Incorporating Special Needs Populations into Emergency Planning and Exercises

By
Elizabeth Davis, JD, EdM
Jennifer Mincin, MPA

June 26, 2005

Sponsored by
Nobody Left Behind: Disaster Preparedness For Persons with Mobility Impairments
Research and Training Center on Independent Living
University of Kansas
www.nobodyleftbehind2.org

Funded by a grant from Centers for Disease Control and Prevention
through the Association of Teachers of Preventive Medicine TS#-0840

Table of Contents

Section I

Introduction	3
Definition of Special Needs	4
Background on Special Needs and Emergency Management	5
The Legal System and Mandates	6

Section II

Special Needs: Planning and Exercises	9
Case Study I – Brownsville Senior Apartment Building Fire	11
Case Study II – Interagency Chemical Exercise	12
Case Study III – September 11, 2001 Terrorist Attacks In New York City	13
Case Study IV – FEMA Top Officials National Drill	18

Section II

How to incorporate Special Needs into Planning And Exercises	20
Planning	21
Exercise Initiatives	23
Planning and Exercises	25
Working with the Disability Community	27
The Reality of Disasters	29
Universal Benefit	31
Conclusion	33
About the Authors	34
References	36

Section I

Introduction

Emergency management as a field was formalized on the federal level in 1979 with the establishment of the Federal Emergency Management Agency (FEMA); however, the functions of first response (fire, rescue, and law enforcement) and relief work (human services and special needs) have been in existence much longer. Both of these functions remain distinct components of emergency management today. It has not been until recent years that the idea of integration and incorporation of emergency management and special needs issues have been placed at the forefront. There have been certain situations, such as the events of September 11, 2001 and specific law suits, which have served as catalysts in terms of placing special needs issues on the agenda of federal, state, and local emergency management. This has spurred further discussion on integration and inclusion. Specific areas in which inclusion and incorporation of special needs issues are particularly lacking are: emergency planning, exercise design, and drills.

This paper will provide background on the issue of emergency management and special needs, challenges facing meaningful integration of special needs issues, current federal and legal trends, and best practices and recommendations for integration and inclusion of special needs issues in planning and exercises. Additionally there are case studies provided that demonstrate both successes and lessons learned with regard to special needs issues and emergency management, gleaning ideas on how the emergency management community can integrate disability and senior issues into all aspects of planning and exercises.

Definition of Special Needs

The term "special needs" has a specific meaning within the context of this paper. Special needs refers to people with disabilities (including cognitive, physical, and sensory); age spectrum (ranging from pediatric to geriatric); and those requiring medical assistance (home care, assisted daily living, etc.). While some emergency managers will include unique planning concerns such as immigrant affairs, multi-language needs, and pet issues, for the purposes of this paper those matters will not be included[1]. However, it is essential that emergency managers understand that not all disabilities are the same and this must be taken into consideration.

People with disabilities are a significant part of the general population. According to the 2000 census, there are close to 50 million people with disabilities, which is approximately 17% of the total population in the United States[2]. It is estimated that of the 50 million who have identified themselves as having a disability, 28% of them are 65 years and over. Disability issues span the age spectrum as well. According to the Federal Interagency Forum on Aging Related Statistics (FIFARS, 2005), in 2003 there were 36 million people 65 years and older in the United States (FIFARS, 2005). While not all older people have a disability, there is a relationship between disabilities and the aging with nearly 14 million of them having one or more disabilities (US Census, 2000). According to the US Administration on the Aging (AOA), people 65 and older are the fastest growing population and "represented 12.4% of the population in the year 2000 but are expected to grow to be 20% of the population by 2030" (US Administration on the

[1] It is important to acknowledge that the term "special needs" has been debated within the disability community. Some advocates think the term does not adequately represent the disability population (Kailes, 2005), p.3). As this debate continues, and again, for the purposes of this paper, special needs will respectfully be used to define people with disabilities across the age spectrum.

[2] Several disability organizations, such as the National Organization on Disability (N.O.D.), place the number of people with disabilities higher; they estimate the number is 54 million with approximately 20% of the population affected by one or more disabilities (National Organization on Disability, 2005).

Aging, 2004). In addition, there are 5.2 million children between the ages of five and 20 with a disability in the United State (US Census, 2000).

Background on Special Needs and Emergency Management

On a federal level, FEMA is the agency that establishes guidelines and grants for state and local emergency management; the state often administers guidelines and grants to local jurisdictions that are then expected to carry out the guidelines. Under the current administration, and after the terrorist attacks of September 11, 2001, FEMA became a part of the newly formed Department of Homeland Security (DHS). FEMA relies on a system known as the National Response Plan (NRP) of which there are 15 Emergency Support Functions (ESFs), which provide guidelines, agency roles and responsibilities, and creates structure and common language for emergency management and first response. Of the 15 ESFs, four are dedicated to human services (mass care, food and water, volunteer and donations management, and animal services) none are specifically dedicated to special needs, yet disability issues are an enormous consideration spanning most aspects of emergency management, despite the fact that disability issues are an important aspect in ***all*** areas of emergency management. Traditionally, special needs issues fall under the purview of Disaster Human Services within the emergency management system. Disaster Human Services is a broad yet specialized field within emergency management and primarily deals with issues that directly affect victims of disasters and local emergencies.

Disaster Human Services is considered to be the longest operation to function after a disaster. Once the disaster has occurred, human service systems are initiated. After the response phase of a disaster (when law enforcement, fire and other first

response entities manage the immediate emergency consequences) has concluded, human services become a primary function and may continue for a long period of time depending on the type of event. Human services operations are complex and usually issues will overlap as victims may require housing, employment and mental health services after a disaster. Human Services deals with, among other things, the following issues both in terms of pre-disaster planning and post-disaster response and recovery, sheltering, temporary and long-term housing needs, mass care, special needs, volunteer and donation management, voluntary agency coordination, disaster mental health (crisis counseling), immigrant and minority affairs, and outreach and education. Since special needs issues are considered a "human" issue, it has largely been relegated to Disaster Human Services in terms of planning, education and outreach, and response and recovery. Until recently, special needs issues have not been incorporated into the other aspects of emergency management. Emergency management, from a command structure perspective (following the NRP discussed above), has four operational aspects: planning, operations, logistics, and finance/administration

The Legal System and Mandates

While the Americans with Disabilities Act (ADA) of 1990 does not specifically address the issue of compliance in emergency planning and response, it does mandate that all covered public and private sector facilities are in compliance, provide reasonable accommodations, and be accessible. Essentially, special needs populations cannot be excluded on account of disability with regard to emergency plans (Davis & Sutherland, 2005). According to the short article published by IAEM, "While not specifically articulated within many of the authorities mentioned [ADA], in a post-Sept. 11 United

States, the interpretations are now shaped by a 'big picture' approach and extend the rights of people with disabilities to share in access to services and programs, to include emergency preparedness planning and response" (Davis & Sutherland, 2005, p. 13). Plans should be designed to address accessibility and accommodations so that special needs issues are incorporated into all aspects of disaster planning.

NOD/Harris Interactive Poll
42% of emergency managers polled said they have preparedness materials for people with disabilities – only **16%** of the materials are *in accessible formats*

Emergency management offices should provide, when feasible, emergency information to the special needs population through the following methods to be most effective:

- Public information materials must be provided in alternate formats including audiotape, electronic, and written materials in large type or Braille and all websites must be 508 compliant.
- Public Service Announcement (PSA) should be Captioned (open or closed) for people who are deaf or hard of hearing.
- Coordination with the disability community in establishing trainings and alternate format of materials should be considered.
- OEMs and other government agencies should have functioning Telecommunications Device for the Deaf (TDD a.k.a. TTY) as well as a public email address. These numbers and addresses should be published in all public information materials and websites.

On July 22, 2004, President George W. Bush signed Executive Order 13347, which essentially mandates that people with disabilities be included in emergency planning at the federal level (Davis & Sutherland, 2005). In support of the Executive Order, an Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities was formed to address the various needs of the disability community and provide guidance for federal agencies (Davis & Sutherland, 2005). It is a multi-agency Council that is broken up into eight subcommittees addressing issues such as accessible communication systems, special needs shelters, and the establishment of voluntary special needs registries (Davis & Sutherland, 2005).

Following the Executive Order, on December 28, 2004, a landmark settlement in Montgomery County, Maryland, reinforced what disability advocates have been saying for years regarding the ADA and emergency evacuation planning. The lawsuit involves the nation-wide retail store, the Maryland shopping mall and a customer, Katie Savage, with multiple disabilities who used a scooter to independently travel. She became trapped within a shopping mall during an emergency evacuation (Washington Lawyers' Committee for Civil Rights & Urban Affairs, 2005). During the evacuation, Savage was instructed to first exit the store and then the mall from the common atrium. Since the store was below street level, the elevators were recalled automatically with the fire alarm, and because the emergency exits lead to stairwells, she was literally trapped for the duration of the emergency (Washington Lawyers' Committee for Civil Rights & Urban Affairs, 2005). Savage filed a suit under the ADA challenging the store's lack of emergency planning for people with disabilities and the mall for the same. Under the ruling in the store matter Judge Debelius, the Circuit Court of Montgomery County,

found that "the ADA requires places of public accommodation to consider the needs of people with disabilities in developing emergency evacuation plans" (Washington Lawyers' Committee for Civil Rights & Urban Affairs, 2005). For its part, the mall in a separate negotiated settlement agreed to a commitment of safety for all and is well on its way to implementing new emergency protocol taking into account people with disabilities. By interpretation, this process could extend to all public places and essentially means evacuation plans need to include people with disabilities as well as the general public. Emergency managers and public facility owners alike should, therefore, keep informed and be aware of recent decisions and mandates, court cases, and the law regarding people with disabilities and emergency planning and evacuations, as well as newly emerging standards of practice in the field of life safety.

Section II

Special Needs: Planning and Exercises

According to a National Organization on Disability (N.O.D.) and Harris Poll Interactive[3], incorporation of special needs issues on local and state levels have increased. However, these plans are not comprehensive and lack adequate planning for children with disabilities, do not utilize experts with disabilities, and have limited training and funding (NOD, 2004). In addition, the survey found that vital information was not in accessible formats (N.O.D., 2004). In many regards, special needs issues are more complex than general population issues. However, special needs issues are equally

[3] In early 2004, N.O.D. and Harris Poll released the results of a follow-up survey to one previously administered post-September 11, 2001 regarding emergency preparedness among people with disabilities and emergency managers. Although numbers have increased in terms of preparedness, people with disabilities are still not adequately prepared for emergencies and the first response and emergency management community has much progress to make in this area (N.O.D., Emergency Preparedness Initiative, 2004).

important and cannot be disregarded simply because they are more challenging. Often, emergency managers and first responders feel overwhelmed by special needs issues and do not know how to incorporate and include people with disabilities in the planning and exercise process. Whether it is first responders who may not know how to communicate with a person who is deaf, or an emergency management planner who simply did not consider incorporating special needs into planning and exercise, disability issues have been largely ignored. And it is not just emergency managers or planners struggling with special needs issues. Often, disaster relief workers and government human services staff may not fully understand the unique disaster-related needs of people with disabilities; they may not know how to assist a person in a wheelchair find a temporary accessible dwelling in a tight housing market, for example. Special needs issues affect most emergency management and response professionals as well as human services and relief workers.

The exclusion of special needs populations can have dire effects and cause undue disruption and perhaps even unnecessary fatalities. The approach to incorporating special needs issues must be a holistic one. The first step is to ensure that special needs issues have been integrated into all aspects of emergency planning. The next step is to exercise those plans with the inclusion of not only special needs issues, but the invitation of people with disabilities into exercises and drills. Presented in this section are four case studies dealing with disability issues in various ways followed by Section III, which provides recommendations on how to incorporate and include special needs populations into planning and exercises.

Case Study I – Brownsville Senior Apartment Building Fire

In 2000, a fire occurred in Brownsville[4] at a senior care facility that housed 300 individuals of various levels of independent living and need. The age range was from the 60s into the 90s. Some individuals had physical disabilities including mobility, hearing and sight issues. A fire occurred on a Friday night at 1 a.m. Firefighters responded and within a few hours, the fire was extinguished. However, the building was not able to be occupied for at least three days and the residents needed temporary shelter and mass care services such as food, water, and mental and physical health services.

Initially, a school was opened, but a few major shortcomings quickly became apparent: there was not enough planning and exercising of the plans nor were communication protocols in place between key agencies. For example, since the senior housing facility technically fell under local government jurisdiction, it was the responsibility of local government to have plans in place for alternate relocation facilities and transportation to those pre-designated sites[5]. In fact, none of the agencies involved in the incident were actually aware of whose primary responsibility it was to relocate and transport the seniors. Additionally, there was a severe lack of on-scene staff with expertise in the area of special needs and a communication failure as a result of the absence of pre-established protocol delineating roles and responsibilities. The situation became unnecessarily more chaotic but served as a valuable lesson to all agencies involved.

[4] Although this is based on an actual situation, the location has been changed for confidentiality.
[5] Often, when managing medically frail individuals during a disaster, it is important that appropriate facilities be designated as relocation sites for emergencies. Depending on the level of care needed, a church basement, community center hall, or school gym may not be adequate as temporary shelter facilities. Emergency managers must also be prepared to transport these individuals from the incident to the safe shelter. Transportation must be accessible.

Despite the lack of planning and exercises, agencies were able to meet and develop a plan to care for the seniors during the incident and within three days residents were allowed back into their homes. Fortunately, no one was seriously injured, and there were no fatalities during the course of the incident. As a result of what happened and the clear lack of planning and coordination, efforts were made to establish protocols and an emergency response team with appropriate staff and volunteers. These were first steps towards integration of special needs issues; next steps would include more comprehensive planning initiatives and exercising of the newly crafted plan.

Case Study II – Interagency Chemical Exercise

In 1997, the New York City Office of Emergency Management conducted, what was then considered to be the largest urban terrorism drill: Interagency Chemical Exercise (I.C.E.). Throughout the course of the drill, disability issues were incorporated to ensure first responders were presented with a realistic situation and so all response agencies could learn how to improve systems. There were four victims with disabilities throughout play[6]: two people in wheelchairs and two people with sight impairments (Byrnes & Davis, 2005). What made the inclusion of disabilities issues perhaps most valuable was that it enabled first responders and OEM to understand the issues from all angles. The victims with disabilities were able to give first-hand accounts regarding how they were treated and what the overall experience was from a disability perspective. Likewise, observers were able to identify problems and first responders had to struggle with a likely, yet additionally challenging situation (Byrnes & Davis, 2005).

There were several problems that were identified, which would not have been identified if people with disabilities were not active participants. These included:

[6] The term "play" refers to volunteers who "play" or act as victims during an emergency drill.

wheelchairs, glasses, and canes that were not decontaminated; triage procedures were handled improperly in regard to people with disabilities; no identification mechanism was in place resulting in delayed care; mobility issues with regard to tyvek suits[7]; unclear handling of service animals; and problematic communication as interpreters were delayed (Byrnes & Davis, 2005). The most critical finding, however, was the re-contamination of the cold zone (safe area) because of the ineffective response protocol to individual auxiliary aids (i.e., wheelchairs). This translates not only to ongoing harm to the individual with a disability but to the entire population including responders themselves. The system was compromised when a few steps in protocol where overlooked or familiarity with the appropriate action was not commonplace. As a result of including people with disabilities during play for the New York City terrorism drill, several key elements were identified and able to be listed for improvement after the drill.

Case Study III – September 11, 2001 Terrorist Attacks in New York City

The events of September 11, 2001 impacted the nation, if not the world[8]. For those in New York City, dealing with the immediate situation and its aftermath proved challenging far beyond what most people could ever have expected. For people with disabilities, dealing with and managing the events of September 11th were significantly different and more difficult than for the non-disabled population (N.O.D. EPI, 2005). During the evacuation of the World Trade Center, several people with disabilities were left behind and it quickly became apparent that there were no consistent formal plans to evacuate people with disabilities (Hart, 2004). Perhaps most disturbing and traumatizing

[7] Tyvek suits are safety suits that protect against contamination and are often used as a fast one-size fits all cover-up after clothing has been removed in the public decontamination process.
[8] Portions of the information in this section are based on the authors' first-hand experience working on special needs issues during the terrorist attacks in New York City.

was that some individuals with disabilities were instructed to wait for rescue workers - - a correct procedure in other types of situations. Some perished as a result (Hart, 2004). For those who did escape, it was because they were carried downstairs to safety or guided by a Seeing Eye dog. Others reported that the independent life style they were once accustomed to no longer existed following the events (N.O.D. EPI, 2004). People with disabilities at Ground Zero were cut off from crucial supplies and assistance necessary for daily living such as not having access to Meals on Wheels and limited access to prescription medications. Telephone service and the TTY/TDD system were down and people who were Deaf were uninformed because Closed Captioning was not functioning (Mincin, 2005). Transportation was either limited, cut-off entirely, or rerouted and disability advocacy and mental health agencies were overwhelmed.

Providing human services to the general population is difficult enough. If government and voluntary agencies are not aware of the unique needs of people with disabilities or prepared for working with special needs populations, response and disaster service delivery can be all the more difficult. Post-disaster human services encompasses everything from basic necessities such as shelter, food, and clothing to longer-term care, such as mental health, short and long term housing, and employment. There were a number of post-disaster issues that non-disabled victims were dealing with, but in a more general way. These issues become more magnified for people with disabilities, who may have very specific needs. Certain issues affect people with disabilities more then those without a disability, and people with disabilities continue to struggle for equality despite legal advances such as the ADA (American Civil Liberties Union, 2005). For example, loss of employment and hiring issues for people with disabilities create a range of

problems for people with disabilities in their daily lives. These include discrimination, job training specific to different disability types, and modifications or accommodations that need to be made both in the job search process as well as on-the job work (N.O.D., 2005). According to the American Civil Liberties Union (ACLU), people with disabilities are among the least employed population in the United States (ACLU, 2005). A study examining how people with disabilities react to unemployment, an issue that affects many people after disasters occur, found that people with disabilities are five times more likely to be involuntarily unemployed than the general population and the emotional impact on the disability population regarding unemployment issues was far greater (Blake, et. al., 2004). Post-disaster employment issues differ for people with disabilities because the job site may change, different skills may be needed, business continuity is often interrupted, and job placement and training services must be appropriate for people disabilities.

People with disabilities are disproportionably affected when they experience extraordinary disruptions in their lives. Loss of health insurance can be a major problem for a person with a disability who is on lifesaving medications or needs on-going medical care (NOD, 2005). Health and mental well-being are related, and individuals who do not have access to healthcare often experience higher rates of anxiety, are more prone to serious illness, and less likely to receive proper treatment (SAMHSA/CMHS, 2004). Transportation for people with disabilities can be particularly difficult; after a disaster it can become even more difficult to negotiate an unfamiliar environment. People with disabilities must deal with a tremendous amount of paper work and bureaucratic agencies just to receive benefits or accommodations. During a disaster, people with disabilities

may have to deal with staff at assistance centers who might have little or no experience with the disability population and are less effective in assisting people with disabilities receive disaster-related benefits. These, and other disaster related trauma can add to an already stressful and challenging time (N.O.D. EPI, 2004).

Recovery from a disaster is difficult for most people, but can be especially difficult for people with disabilities because they may be dealing with loss and vital connections with attendants, guide dogs, neighbors, and family members (N.O.D., EPI, 2004). This may cause additional emotional and mental stress as it forces the individual with a disability to deal with the limitations imposed by their disability during a disaster, which may take many months from which to recover (N.O.D. EPI, 2004). In addition, people with disabilities exposed to on-going, traumatic hospitalization may relive these experiences making recovery from the disaster all the more difficult (N.O.D. EPI, 2004).

The disability population reported that the World Trade Center attacks triggered past anxieties (most related to the experiences associated with having a disability) as well as heightened anxiety in direct relation to the disaster, which triggered dependency issues for those living independently. During the September 11th attacks, people with disabilities experienced a change in their normal routine, much like the general population. However, for people with disabilities, the change was often more dramatic and had a different impact. During and after the disaster, people with disabilities had a challenging time accessing services, which continually heightened anxiety and caused a sense of isolation and loss of control.

After spending years of advocating for specific services, reasonable accommodations, anti-discrimination legislation, and accessibility, some people with

disabilities directly affected by September 11th found themselves in a position of dependency. One blind individual who worked downtown reported that the most difficult part of returning to work after the attacks was that the landscape had changed so dramatically it became difficult to navigate the streets and physically get to work. The events of September 11th left some in the disability community feeling as though they had no control over their own lives and safety.

It is equally important to note that some agencies did learn from previous events, such as the 1993 terrorist bombing of the World Trade Center. After the bombing, at the urging of New York City OEM, The Associated Blind, an area agency servicing the vision impaired and Blind, worked with the Fire Department of New York (FDNY) to develop emergency evacuation plans for staff and clients (N.O.D. EPI, 2004). In addition to plan development, drills were conducted so plans could be tweaked and staff made familiar with evacuations. As a result, on September 11th, staff safely and independently evacuated the building (N.O.D. EPI, 2004).

In many ways, because New York City OEM had dedicated staff to special needs issues and had tested plans that incorporated people with disabilities into them (as seen with the I.C.E case study), the City was able to assist the disability population and was better prepared to do so, perhaps more than other municipalities would have been. In addition, New York City OEM had a dedicated, fulltime disability specialist. Following the attacks, New York City OEM, in partnership with FEMA, utilized additional disability and human services experts to manage daily issues affecting special needs populations assisting with coordination and communication with various disability agencies and homecare and senior facilities. Disability experts provided overall guidance

and understanding of special needs issues post-disaster. This helped ensure that services were provided to the disability population and that information was accessible and appropriate. Had planning and drills not already taken place and special needs experts not already involved, the already dire and fatalistic scenario may have perhaps been unimaginably far worse for people with disabilities. Every disaster presents success and lessons learned and September 11th was no exception. Although lives were lost, people injured, and New York City deeply impacted by the events, the heroic efforts of first responders, relief workers, coworkers, and individuals are acknowledged and honored.

Case IV – FEMA Top Officials National Drill

April 4 through the 7th of 2005 marked the Department of Homeland Security's (DHS) third national Top Officials (TOPOFF3) drill. The drill took place in Connecticut, New Jersey, and Washington, D.C. all concurrently. Information in this section includes input from disability specialists and emergency managers who were invited for the first time to observe special needs issues for the duration of the drill in all three locations.

Significantly, many observations were analogous, whether information was reported from the emergency managers or disability specialists. It is necessary to acknowledge upfront the efforts of DHS in including the disability community as a first and major step towards full integration of special needs issues in the planning, exercise and drill process. Although there are items recommended for improvement, efforts toward this inclusion cannot be underestimated. As DHS continues to work towards integration, it will set an example for state and local entities to also move in that direction.

Special needs observers were specifically looking for various items during the drill including: integration of people with disabilities during drill as actors (volunteers participating during "play"), evaluators and controllers, inclusion of disability agencies (advocacy and service agencies) in the disaster assistance centers, accessible facilities, information presented in alternate formats and available across varying mechanisms (low or high-technology capabilities), open captioning; and available interpreters at all sites, among other pertinent special needs issues. Since DHS chose to include special needs issues, observers noted that at some of the locations (notably New Jersey), people with disabilities were included as observers and actors participating in the drill. Local New Jersey health and emergency management personnel acknowledged the importance of incorporating disability issues into emergency planning and stated that those issues were in fact included in county plans.

Towards improvement, observers noted a few areas that need to be addressed including ensuring all facilities are accessible (not all the areas were amendable to people in wheelchairs moving with ease), providing information in alternate formats and Closed Captioned, and better inclusion of people with disabilities during play (only one location was observed as having people with disabilities included). Specifically, special needs objectives need to be clearly included in the exercise plan and disability organizations should be contacted to either provide input or observe and should be invited in a timely manner. This ensures that other players (responders), exercise facilitators and controllers are aware of special needs issues and are able to operate with these issues in mind. These recommendations are not criticisms, but rather essential lessons to be learned not just for the federal government, but for all entities involved in emergency management and first

response. A key aspect to emergency management is that we share and learn from each other, and these recommendations are critical for all planners and first responders to consider during the planning, exercise design and drill phases.

Again, DHS is applauded for including disability issues and inviting experts from emergency management and the disability community to observe TOPOFF 3. With time before the next series of TOPOFF drills (and all exercises for that matter), testing the inclusion of disability issues and their impact on the play should be developed as true exercise goals and objectives. This will ensure disability issues being measured against real outcomes and the ability for all systems to expand in its response capabilities.

Section III

How to Incorporate Special Needs into Planning and Exercises

According to the Research and Training Center on Independent Living (RTCIL) at the University of Kansas, disaster preparedness is usually focused on the non-disabled population and evacuation plans built on the assumption that those being evacuated do not have a disability (RTCIL, Nobody Left Behind, 2005). Plans often do not address the transition needs of people with disabilities to assist them in returning to pre-disaster functioning (RTCIL, Nobody Left Behind, 2005). Nor are plans exercised to examine whether or not special needs issues have been adequately incorporated. In 2003, southern California experienced its worst and most devastating wildfire disaster; people with disabilities were, again, disproportionately and adversely affected. People with disabilities reported the inability to evacuate themselves and of those who received evacuation assistance, mobility devices were left behind restricting movement once the person with a disability was in a safe location (California State Independent Living

Council, 2004). In addition, evacuation plans apparently did not take into consideration the need for accessible transportation (California State Independent Living Council, 2004). Post-disaster recovery issues were also challenging because a portion of the evacuation shelters were not accessible and communities were not prepared to rebuilding accessible homes (referred to as "retro-fit housing") (California State Independent Living Council, 2004).

While strides have been made within the disability community with regard to preparedness, they are not enough either. Emergency managers must be aware of the fact that the disability community is not as prepared as it should be (nor is the general population for that matter). A 2004 N.O.D. survey revealed that 66% of people with disabilities do not know whom to contact regarding emergency plans, 61% have not made plans to evacuate their homes, and 32% say their workplace lacks evacuation plans (N.O.D., 2004). This survey points to the need to better educate, provide more information, and establish outreach methods to the disability community. In addition, the disability community must become more prepared itself. This level of preparedness within the disability community must be considered within planning and exercise initiatives.

Planning

Planning and outreach initiatives must always be ***ability*** focused and inclusive in terms of disability type and criteria with planning efforts that assist special needs populations. To start, emergency planners should begin with some reasonable assumptions about the hazards their community faces and how these will affect the

disability population. The following issues may directly affect the special needs population during various types of emergencies and disasters and should be anticipated:

- Hesitancy/refusal to evacuate especially if the home is retrofitted (made accessible)
- Emotional trauma and physical discomfort because of evacuation
- Loss of possessions and/or homes (again, an issue for homes that have been retrofitted or other accommodations were made)
- Disorientation and confusion caused by disaster conditions resulting in a temporary loss of memory or the triggering of other cognitive issues
- Increased need for assistance services to residents at home (meals, at home nursing, chore services)
- Increased demand for placement in residential care facilities
- Increased mortality rate following a catastrophic disaster
- If feasible and appropriate, efforts should be made for local municipalities to consider voluntary special needs registry focused on assisting the most medically vulnerable populations (i.e., those medically dependant and bed bound with little support).

Fire, emergency services and law enforcement are often first to arrive on scene in any situation, whether it is a bomb explosion or house fire. It is important to recognize that local jurisdictions not only need to fully integrate special needs issues into emergency planning, but also educate and work with first responders to better understand the unique needs of people with disabilities and seniors, especially the frail elderly. It is equally important to acknowledge that on very local levels, some fire departments, for

example, already have relationships with isolated seniors in their community and may even have a communication or voluntary simple registry. Evidenced in a village on Long Island, the fire department and local emergency manager have working knowledge of where frail or medically dependant seniors live and all medical care and nursing home facilities are located (including assisted living and dialysis centers) as well they have strong communication with these facilities. During the August 14, 2004 blackout, across most of the mid to northeast, the local emergency managers were able to conduct routine call outs to the nursing homes and other care facilities and report to the county. The village first responders were better positioned to respond to their immediate community with the added benefit of knowing where residents live. Should assistance be required, a request to the county Emergency Operations Center (EOC) could be made and additional assistance would be provided to the village. The key aspects here are: pre-planning and testing of systems, joint efforts between local (village), county, and special needs populations via individuals and facilities; and the establishment of communication plans and protocols.

Exercise Initiatives

Once administrative entities are familiar with the contents of emergency plans, the next logical step becomes the exercising of the plans. There are different levels to exercises and drills: table top, functional, and full-scale. Tabletop exercises focus on the developed emergency plan where local entities involved will "talk through" an emergency scenario (hurricane, flooding, biological attack, etc.) using the already developed plan and discover areas for improvement. A functional exercise follows a tabletop and takes the exercise one step further. Often EOCs are activated to test the

management of communication systems and information sharing. Functional exercises require all involved entities (local, state, and federal agencies and relief organizations) to send representative to the EOC to test communication systems and learn how to coordinate better on an interagency level. At the conclusion of the exercise, gaps will also be identified and changes to the existing plan are considered. A full-scale exercise which follows the functional exercise, is designed to be as close to a real-life/real-time situation, as is safe and feasible, and is conducted within the confines of a "controlled" environment. During a full-scale exercise, EOCs will be activated, assets (or resources such as staff, food, equipment, etc.) will be shared, interoperable communication systems will be tested, and joint decision-making will be expected.

Exercises and drills are designed to provide an objective assessment of response systems during an emergency or disaster including identification of planning and procedural strengths and areas for improvement. A crucial aspect of emergency management, exercises and drills allows planners and responders to test systems. It is common for drills in particular to involve volunteers to "act" as victims during the simulated event to add as much realism as possible for first responders. Victims are usually recruited from various community organizations including Boy and Girl Scouts, volunteer agencies, Community Emergency Response Team (CERT), among others. However, and unfortunately, rarely are disability and senior organizations invited to participate in exercises and drills. In addition, exercises and drills are meant to progressively become more difficult to challenge already existing systems, which allows responding entities to share ideas and information.

Goals for future exercises should be to incorporate special needs issues in the early stages of exercise design. By developing these issues as true exercise goals and objectives, they can be measured against other objectives and outcomes. It is also important to identify the appropriate disability organizations for logistical involvement. In addition, it is imperative that once municipalities begin to incorporate special needs issues into planning and exercise, the information be shared and the disability assessment be included in official exercise reports so that these issues can be addressed and standardized throughout the field. This will assist in awareness and education for both the emergency professionals and the disability community. For exercise programs to be effective and truly educate and challenge first responders and officials, entities involved must retain qualified subject matter experts in emergency preparedness for people with disabilities, as well as disability service provider experts to have value-added substance to any exercise design.

Planning and Exercise Basics

Below are some questions to consider when initially developing a disability component to an emergency plans and exercise design:

- Are all public information materials accessible and available in alternate formats?
- Are interpreters readily available for meetings and counseling sessions?
- Do outreach workers (disaster staff), first responders and planners fully understand issues concerning the disability population affected by the disasters?
- Are people aware of sensitivities regarding people with disabilities and terminology? What kind of education is provided to first responders, disaster staff, and planners regarding disability issues?

- Are disability issues being incorporated and integrated into the whole program?
- How are you ensuring accessibility and “reasonable accommodations?”
- Is the disability community incorporated in the actual development plans and exercise design?
- Needs of each target group because not all disabilities are the same (i.e. Mentally Retarded Developmentally Disabled, Deaf or hard of hearing, Blind, people in wheel chairs, etc.).
- Existence of internal service agency disaster plans.
- Communication of member agency disaster plans.
- Existence of inter-agency and community partnerships.
- Information relayed during a disaster from governmental agencies and during the following recovery period as well as having the availability of local, state and federal resources.
- Ongoing identification of service gaps and failures as well as recommended improvements for the overall response and human services disaster system.
- Communication and planning for the needs of people with disabilities during disaster and recovery periods.
- Identify the specific needs of each special needs target group.
- Ensure that member agencies and others develop their own internal disaster plans, and provide assistance with development of individual plans for member agencies and others.
- Establish communication with local emergency management and other Voluntary Organizations Active in Disaster (VOAD) affiliate agencies and planning groups.

- Development of inter-agency and community partnerships.
- Development of a system for making referrals in coordination with other available resources.
- Provide emergency preparedness workshops and presentations for the disability community and train those in the community to provide presentations.
- Identify the specific challenges of each special needs target group.
- Identify ongoing service gaps and failures based on disaster experiences and make formal recommendations on improvements for the system.
- Establish an advocacy group or special needs task force that will identify and support individuals with disabilities and retain the required services from local, state, and federal government entities as well as other social service agencies.

Working with the Disability Community

Teach out and incorporate all agencies that provide traditional services (mental health, employment and job training, home health aids, etc.) to the disability community as well as disability advocacy agencies (state and local Independent Living Centers, Administration on the Aging area offices, etc.). Coupling advocates with professionals allows for better outreach and delivery of services during a disaster as well as better informing during the planning and exercise design phase. Outreach to the disability community includes holding a special needs meeting with key agency representation and perhaps establishing a special needs task force. Disability leaders, experts, and people with disabilities themselves can help emergency managers tailor the planning initiatives and drills to meet the needs of the community as well as instruct how to best reach out to the community to increase awareness on emergency preparedness. Be willing to explore

creative solutions and resources that may at first appear unlikely, but prove useful in planning and exercise. The planning and exercise process should include not only disability experts, but people with disabilities to allow for a deeper understanding of the issues and ways to build awareness and resiliency.

Also work with advocacy organizations to discuss ways to conduct meaningful outreach, problems or concerns with the development of emergency plans and exercise design. For example, in New York City during the 2001 terrorist attacks, some service centers located in predominantly low-income, minority communities had several different and complex issues to address in addition to disability. For example, issues of disability, race, economics, and inequity of services around the terrorist attacks became prominent during mental health service delivery. Engaging the independent living centers and similar advocacy agencies was one way to address these types of concerns as well as enhancing outreach, awareness, and services to the disability population.

Disability agencies are key in providing planning concepts and post-disaster services because they have an in-depth knowledge of issues pertaining to people with disabilities before an important reference point and after a disaster. Having dedicated administrative staff is equally important. For too long, many individuals and disability agencies have felt slighted by the "system," misrepresented, ignored and marginalized. Recognition is a key aspect of inclusion in planning, exercises, drills and ultimately in provision of services. That "systems" acknowledge the disability community and its unique needs, especially in a crisis, can be a first step in building stronger, more trusting relationships. This type of community and relationship building can further enhance programs and have a lasting effect on communities and individuals.

Planning initiatives and exercises that include people with disabilities can also prompt educational initiatives when people with disabilities are included; they learn how to better prepare themselves. Recognize these individuals in more than just planning and drills; bring them into the fold in meaningful ways. People with disabilities and seniors are often vital members of a community and offer an enormous amount of skill and expertise. Provide training on preparedness so they can teach in the disability and senior community as well as the general population, and recruit these individuals in volunteer programs such as Community Emergency Response Teams (CERTs) and Retired Seniors Volunteer Program (RSVP).

Communication is another critical issue that should be addressed; indeed it can be considered a cornerstone. If information is not accessible, than many parts of the disability community will not be aware of available services and perhaps even life-saving information. Likewise, if information is not presented in a relevant manner, than individuals will not respond to services. For example, it is important that there is a working TTY number for crisis and registration hotlines for services. Information must be available in alternate formats such as Braille, and issues should be addressed in a manner that targets the community in an appropriate and understandable way so special needs populations will respond to services being offered. For example, during the September 11th terrorist recovery, FEMA noticed enrollment numbers of seniors was abnormally low. To better reach the senior population that may have been affected and in need of services, a flyer was created specifically for the senior population and disseminated to nursing homes, senior centers, and the like. Shortly after the outreach, the senior population began to register with FEMA.

The Reality of Disasters

Planning initiatives and exercise outcomes will be more substantial if people with special needs are incorporated into the emergency planning, initial and long-term exercise design phase, during play and observation, and the after action process. Keep in mind, if a drill were a real event, first responders would have to manage the general population, as well as the populations with varying special needs. It is also important to increase realistic elements to challenge first responders. By fully incorporating the special needs issues into exercise design, players will be able to further recognize and mitigate against stressors on their system resources during emergencies and disasters. Although the sentiment that disability and senior issues can be overwhelming, again, it is no excuse to not fully integrate special needs issues. Often times, these issues are not a part of exercise design and drill because planners and responders are not comfortable with the issues and, perhaps are not even aware as to how to integrate and include people with disabilities and seniors. In addition, first responders may not be versed in or accustomed to the utilization of new technologies or evacuation equipment. While this is understandable, it will not hold in real-life emergencies and disasters. Any emergency personnel will state that fires, earthquakes, floods, and hurricanes do not discriminate; these disasters will affect all in its path – those with as well as without special needs.

Universal Benefit

- Persons 65 years and older account for 12.7 % of the population in the U.S.
  - In 2000 that was ~ 34.7 million people (1:7)
  - By 2030 that number will increase to 64.9 million people (1:5)
- People with disabilities in the U.S. today total ~ 54 million (1:5)

These numbers overlap as in concentric circles
but are not the same populations.

Although many jurisdictions may feel overwhelmed with issues concerning people with disabilities and the elderly, especially the frail and medically dependant, with regard to emergency management, it is crucial to fully incorporate special needs issues and concerns in emergency planning in a meaningful and realistic way. In fact, if emergency management agencies can integrate special needs issues into the emergency management program, overall planning can impact positively, perhaps even enhance already existing plans that affect the whole population. According to Davis & Sutherland, "…people with disabilities have a great deal to offer to society because they and their families have thought a great deal about how to overcome vulnerabilities in times of crisis. These individuals bring innovation and determination to solving problems. By addressing this specific population's needs, all Americans will benefit" (Davis & Sutherland, 2005, p. 14).

An illustration of universal benefit can be seen with the Washington D.C., terrorists attack at the Pentagon. The Pentagon had previously installed way finding equipment to assist visitors and staff with vision impairments navigate the building on a usual basis (NOD EPI, 2004). The equipment installed made a specific tone that aided people with low or no vision within the building. During the attack, the technology not only assisted those with vision issues, but all evacuating the smoke filled building (NOD EPI, 2004).

The absence of disability subject matter expertise is often apparent in drills and exercises as it is also in planning, response, and recovery. It is strongly recommended that special needs issues be fully incorporated into the planning and response phases of the any drill program, whether it is a chemical release, a school shooting, hurricane scenario, or fire. This includes incorporating all the various human service issues that will specifically affect people with special needs including but not limited to: mental health; accessibility to family assistance centers; links to disability organizations; and long-term, post-disaster issues unique to people with special needs.

Accessibility issues are concerns for ALL observers, as well exercise personnel, and the public. All facilities chosen for purposes of conducting an exercise should be accessible to ensure that players, observers, staff, and the public will be able to fully participate and receive any necessary services. If facilities are not accessible, special needs issues cannot be incorporated into planning, response or recovery – whether a drill or real life response.

Conclusion

In response to the inevitable reality of future disasters, it is vital to have a disability component when developing and implementing emergency plans and exercises. Without having the expertise of special needs subject matter experts, plans and exercises risk not addressing specific issues unique to the disability population and others with special needs such as communication issues and outreach, better provision of services, and perhaps enhancing life-safety strategies. Keep in mind that if a drill scenario were a real event, the impact would go beyond the disability community and also include the responders, the general population, and entire response, as illustrated in the I.C.E. drill outcomes. If these issues and concerns are not resolved or considered, consequences could be devastating. Impact would be felt within the decision making processes, deployment and utilization of resources (or lack of), and limiting damage or death (or lack of). One cannot overemphasize the value of fully incorporating special needs issues into emergency planning, preparedness, response, and recovery. Not dealing with disability issues in an appropriate and meaningful way results in the "disabling" of the whole response.

About the Authors

Elizabeth Davis is an emergency management consultant focusing on special needs planning and related issues through her firm EAD & Associates, LLC in New York.

Davis received her JD from Boston University School of Law and her EdM from Boston University School of Education with a degree in the Socio-Bicultural Study of Deafness and American Sign Language. She holds an undergraduate degree with a major in Sociology and a minor in Political Science from Barnard College at Columbia University.

After many years as an advocate in the disability community, she began public service with the NYC Mayor's Office for People with Disabilities as Assistant to Counsel and Senior Policy Advisor. Due to her role in the Deaf Mexican Nationals slave-ring case in Queens, she was transferred to the NYC Office of Emergency Management as Special Needs Advisor. There she was responsible for ensuring that all elements of planning, response and recovery incorporated the unique needs of the disability community, senior population, and medically dependent persons. She functioned in this capacity throughout the events of September 11th.

Davis now consults for public jurisdictions and agencies, private businesses, home based care agencies, and residential health care organizations. She retired as the first Director of the National Organization on Disability's Emergency Preparedness Initiative but remains an advisor to DHS and FEMA, sits on several national advisory boards, participates in many major conferences and web forums and has had materials published on the subject of Special Needs emergency preparedness. Ms. Davis is the Co-chair of the National Hurricane Conference Health Care/Special Needs Committee; the Chair of the International Association of Emergency Managers (IAEM) Special Needs Committee; and is Chair of the Homeland Security Working Group of the FCC's Consumer Advisory Committee on which she holds a two year appointment.

Jennifer Mincin is the Executive Director of Families of September 11th (FOS11), a nonprofit organization founded in October 2001 by families of those who died in the September 11 terrorist attacks. Prior to joining FOS11, she was the Director of Human Services at Nassau County Office of Emergency Management where she oversaw all disaster human services for the county including sheltering, special needs, mass care, Citizen Corp, and voluntary agencies.

Mincin spent a year and a half assisting with the human services recovery efforts both as a FEMA human service specialist assigned to New York City Office of Emergency Management as well as a Manager of the September 11th crisis-counseling program, Project Liberty. While at Project Liberty, Mincin coordinated disability and uniformed

service crisis counseling programs in addition to special events. Additional human service experience includes work at the New York City Mayor's Office for People with Disabilities, where she served on the Emergency Management Task Force, an HIV Counselor at Beth Israel Medical Center, as well as work abroad in Ecuador.

Mincin received her MPA from Columbia University School of International and Public Affairs with a degree in social policy and environmental studies. She holds an undergraduate degree with a major in Comparative Religion and a minor in Environmental Science from Barnard College at Columbia University. Ms. Mincin is currently pursuing her PhD in Social Welfare Policy at Hunter College/CUNY.

Sponsored by **Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments** research project**,** at the Research and Training Center on Independent Living, University of Kansas. www.nobodyleftbehind2.org.

This project is funded by the Centers for Disease Control and Prevention through the Association of Teachers of Preventive Medicine, TS#-0840. The views expressed in this paper reflect those of the authors and are not necessarily those of the sponsoring agency.

References

American Civil Liberties Union, retrieved January 17, 2005, from: http://www.aclu.org/DisabilityRights/DisabilityRightsMain.cfm

American Red Cross, Frequently Asked Questions, retrieved January 17, 2005 from: www.redcrossomaha.org/faqs.htm

Byrnes, Michael & Davis, Elizabeth (2005). Preparedness for All: Why Including People with Disabilities in Drills is a Learning Tool: Interagency Chemical Exercise (I.C.E). *International Association of Emergency Managers Bulletin*, April vol. 22 (4) 7-8.

California State Independent Living Council, 2004, retrieved on May 25, 2005 from www.calsilc.org. *The Impact of 2003 Wildfires on People with Disabilities, April 1, 2004*.

Davis, Elizabeth & Sutherland, Daniel (2005) It's the Law: Preparedness and People with Disabilities. *International Association of Emergency Managers Bulletin*, vol. 22 (3), March 13-14.

Danielli, Yael, Editor. (2005). On the Ground After September 11th: Mental Health Responses and Practical Knowledge Gained. NY: Haworth Press., Inc. Mincin, Jennifer. *Providing Disaster Mental Health Services to People with Disabilities After September 11th*, Chapter 18.

Federal Emergency Management Agency, retrieved January 17, 2005, from: http://www.fema.gov/library/factshts.shtm

Federal Interagency Forum on Aging Related Statistics, retrieved May 4, 2005 from: http://www.agingstats.gov

Hart, Liam. September 11th. *New York State Disability Awareness Newsletter*, Summer 2004, retrieved January 17, 2005, from: www.cqc.state.ny.us/Danweb/pastissues/oldissues/2002/september_11th_editorial.htm

National Organization on Disability, Emergency Preparedness Initiative (2004, 2nd Edition). Guide on the Special Needs of People with Disabilities for Emergency Managers, Planners and Responders. Washington DC: NOD.

National Organization on Disability, retrieved January 17, 2005,

New York State Office of Mental Health, Project Liberty educational pamphlet, retrieved January 24, 2005, from: http://www.projectliberty.state.ny.us/educational/English_terror_3-9-04.pdf

Research and Training Center for Independent Living, University of Kansas, retrieved on May 25, 2005 from http://www.rtcil.org

Turner, J. Blake; Turner, R. Jay (2004). Physical Disability, Unemployment, and Mental Health. *Rehabilitation Psychology*, Aug Vol 49(3) 241-249.

United States Administration on Aging, retrieved on June 25, 2005 from: http://www.aoa.gov/prof/Statistics/statistics.asp

United States Census, retrieved January 17, 2005, Disability Status: 2000, Issued March 2003 retrieved on May 25, 2005 from: http://factfinder.census.gov/jsp/saff/SAFFInfo.jsp?_pageId=tp4_disability

United States Equal Employment Opportunity Commission, retrieved January 17, 2005 from: http://www.eeoc.gov/types/ada.html.

United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (1996). Responding to the Needs of People with Serious and Persistent Mental Illness in Times of Major Disaster. Washington DC: DHHS Publication No. (SMA) 96-077.

Washington Lawyers' Committee for Civil Rights & Urban Affairs, Press Release, May 4, 2005, retrieved on May 4, 2005 from http://www.washlaw.org.