

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The purpose of this qualitative study is to gain a better understanding of disaster preparedness for and the difficulties faced by persons with mobility impairments to guide future research and policy development. From an online Internet survey, 56 persons with mobility impairments who have experienced a catastrophic event described what was helpful for survival, what difficulties were experienced during and after the event, lessons learned, and future directions for emergency management. From a consumer perspective, it was found that both general and disability-related disaster preparedness efforts were useful for the survival, independence, health, and safety of persons with mobility impairments. It was also found that coworkers, family, friends, neighbors, and strangers often formed spontaneous networks during and after disasters that provided needed assistance. Difficulties surfaced when there was a lack of community and workplace evacuation plans, someone was left behind during an evacuation, there was no accessible sheltering or temporary housing, and infrastructure broke down (power, public transportation, and elevators). Persons with mobility impairments encouraged their peers to develop individual preparedness plans and to be active in community-based disaster planning. Emergency management was asked to address the needs of persons with disabilities and to include them in emergency management.

Persons with mobility impairments or other disabilities are often not prepared for disasters. For example, only 47% of persons with disabilities report having a household evacuation plan in place, and only 57% report having a workplace plan (National Organization on Disability [NOD], 2005b). Community-level disaster preparedness plans designed to meet the needs of persons with mobility impairments or other disabilities often do not exist (Center for Independence of the Disabled New York [CIDNY], 2004; Fox, White, Rooney, & Rowland, 2005; Kendall-Tackett & Mona, 2005).

Local emergency management preparedness efforts rarely include input from persons with mobility impairments (Fox et al., 2005). In addition, a majority of emergency managers are not trained in the unique preparedness, response, recovery, and mitigation needs of persons with mobility impairments (Fox et al.) or other disabilities (Kendall-Tackett & Mona, 2005). This lack of preparedness for persons with mobility impairments continues to occur despite evidence identifying persons with physical disabilities as at risk for death in natural disasters (Chou et al., 2004; Osaki & Minowa, 2001) and residential fires (Runyan, Bangdiwala, Linzer, Sacks, & Butts, 1992).

In privately owned businesses, disaster preparedness for persons with mobility impairments and other disabilities is also often overlooked, as was the case with the 9/11 terrorist attacks (Kendall-Tackett & Mona, 2005). This lack of preparedness is being challenged by a 2004 ruling by a Circuit Court of Maryland for Montgomery County (Comstock, 2005; Gardner & Hollman, 2005). The ruling requires shopping malls, stores, restaurants, and other private entities to follow the Americans with Disabilities Act (ADA) by accommodating persons with disabilities in disaster evacuation plans (Gardner & Hollman, 2005). Katie Savage, a wheelchair user, filed the suit after being trapped in a shopping mall with no accessible exits during an evacuation. Store employees did not provide assistance, and she was left behind at an elevator that automatically shut down during an emergency situation (Comstock, 2005; Gardner & Hollman, 2005). This ruling also has implications for public buildings that have inaccessible wheelchair escape or egress routes (Comstock, 2005).

Accessibility problems for persons with mobility impairments persist in disaster response, recovery, and mitigation stages as well (CIDNY, 2004; National Council on Disability [NCD], 2005). For example, persons with mobility impair-

ments continue to report difficulties during and after a disaster when shelters, shelter restrooms, and other temporary housing are not accessible, or when nonaccessible public transportation is the only means available (CIDNY, 2004; Kendall-Tackett & Mona, 2005; NCD, 2005). These problems remain despite ADA requirements for accessibility (Access Board, 2002) and repeated reporting of these incidents in the mitigation process of emergency management (CIDNY, 2004; NCD, 2005).

Evacuation plans often overlook the need to prioritize evacuation of users with mobility devices or the need to reunite users with their own devices shortly after the evacuation (California State Independent Living Council [CSILC], 2004). Any separation from a mobility device during a disaster results in the loss of self-sufficiency in postdisaster settings such as shelters (CSILC, 2004; CIDNY, 2004). Being without a wheelchair that is designed for the unique needs of the user may also lead to compromises in functioning, safety, and physical and mental health (FEMA & U.S. Fire Administration, 1996).

Saving lives and preventing injuries are the premises behind disaster and emergency plans. Past experiences illustrate the importance of these plans for persons with disabilities. For example, a customized plan and regular drills made it possible for low-vision and blind employees in a Twin Towers office to evacuate safely and efficiently down nine flights of stairs during the 9/11 terrorist attacks (NOD, 2005a). In this same event, several persons with mobility impairments were assisted by coworkers down flights of stairs to safety using evacuation chairs purchased by employers (Byzek & Gilmer, 2001). Another person's prosthetic leg and his experience acquired in fire drills allowed him to keep pace down 70 flights of stairs with workers without disabilities (NOD, 2005a). In contrast, other persons with mobility impairments died because either workplace plans did not exist to meet their needs, or the plans called for being left behind in an area of safe refuge until fire personnel could come to assist them (Byzek & Gilmer, 2001; Kendall-Tackett & Mona, 2005).

In view of the needless loss of life of people with disabilities under disaster conditions, we sought to gain knowledge from persons with mobility impairments who had experienced a catastrophic event. Specifically, we wanted to learn from a consumer perspective whether preparedness and relief efforts were useful, what difficulties were encountered during and after the disaster and emergency, what lessons were learned to share with peers, and what new directions should be taken by emergency management to better assist persons with mobility impairments.

Method

Participants

A "key informant" sample was selected for this preliminary qualitative study. This sample type was selected because it matched the purpose of the research, which was to explore effective preparedness and relief efforts and identify difficulties experienced during and after disasters, lessons learned, and fu-

ture directions of consumers. Key informants were selected as research participants because of their unique expertise or experience (Patton, 2001). In this case, the key informants were persons with mobility impairments who experienced firsthand a natural or man-made disaster. A person with a mobility impairment was defined as "someone who has difficulty walking or moving around, or uses equipment such as a cane, walker, or wheelchair to assist with mobility" (Consumer Survey, 2006, p. 1).

Natural disasters included flooding, heat waves, fires, tornadoes, earthquakes, mudslides, severe storms including rain, hail, snow, freezing temperatures, winds, hurricanes, and avalanches. Man-made disasters included fires, bomb threats, actual bombings, or other forms of terrorist attacks, vehicular (bus, plane, auto) accidents, and chemical, nuclear, or other toxic spills. (Consumer Survey, 2006, p. 1)

Recruitment efforts for participants were directed at organizations that serve persons with disabilities. A letter asking to post an announcement for participation in the study was sent to 25 nationally known disability organizations, 6 national disability-related conferences, 2 national disability-related emergency management organizations, and Centers for Independent Living (CILs) in states with regularly occurring disasters or states that had recently experienced a FEMA-declared disaster. These efforts resulted in announcements for research participants being posted on 5 national Web sites and in 15 organizational newsletters. Five CILs agreed to have copies of the survey available in lobby areas for clients. Researchers observed that participation in the research immediately followed the announcements at conferences or on Web sites.

Instrument Development and Description

To collect the desired information from participants, an online Internet survey was developed as a component of a research project titled *Nobody Left Behind: Preparedness for Persons with Mobility Impairments* (Consumer Survey, 2006). The researchers in collaboration with an advisory team of persons in the fields of disability, health services administration, and emergency management developed the survey. It consisted of several questions, including three presurvey questions that probed for the respondents' eligibility to take the survey and the type of disaster they had experienced. Then potential participants selected from a list of possibilities the type of mobility impairment that best described their situation. These inquiries were followed by regular survey questions, which included the following:

1. What preparations helped you to survive?
2. What was helpful or not helpful with your evacuation or escape routes, shelters, and temporary housing?
3. What difficulties were experienced returning to your daily life after the disaster event?

4. How would you rank, from 1 to 5, with 1 being the *least satisfied* and 5 the *most satisfied*, your experiences with relief or disaster services during and immediately after the event?
5. If any services received a *not satisfactory* rating, please describe why.
6. Has your experience increased participation in disaster planning and preparedness at home and/or in the community?
7. What lessons did you learn that are important for others to know?
8. What new directions should be explored to help persons with mobility impairments survive disasters?

Data Collection Procedures and Analysis

The survey was administered through the Nobody Left Behind project's Web site, www.nobodyleftbehind2.org. The survey was first developed in HTML and then CTI and Perl software to allow the completed survey to be automatically returned by e-mail to the researchers. The survey was piloted and reviewed by two study advisors who use wheelchairs and 10 participants at a national conference for persons with disabilities. Revisions were made to enhance survey clarity based on the participants' feedback. Survey data were collected from March 2004 through January 2005.

A constant comparative analysis approach as outlined by Glaser (1965) was used to identify patterns, code data, and categorize findings. Each survey response was analyzed and compared against the previous ones to find common theme categories, and then the survey responses were compared within categories and between categories (Anfara, Brown, & Mangione, 2002). Specific language used in the responses to describe an occurrence, lesson learned, or recommendation for future directions by the key informants was coded to correspond with a specific emerging theme. The identified patterns and evolving theme categories of one researcher's analysis were discussed with the principal investigator to ensure that themes were logically consistent and reflective of the data (Law et al., 1998). The last step in the analysis required three student research assistants to independently review the data codes and match each response to the identified themes to test analytical preciseness (Law et al., 1998). These reviews resulted in reassigning several responses under theme categories and in a few cases condensing various themes by placing them under an overarching theme category. The constant comparative analysis approach allowed for study findings to emerge from the data (Anfara et al., 2002; Law et al., 1998). Each of these theme categories is described further under the various headings of the results section.

Research Quality and Rigor

Anfara et al. (2002) list criteria for assessing research quality and rigor in qualitative research to include credibility, trans-

ferability, dependability, and conformability. In this study, credibility is affirmed, as there is a clear link between the survey questions and the purpose of the study. The survey questions were developed by the researchers under the guidance of peers (persons with mobility impairments and persons with general and/or disability-related emergency management backgrounds). Transferability lends itself to the purposive sampling of this study, which created a realistic portrayal of key informants due to the sample including varying causes of the mobility impairments (e.g., spinal cord injuries, multiple sclerosis, arthritis) among the informants and experiences with different types of natural and man-made disasters and emergencies. Dependability in this study included the "audit trail" of reasons for how decisions were made to organize the data, code and recode the emerging theme categories, and include multiple researchers to provide cross checks. Conformability included the emergence of a meaningful and descriptive picture of the phenomenon under study that is useful for future research and policy development.

Results

Participants Characteristics and Disaster Experiences

A total of 62 surveys were submitted by persons who met the eligibility criteria for key informants. Out of the 62 returned surveys, 6 were only partially completed; thus, they were excluded from the data analysis. This resulted in a survey sample of 56. The primary diagnosis for mobility impairments among the key informants was reported as spinal cord injuries (28%), multiple sclerosis (13%), arthritis (13%), muscular dystrophy (7%), cerebral palsy (7%), spina bifida (3%), short stature (3%), postpolio (3%), and various other conditions (16%) such as limb loss and sensory disabilities. Seven percent of the informants did not identify the etiology of their mobility impairment but noted that they used crutches for ambulation. Forty (or 71%) of the informants listed only one diagnosis, while 19 (or 29%) reported multiple diagnoses contributing to the mobility impairment. Table 1 depicts the wide range of natural and man-made disasters and emergencies experienced by key informants. Hurricanes, tropical storms, and earthquakes were the most frequently reported natural disasters. Of the man-made disasters reported, fires, terrorist bombings, or bomb threats were most common. Nearly all (95%) of the participants experienced a disaster in an urban area, defined as 150 persons per square mile (Kansas Department of Health and Environment, 2005). The remaining key informants (5%) did not provide sufficient information to determine whether the event took place in an urban, rural, or frontier location. Despite recruitment efforts targeting rural residents, no participants identified themselves as living in rural areas. Survey participants resided in 20 different states and 47 cities.

TABLE 1
Natural and Man-Made Disaster or Emergency Types and Total Number
of Key Informants Experiencing Them

Natural disaster types		Man-made disasters or emergency types	
Disaster	Informants who experienced them (<i>n</i>)	Disaster	Informants who experienced them (<i>n</i>)
Hurricane or tropical storm	12	Fire	5
Earthquake	11	Terrorist—bomb or bomb threat	4
Flooding	5	Blackouts	4
Severe storms	5	Fire drill or fire alarm	2
Tornadoes	3	Vehicle accident	1
Power outage	2	Airplane accident	1
		Terrorist—9/11	1

Experiences Helpful for Survival

Key informants identified three common themes regarding what was helpful for survival. These included preplanning and preparedness measures, personal networks, and help from first responders during and after the disaster.

Preplanning Experiences. Preplanning and preparedness measures included having assembled general disaster supplies, disability-related or specific medical supplies, equipment, and medications. Other preparedness initiatives included evacuation plans, preregistration for emergency assistance, and disaster preparedness training. Preplanned actions taken before the event occurred, such as refilling medications, charging equipment (e.g., power wheelchairs), and evacuating early were reported as helpful activities. Useful items to have readily available after evacuation included food, water, generators, cash, and specialized mobility and/or medical equipment. Other beneficial disaster preplanning actions taken by key informants were due to self assessments of possible hazards or disasters, individual abilities, and limitations during a disaster, possible assistance needs, supplies, and equipment, and the environmental surroundings (exits, accessibility, locations). For example, one respondent reported hurricane-proofing the home because local shelters were not accessible. This action allowed the respondent to endure the storm safely at home.

Personnel Networks and First Responders. Key informants also reported that personal networks were helpful during and after disasters. Coworkers, family, friends, neighbors, and even strangers often formed spontaneous networks to provide assistance during or after the event. For example, key informants reported incidences of coworkers carrying them down stairs, and a hotel guest assisting another guest with sight

and mobility problems down a flight of stairs to evacuate. The sharing of electricity produced by a neighbor's generator was frequently reported as helpful for refrigeration, for recharging durable medical equipment, and for a brief relief from the high temperatures. Many key informants reported that family and friends provided housing and transportation assistance. Firefighters were integral to saving the lives of two key informants who were trapped in homes that were on fire.

Identified Problem Areas Prior, During, and After Disaster

Researchers categorized problems reported by key informants prior, during, and after the disaster into six major themes:

1. lack of worksite or community evacuation plans
2. being left behind when persons without disabilities were evacuated
3. inaccessible shelters and options for accessible temporary housing
4. disaster relief personnel who were unaware of disaster relief options for persons with disabilities
5. inadequate infrastructures, such as power, public transportation systems, and access to potable water, elevators, and air conditioning
6. difficulties returning to daily routines

All of these difficulties were commonly reported by persons with disabilities in other disasters (CSILC, 2004; CIDNY, 2004; NOD, 2005a).

Lack of Evacuation Plans. Six key informants told of their experiences and concerns with the lack of evacuation

plans to address their needs as persons with mobility impairments. One informant wrote:

I ambulate with forearm crutches and my leg stamina is limited. An actual disaster did not occur but I was in a tall building when they had an evacuation drill and there was no plan or equipment to assist me. I was told to ignore the drill and just wait for it to be over. I found this quite distressing and registered my concerns with management. I felt very vulnerable because I attend regular work meetings in this building. (Speak Out 1, 2006, p. 1)

Another informant who uses a wheelchair described the situation this way: "There were no disaster preparations for the work fire, no evacuation plan, or escape options except to walk down three flights of cement stairs, which is not an option. I was left at a stairwell because no one knew what to do" (Speak Out 1, 2006, p. 1).

Being Left Behind During Evacuation. Seven key informants found themselves in frightening situations after being left behind, while persons without disabilities evacuated. Out of the seven key informants who were left behind during evacuations, four noted that there were no disaster plans in place to meet their disability-related disaster needs. One respondent from Los Angeles explained:

I have juvenile rheumatoid arthritis and use a wheelchair. We had a bomb threat at work, which was very scary. Everyone evacuated, but I was still left on the third floor by the stairwell for the firefighters to come get me. But, no one came. Finally, I just struggled, and I used pure fear to get myself down the stairs and outside. It was scary just to realize that there are not really any procedures in place to help someone like me in an emergency. (Speak Out 1, 2006, p. 1)

Nonaccessible Shelters and Temporary Housing. Seven incidents were reported concerning difficulties arising from lack of accessible shelters and temporary housing situations. A common response was: "I didn't use the shelters, as they were not wheelchair accessible." Another key informant wrote: "Places [hotels and motels] that people were being referred to weren't accessible to me in my scooter. And, because of the lack of accessibility of temporary housing options, it cost us much more than if I had no disability."

Uninformed Disaster Relief Personnel. Several key informants described difficulties associated with relief volunteers not knowing about the options available for disaster relief services for persons with disabilities. As the quote below illustrates,

The disaster volunteer was not trained on accessibility issues. He said that the shelters would be ac-

cessible since the law requires it. He didn't understand the impact of me getting there [due to heart disease, mobility limitations, accessibility issues with exiting from home, and lack of accessible transportation] only to discover they were in violation of the law. (Speak Out 1, 2006, p. 1)

Inadequate Infrastructure. Eighteen key informants experienced difficulties due to infrastructures breaking down because of the disaster, leading to a lack of power, drinking water, food, and transportation. Several key informants reported potential life-threatening situations due to a lack of electricity for 7 or more days. Power was needed to operate standard equipment to maintain health, mobility, and independence. For example, two key informants could not use mobility devices and other durable medical equipment to routinely rotate positions while sitting or lying. This exacerbated their medical conditions. Others reported that they required fans or air conditioning to keep cool since their disabilities did not allow them to perspire. The heat also exacerbated health conditions associated with specific disabilities, such as multiple sclerosis.

Difficulties Returning to Daily Routines After Disasters

Three additional themes were identified by key informants relating to difficulties experienced in returning to daily routines after the catastrophic event. These themes were emotional trauma, lack of mobility, and the need for clean-up and repair to assure independence, safety, and health.

Trauma. Previous research studies on personal adjustment after various types of natural disasters suggest that those affected display the symptoms of posttraumatic stress disorder, depression, guilt, fear, nightmares, and increased use of drugs and alcohol (Beck & Franke, 1996). Eight key informants reported postdisaster emotional trauma characterized by fear, grief, nightmares, and generalized stress. For example, one wheelchair user described his fear of re-entering a previously burned building and of false fire alarms. He had been left behind for a total of 8 hours during a fire before firefighters found him and carried him to safety. He spent 4 of those 8 hours in a smoke-filled hall after the fire had been put out. Another respondent reported that her postdisaster grief lasted more than 2 years, and at one point she could not stop talking about the flood.

Lack of Mobility. Several key informants reported mobility-related difficulties in postdisaster conditions involving the lack of accessible public or private transportation for travel to work and lack of access to postdisaster shelters and medical facilities. Respondents also reported the inability to enter or exit multistory residences due to inoperable elevators that deterred access to apartments in high-rise buildings.

The Need for Clean-Up and Repair. Several key informants spoke about damage to buildings and debris left scattered by the disaster that often rendered mobility aids such as ramps, wheelchairs, and accessible vehicles useless. Recovery was also hampered by the inability to get repair work done promptly to restore accessibility and facilitate independence after the disaster. One respondent reported that the ramp of her deck was washed away. She had the money to replace it, but there was no one to hire to do the work because everyone was busy with other more profitable repairs. For other key informants, relocating to temporary housing was not a viable option because the housing was often neither accessible nor affordable. Similar problems for persons with disabilities were documented in other natural and man-made disasters (CSILC, 2004; CIDNY, 2004; NOD, 2005a). The lengthy recovery period was cited as a difficulty for many key informants as illustrated by the following quote: “My life was totally disrupted for a year; everything else had to go on hold while I hired, selected insurance, supervised, picked out appliances, and so on.”

Ranking of Relief and Disaster Services

Eleven relief and disaster services were ranked for satisfaction by the key informants. Five was the highest ranking for satisfaction and 1 was the lowest ranking of satisfaction with services provided during and after the disaster or emergency. Table 2 illustrates the ranking and overall percentage of key informants receiving services provided by these 11 types of personnel, which range from firefighters to family. A majority of the disaster and relief services are reported as being provided by family, friends, and neighbors, private citizens (strangers), and police. These three categories of service providers also received the highest satisfaction ratings. Family, friends, and neighbors received a ranking of 4.5. Police received a 4.0, and private citizens received 3.9. Only 16 of the key informants received services by way of temporary housing, and only 18 sought refuge in shelters. Satisfaction ratings were lowest for temporary housing at 2.8, Red Cross at 2.9, and shelters at 3.1.

Lessons Learned

Fifty out of 56 key informants provided a response to the question on describing lessons learned from the disaster experience. Informants provided a total of 58 lessons learned. These responses covered a wide range of topics. A majority of topics are covered under the headings of disaster planning, evacuation and escape, equipment and supplies, community planning, and emotional survival suggestions. There were 24 suggestions on the topic of having a plan and being prepared, such as “If you need an accessible room at a hotel, it is best to plan early.” One of the nine responses on evacuation and escape was: “Know where the exits are and don’t go up in a building if you don’t know how to get out.” Seven statements dealt with types of general or disability-related supplies and equipment to have

on hand, such as extra medications, manual wheelchair, generator, or flashlight. There were 11 suggestions about various aspects of community disaster planning or knowing about these plans. For example, one response was: “Citizens should know where emergency shelters are likely to be located before a disaster strikes.” Many of these responses were similar to the survival tips provided to the first survey question on what preparations were helpful during a disaster. Seven respondents gave advice on emotional survival tips, such as “Don’t panic! Keep your head and keep your life.”

Many of these suggestions, along with the responses to the question on survival tips, were formatted by researchers into a “do’s and don’ts” checklist format. Table 3 is a summary in the “do’s and don’ts” format of lessons learned and survival tips from key informants in the area of individual disaster preparedness and getting involved in community preparedness initiatives.

While there were many lessons learned, only 12 participants (21%) reported that the disaster experiences led to increased participation in home and community preparedness. This increased preparedness was accomplished by restocking or securing extra or new supplies and equipment, receiving additional preparedness training, and taking a leadership role in city, county, and workplace preparedness for persons with disabilities.

TABLE 2
Relief and Disasters Service Types, Total Number of Key Informants Obtaining Services, and Average Satisfaction Ranking of Services

Relief and disasters services type	Informants obtaining services (n)	Average satisfaction ranking for service ^a
Firefighters	32	3.5
Emergency medical services	30	3.5
Police	43	4.0
Hospital	25	3.3
Emergency management	41	3.3
Federal Emergency Management Agency	29	3.0
Red Cross	23	2.9
Shelter	18	3.1
Temporary housing	16	2.8
Private citizens	59	3.9
Family/friends/neighbors	64	4.5

^a5 = highest, 1 = lowest.

TABLE 3
Recommendations for “Do’s and Don’ts” Related to Disaster Preparedness for and by
Persons With Mobility Impairments (Resources, 2006)

Do ...	Don't ...
Individual disaster preparedness	
<ul style="list-style-type: none"> • Create an individualized emergency plan • Assemble a “to go” kit that includes a week’s supply of meds • Register with or form a registry with emergency responders • Develop a network of family, friends, and neighbors to assist • Check out accessibility of local shelters and hotels • Have a portable generator or adaptor and car battery for power • Have adequate rental or home insurance • Get training on and then direct others to turn off gas and water 	<ul style="list-style-type: none"> • Wait until it happens to you • Forget to conduct quarterly drills of your personal plan • Leave out those who can assist you in the planning process • Forget a flashlight, radio, and two routes for exiting your home • Put yourself in a dangerous situation when the power goes out • Think it won’t happen to you • Forget small details, including having extra ready cash • Procrastinate with safety
Community disaster preparedness	
<ul style="list-style-type: none"> • Get involved at work, residential, and community disaster planning • Get prepared at home and expand preparedness to public setting • Form an “Accessibility Committee” at work and other public places • Explore evacuation options with emergency managers and others 	<ul style="list-style-type: none"> • Wait until a disaster and persons with disabilities are left behind • Assume disaster preparedness plans exist for persons with disabilities • Assume you will be evacuating with everyone else • Overlook alternatives, such as evacuation chairs

Future Directions

Eighty-six percent of the key informants responding to this survey provided suggestions for ways to help persons with mobility impairments survive future disasters. The themes that emerged from these responses are divided into the following four categories:

1. preparedness planning for public areas
2. initiatives to address specific problems
3. disaster preparedness actions to be taken by emergency management
4. disability-related disaster preparedness training and education

Due to space limitations of this article, only a few examples of the informants’ response for each of the future directions categories are provided in Table 4. These future directions address shortcomings in current emergency management systems as related to persons with mobility impairments and other disabilities. They include recommendations to address specific concerns with the lack of disaster plans in public buildings (e.g., malls, hotels), the inability to stockpile prescription medications, and the lack of disability-related disaster education and training of personnel in the field.

Discussion

Summary

The premise that general and disability-specific disaster preparedness measures are useful for the survival, independence, safety, and health of persons with mobility impairments is

supported by the experiences of our key informants. Pre-established and spontaneously formed networks to provide assistance are also important for persons with mobility limitations to survive disasters and emergencies. If assistance was needed during and after the catastrophic event, a majority of this assistance was provided by family, friends, neighbors, and the general public (strangers). Persons with mobility impairments continue to face unnecessary difficulties and life-threatening situations due to the lack of community and workplace evacuation plans; being left behind during an evacuation; or infrastructures failing, such as power, public transportation, and access to potable water, elevators, and air conditioning, or being without accessible shelter or temporary housing. All of these difficulties were commonly reported by persons with disabilities in other disasters (CSILC, 2004; CIDNY, 2004; NOD, 2005a).

Persons with mobility impairments in this study, as well as others (Kailes, 2002; NOD, 2006) encourage their peers to take responsibility for their own well-being during and after catastrophic events. Persons with mobility impairments who have survived a catastrophic event have much to offer emergency management efforts among peers; employers; community; and rescue, relief, and emergency management agencies to assure that the needs of persons with disabilities are met.

Limitations

The limitations of the methodological approach taken included the lack of prolonged engagement with the participants and the inability of researchers to follow up and develop extended dialogue or verification of the identified themes among the key informants (member check). Also the use of a single

TABLE 4
Examples of Recommended Future Directions for Emergency Management to Assist Persons
With Mobility Impairments as Provided by Key Informants, by Topic Area

Preparedness planning for public places	Initiatives to address specific problems	Disaster preparedness actions for emergency managers	Disability-related disaster training and education
<ul style="list-style-type: none"> • Mandate that all buildings develop a disaster plan that includes disability-related preparedness; secure alternatives for escape if the buildings are dependent on elevators, make evacuation chairs standard equipment, and train staff to assist with evacuation. 	<ul style="list-style-type: none"> • Develop insurance policies allowing for stockpiling at least 1 week's worth of medications for emergencies. 	<ul style="list-style-type: none"> • Remind emergency responders to get whatever mobility devices and durable medical equipment are needed out of the building (e.g., wheelchairs, walkers, ventilators, oxygen delivery devices) and reunited with the person as soon as possible. 	<ul style="list-style-type: none"> • Make training available for developing home preparedness and evacuation plans for persons with mobility impairments and planning for evacuation to a shelter and other forms of temporary housing.
<ul style="list-style-type: none"> • Require disaster plans in hotels and other public buildings to develop a system to track persons with disabilities and then be able to evacuate them if an emergency occurs. 	<ul style="list-style-type: none"> • Create accessible shelters, temporary, and long-term housing solutions. 	<ul style="list-style-type: none"> • Pay more attention to meeting the needs of persons with disabilities in preparedness and response and include input from them in emergency management. 	<ul style="list-style-type: none"> • Require regular training on disability-related disaster preparedness and response measures should be received by emergency management, first responders, and relief personnel.
<ul style="list-style-type: none"> • Increase participation of persons with disabilities and organizations representing persons with disabilities in disaster and emergency planning. 	<ul style="list-style-type: none"> • Create separate lines for distribution of water, food, ice, and other supplies during a disaster for persons with disabilities and other conditions who cannot stand or wait for long periods of time. 	<ul style="list-style-type: none"> • Have a shelter that takes in a lot of different disabilities, not just persons with disabilities needing oxygen. 	<ul style="list-style-type: none"> • Improve sensitivity of emergency service providers through training.

data source (i.e., the written responses to a survey) is a limitation because of the inability to triangulate with other data sources (e.g., interviews, participant observations). In addition, the key informants' overwhelming support for disaster preparedness may be in part due to any bias that might have been created from the sampling method. A majority of the key informants were conference attendees or Web site browsers of disability organizations. Thus, the diversity of persons with mobility impairments according to interests, age, income, education, geographic locations, and physical capabilities may not be reflected in the sample. The collection of additional information is also recommended on demographics, such as age, sex, income, and education. Other useful information could include more specifics about individual disaster plans (i.e., whether a disaster plan exists, the advantages and disadvantages of aspects of the plan during and after the disaster, and any modifications made to the plan after the event).

Implications

A better understanding of disaster preparedness for and the difficulties experienced prior, during, and after disasters by persons with mobility impairments has been gained by this study that can be applied to preparedness and response efforts,

and policy decisions. The developed themes and identified issues generated by this preliminary or pilot study lend themselves to exploration in subsequent, more in-depth qualitative or quantitative investigations. Areas for consideration in further research, practice, and policy include the following:

1. exploring the issue of networks in emergency response
2. identifying preparedness strategies for persons with disabilities
3. identifying best practices for evacuation plans in business and other public settings
4. establishing national consumer standards for emergency evacuation technology (e.g., stair descent devices) and testing these standards on existing and new equipment
5. developing alternative and affordable electricity sources to be used in power outages
6. creating model education and training curriculum using Participatory Action Research (Law et al., 1998) to help persons with disabilities create personal plans and become involved in community preparedness planning

Conclusions

In the last 50 years, a reluctance to get involved or render assistance due to fear and mistrust has evolved in the general public from such factors as increases in lawsuits and overall crimes against persons. Yet, the 9/11 terrorist attacks, 2004 Tsunami in South Asia, and Hurricane Katrina reminded us of the many facets of human compassion that still exist—be it television coverage of heroic rescues, kind actions toward those suffering or in need, or the outpouring of disaster relief donations. Thinking of others during and after a disaster leads to spontaneous networks of assistance among strangers, neighbors, friends, and family members as shown by these events and our study. This has been confirmed by other studies, such as one conducted by the Kaiser Family Foundation (2005), which found that neighbors and friends were almost as instrumental in rescue efforts as the National Guard, Coast Guard, and military during the flooding in New Orleans after Hurricane Katrina. One of our key informants echoed the sentiment of other key informants with his advice that persons with disabilities not only be prepared but “Educate, Educate, Educate.” To educate is to become involved and render assistance by becoming a voice for others. Consumer representation in disaster preparedness and response is imperative for meaningful changes.

It is not hard to imagine how it must feel to be left behind in your wheelchair while others evacuate to safety, use public transportation, and access shelters or other forms of temporary housing during disasters. Without meaningful changes, persons with mobility impairments or other disabilities will continue to risk their lives, safety, and independence needlessly due to a lack of, or inadequacies in, preparedness and response measures. There is no reason for another 20 years of consumer reports reminding us of this discrimination.

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