

University of Delaware
Disaster Research Center

ARTICLE #530

ACCESS AND FUNCTIONAL NEEDS

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2014

In Critical Issues in Disaster Science and Management: A Dialogue Between
Researchers and Practitioners ed. by Joseph E. Trainor and Tony Subbio
(Emmitsburg, MD: FEMA Higher Education Project, 2014): 110-153.

CRITICAL ISSUES IN DISASTER SCIENCE AND MANAGEMENT:

A Dialogue Between Researchers and Practitioners

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TABLE OF CONTENTS

Table of Contents	i
Acknowledgements	iv
Foreword	vi
Henry (Hank) W. Fischer, III, PhD	
Chapter 1: Exploring the Academic/Practitioner Divide	1
Tony Subbio and Joseph E. Trainor	
Introduction	1
About the Project (Methodology)	3
Final Thoughts on the Process	7
References	8
Chapter 2: Whole Community: Local, State, and Federal Relationships	9
Academic Contributor: Dr. Yvonne Rademacher	
Practitioner Contributor: Amy Crabill	
Abstract	9
An Academic's Perspective	11
A Practitioner's Perspective	29
Bridging the Divide	39
References	48
Chapter 3: Volunteers and Nonprofits in Disaster	53
Academic Contributor: Dr. Lauren E. Barsky	
Practitioner Contributor: Jeremy A. Horan	
Abstract	53
An Academic's Perspective	54
A Practitioner's Perspective	62
Bridging the Divide	73
References	82
Chapter 4: Public/Private Partnerships in Emergency Management	84
Academic Contributor: Dr. Gregory L. Shaw	
Practitioner Contributor: Benjamin L. Muncy	
Abstract	84
An Academic's Perspective	85
A Practitioner's Perspective	95
Bridging the Divide	103
References	107
Chapter 5: Access and Functional Needs	110
Academic Contributor: Rochelle Brittingham	
Practitioner Contributor: Mary Goepfert	
Abstract	110
An Academic's Perspective	111
A Practitioner's Perspective	122
Bridging the Divide	137
References	146

CHAPTER 5: ACCESS AND FUNCTIONAL NEEDS

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ABSTRACT

Access and functional needs (AFN) are increasingly emphasized in disaster policy and practices. People with AFN have legal and moral rights to services, but have historically been underserved or omitted with regard to disaster-related activity. A recent change in disaster policies and planning moves from a focus on groups with “special needs” to an “access and functional needs” approach focused on fulfilling functional needs. Any member of a community may have AFN, as AFN are not limited to specific groups. Indeed, disasters may increase the number of people who have AFN. In this chapter to investigate issues surrounding AFN, a researcher and a practitioner discuss the state of research and practice, respectively, and explore areas of agreement, conflict, and tension.

Disability models including the medical model, the charity model, the social model, and the functional model are applicable in explaining potential views of AFN. Research indicates that factors associated with disabilities and AFN influence evacuation sheltering choices. Current research and practice trends regarding viewing disabilities, functional needs, preparedness, outreach, and inclusion of people with AFN in planning and policies are covered.

Macro-level approaches to AFN planning involve communities, emergency plans, and policies. FEMA promulgates a Whole Community planning initiative, in addition to other preparedness documents that offer guidance on planning for AFN. Planning approaches focus on organizations and management systems and policies at the local, state, and municipal levels of government. Planning for AFN also takes into consideration hazard assessment and community profiling, while acknowledging the role of multidisciplinary planning committees and memorandums of agreement. Inclusion of people with AFN in emergency planning, preparedness, and the salience of AFN registries are micro approaches to AFN. People with AFN and agencies that serve individuals with AFN should be part of a planning process that fosters inclusion, evaluates resources, engages service providers, and manages expectations in maintaining a system that supports independence.

Finally, the last section considers five AFN issues where there may be consensus, conflict, or tension. They are the ongoing evolution of terms and concepts that surround AFN, implementation of policies and frameworks, collective and individual responsibilities, organizational involvement, and knowledge regarding outreach and preparation with respect to practitioners’ and researchers’ perspectives.

AN ACADEMIC'S PERSPECTIVE

Introduction

A growing concern and challenge in planning for disasters is how to incorporate access and functional needs (AFN) adequately and consistently in disasters. There may be negative consequences for those whose needs or abilities do not fit with mainstream emergency planning (Santora & Weiser, 2013; Sonenshine, 2013). Any individual with AFN who is not part of the disaster plan bears a differential amount of risk compared to the rest of the population. While there has been some research investigating disabilities and disasters, the disability community is regularly overlooked and planned for without gaining buy-in from the group at large (Parsons & Fulmer, 2007). Moreover, there is limited research on best practices for incorporating AFN into disaster plans. This type of imprecise planning becomes problematic when catastrophic disaster events occur, as current plans ignore AFN by creating one-size-fits-all plans (Kailes & Enders, 2007).

As the frequency of disasters increases (McEntire, 2006), it is important to understand how AFN are considered in community disaster plans and what people realistically require to survive and maintain independence in disasters. This leads to a difficult challenge for planners: to recognize and address the myriad of AFN that affect disaster service provision. When dealing with a diverse public, daily living needs may vary drastically from person to person and are met only rarely by one-size-fits-all solutions.

A person with AFN may be anyone in the community: seniors, children, people with disabilities, people with limited access to transportation, individuals who are economically disadvantaged, those with limited English proficiency, among others. Incorporating people with disabilities and AFN as part of the planning process includes people who might otherwise be marginalized in the disaster planning and response process. The inclusion of AFN in planning by emergency managers ensures equal access to disaster services and resources for all people. However, people in the community must also take responsibility for their own disaster preparedness. Although disaster planning and response is a function of emergency management, individuals are likely to have a better and more in-depth understanding of their own needs.

Academic researchers may recognize the challenges planners face supporting a functional paradigm, and support the phrase *access and functional needs*. The term more accurately describes how people can best prepare for and respond to a disaster. It shifts the planning paradigm from people who are “special” and require “special” accommodations to a “functional” approach that acknowledges people are able to be independent. There is a greater ability to be accurate and flexible in the planning and response framework based on essential, sometimes overlapping, functional needs (Kailes & Enders, 2007).

To explore AFN, this section covers four areas. The first is terminology associated with disability and AFN. The second area is an overview of several disability models that shape how people might perceive and treat people with disabilities and AFN. The third area uses evacuation and sheltering scenarios to examine trends in research. Finally, the fourth area addresses directions in research and emergency management as it pertains to AFN. It should be noted that the approach here is not intended to provide a complete overview of this issue, but rather to provide readers with a sense of the evolving ideas in this area of study.

Responsibility for AFN

Civil rights protection for people with disabilities comes from federal law. One such law is the Americans with Disabilities Act Amendments Act of 2008 (ADAAA) (Americans with Disabilities Act [ADA], 2009). The ADAAA creates a legal definition of *disability*. The ADAAA describes a disability as “(A) physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having an impairment” (ADA, 2009). A person must meet one of these three criteria to be afforded civil rights protection based on their disability under the ADAAA (Job Accommodation Network, 2011). People with disabilities are protected from discrimination and have an equal right to participation and to enjoy and use services. This includes the ability to have the same access to disaster services and resources as other members of the community.

State and local governments have the responsibility for overseeing disaster preparedness and response activities for the entire community. For individuals with disabilities, the state or local entity responsible for emergency management must, at minimum, ensure “meaningful access” to benefits, activities, and services offered to the public by the entity (Brooklyn Ctr. For Independence v. Bloomberg, 2013). To ensure “ensure “meaningful access,” changes to existing plans, policies, and procedures may be necessary to avoid discrimination and ensure equal access to services (Brooklyn Ctr. For Independence v. Bloomberg, 2013). Without full inclusion in community planning, people with disabilities may encounter situations that put them at increased risk of harm during disasters.

While the ADA and amendments provide statutory obligations, other terminology does not carry legal protection. As described by Davis, Hansen, Kett, Mincin, and Twigg, (2013), the use of the term *special needs* by emergency managers, disability advocates, and health care workers described an array of groups and issues. The use of this term described a myriad of people, including those of low income, those who have limited, if any, English proficiency, the young, seniors, and, among many other concerns, those having a disability. As a result, “special needs” described over 50% of the population (Kailes & Enders, 2007). The approach written into plans was to take actions *for* someone rather than *with* someone. This perpetuated the mentality that people who met criteria to be part of the special needs

group were somehow different than everyone else in a way that left them unable function as fully fledged members of society. Oftentimes the view of individuals with disabilities was as a homogenous group requiring specialized assistance provided by other people.

To move the focus from a person's disability that placed them in a "special" category, the term *functional needs* was proposed to focus on the issue a person may live with and their ability to live independently (Kailes & Enders, 2007). The Federal Emergency Management Agency (FEMA) (2010b) recognized this shift in terminology as key to focusing on the abilities people have to maintain their independence. The change in terminology to create the term *access and functional needs* has created a shift in planning that recognizes people are able to be independent during times of disaster. Plans must address AFN rather than categories of people.

Terminology

Over time, an evolution in terminology to describe people with disabilities and AFN in emergency management has occurred. Terminology regarding disability differs in an attempt to be sensitive and specific to the way the disability community interacts with society (Jette, 2006). A term or definition can have multiple interpretations or meanings that vary among different people and different organizations. Recognizing preferred terminology and understanding the differences between terms assists with planning and response. A preference for a particular term may be due to a particular emphasis in the terminology with which a community most closely identifies or because a term carries particular legal protection (Davis et al., 2013).

A recent terminology shift for those who identify with a disability focuses on "people first" language. This terminology change recognizes people as individuals, rather than objectifying the person by placing emphasis on the disability (i.e., "a person with diabetes" rather than "a diabetic"), because a disability should not be the primary, defining characteristic of the person. People-first language uses the term *people with disabilities* to refer to a protected class of individuals within the United States.

While different terminology exists, the agreement on a term or concept at a single moment in time does not ensure that a terminology change will never occur in the future. According to Weiss (1989), there is no way to definitively settle on a term because different actors in the policy process shape different policies. As changes to policies and implementation occur, different terminology becomes appropriate to use. New terms may evolve or become more salient as different groups advocate for terminology because of a shift in thinking or discourse.

Conceptual/Theoretical Approaches to Framing

Among other approaches to disability studies, one area of focus is framing or exploring “approaches” to viewing disability. Four major categories of approaches exist in this area: the medical model, the charity model, the social model, and the functional model. The models vary in their focus from disability as a condition with a medical solution to the provision of appropriate supports and resources to meet AFN. These models do not encompass a complete list of disability-related models. Rather, the models illustrate the assumptions people have regarding people with disabilities and AFN. These assumptions can subsequently influence the treatment of people with disabilities and AFN by how emergency plans incorporate functional needs in planning and response activities.

The first approach is the *medical model*. This model asserts that the difference in service provision is a result of medical requirements. This model frames the disabilities themselves as a primary cause of limitation or vulnerability (Tierney, Petak, & Hahn, 1988). Moreover, the medical model considers a disability a treatable condition, provided both a treatment is available and medical providers attend to the need. In other words, the disability is framed as a problem with a medical solution.

The *charity model*, a second theory with a slightly different approach than the medical model, includes pity and the necessity of aid provision. That is, people without disabilities feel badly for those with disabilities. There is a sense that people who have either a disability or AFN require help doing activities because they are unable to do it on their own. People with disabilities routinely live independently and do not need assistance performing daily living tasks. Therefore, both the medical and charity models are problematic in their discriminatory practices (Twigg, Kett, Bottomley, Tan, & Nasreddin, 2011). Neither model addresses the needs of people by engaging in inclusive planning.

To move beyond characterizing a person by their disability, a *social model*, the third approach, may be more appropriate in describing people with disabilities and AFN (Twigg et al., 2011). The social model explains the disability as a social construction within society. Social construction influences the individual roles people take part in or are assigned to carry out in everyday life and implicitly limits them in what they can and cannot do within their societal roles (Tierney et al., 1988). Excluding or denying equal access to someone with a disability limits their participation in society (Shakespeare & Watson, 2001). This means someone who identifies with a disability may be assigned a role as a nonfunctioning member of society, as their disability is viewed as a hindrance. However, identities determined by society can be incorrect. A role assigned by society may not be an accurate reflection of what a person with a disability can do. A person with a disability may be completely independent at home, and in society, but the perception of others is that the disability stops the person from taking part in daily activities. This may be because the person has a disability noticeable to others that affects the treatment they receive. For instance, a person who is blind may use a cane when out of the home. When other

members of society see the cane, the assumption may be made that the person, because they cannot see, cannot work. However, people who are blind work in society just as society's other members do.

A fourth approach is the *functional model*. Clive, Davis, Hansen, and Mincin (2010) describe this as the most recent movement to recognize disabilities as heterogeneous and to discard the paradigm that views illness as the crux of disabilities. Instead, the functional model recognizes everyone has specific capacities. Some disasters may — but not always — require emergency managers to address specific functional needs for individuals on a case-by-case basis. For example, someone with a catheter may seek a public shelter during a disaster. In the shelter, it may be necessary to change the catheter, as is usually done in the home. A privacy screen would allow the person to handle the health-related function as he or she ordinarily would. It also negates the need for a medical professional to intervene to assist in what, for the individual, is a routine health function. It is therefore important for plans to take into account disaster-related functional needs by including individuals with AFN, or their caregiver, to provide practical solutions and appropriate resources.

Review of Selected Empirical Research Findings on AFN in Evacuation and Sheltering

Society, defined colloquially as a group of people who live in a community sharing norms, is heterogeneous and includes many groups that participate and contribute in many different ways. The utilization of evacuation and sheltering research to examine different variables that can affect the community illustrates possible challenges to planning for AFN in the event of a disaster. Consequently, specific resources, information, or methods of service delivery that do not take into consideration AFN may make people vulnerable to disasters. Further, AFN are not limited to a single group of people, but present in members throughout society.

Evacuation

Disaster evacuations can take place in the lead time before an event (e.g., hurricane), during an event (e.g., flooding), or immediately following an event (e.g., nuclear release). Evacuation rates vary dependent upon the type of event. However, research shows some households with members with disabilities evacuate at different rates compared to households without members who identify with a disability.

Most households that evacuate make the decision to leave with their household unit (Carter, Kendall, & Clark, 1983). Most often people will go to the homes or family members or friends rather than seeking out a public shelter (Drabek & Boggs, 1968). However, when a household includes a person with a disability, the household is less likely to evacuate (van Willigen, Edwards, Edwards, & Hesse, 2002). This has been documented as the primary reason some households did not evacuate during Hurricanes Hugo and Andrew (Riad, Norris, & Ruback, 1999). The decision not to evacuate when there is a household member with a disability may be due to a perception that there would be a lack of resources or

access to assistance or services at a new location (e.g., public shelter or hotel) (van Willigen et al., 2002). Without access to services that may be needed to avoid potentially life-threatening problems, there is the risk of an elevated loss of life within the disability community compared to the rest of society (Weston & Tokesky, 2010). As lack of trust in disaster services poses a barrier for evacuation, questions arise regarding the extent to which remaining in the disaster impact zone introduces other risks to health and well-being. This is particularly troublesome to a household of low socioeconomic income, as is often the case when one or more of the household members has a disability (Clive et al., 2010), because evacuating can become cost prohibitive (Gladwin & Peacock, 1997). A household with limited economic capacity may be less inclined to seek shelter in a location where access to services and resources would need to be purchased.

The ability to access necessary resources is linked to a person's socioeconomic status and affects the extent to which a person may be vulnerable to a disaster. The socioeconomic status of a household including a person with a disability is likely to be markedly lower than a household with no members with disabilities (Clive et al., 2010). People with disabilities who receive Social Security Income (SSI) or Social Security Disability Insurance (SSDI) payments decrease their monthly entitlement if they exceed their maximum number of allowable work hours. However, receiving only the maximum monthly payment of SSI or SSDI keeps their income at or below the minimum wage (Atkins & Guisti, 2003). The income disparity between minimum wage earners and those who make more has direct implications on shelter selection, as evacuation and sheltering carry an economic cost to the household (Gladwin & Peacock, 1997; Stalling, 1984). Hotel lodging also introduces financial expenditures. If a household has economic constraints, members of the household may delay evacuation or rely on public shelters.

Transportation to leave an area — which could include plane or train tickets, access to an automobile, and gasoline — bring additional costs to a household (Gladwin & Peacock, 1997; Sorenson & Sorenson, 2006). For instance, Kailes and Enders (2007) find that the design of emergency plans focuses on strategies for those who have access to transportation. Often, people who live in cities rely solely on public transportation because it is cost prohibitive to own a car. Plans must therefore be realistic with regard to the type of evacuation transportation. Planners must know an approximate number of individuals relying on public transportation, be able to provide accessible transportation, and disseminate accessible information regarding where to go to gain access to evacuation transportation (i.e., a designated pick-up location). When individuals lack transportation – or transportation that accommodates mobility needs – incorrect planning assumptions could prove fatal.

Sheltering

Large-scale disaster events may necessitate the need for public shelters (McEntire, 2006). The larger the disaster area, the more likely people will require evacuation or sheltering. The

need for public shelters may be prompted by a sudden, severe event like an earthquake or an event predictable in advance, such as a hurricane. Depending upon the population density of the area, a very large number of people may be affected, especially as coastal areas of the United States are increasing in the number of residents (Crossett, Culliton, Wiley, & Goodspeed, 2004). Research shows that approximately 13% of the population relies on public shelters in disasters (Mileti, Sorenson, & O'Brien, 1992). In instances where social networks do not extend beyond the impacted region or, in the case of a sudden onset event where a large area is affected, the reliance on public shelters might be great in the immediate aftermath.

When people with disabilities are not adequately involved in the planning process, the available services in shelters may fall significantly short of their needs (Wisner, 2002). When a person with a disability or AFN leaves their daily residence to go to a shelter, the shelter needs to be prepared for all types of health and access concerns. How disabilities are framed based on the different approaches to disabilities and AFN may make a difference in how sheltering operations are carried out during times of disasters.

Public shelters are not built to be exclusively used as shelters, but are used as such, typically in times of disaster, deviating from their normal operations as schools or other community buildings (Kar & Hodgens, 2008). This means these locations are not, during times of normal operation, a place designed exclusively for certain AFN. Shelters are chosen because they are considered safe (Pine, Marx, Levitan, & Wilkins, 2003), not always because of their accessibility or suitability. For instance, schools that serve as shelters typically do not have backup generators hardwired into their system and do not have the correct connectors to make it possible to charge battery-operated wheelchairs or utilize durable medical equipment during a power outage, an important requirement for some AFN. Beyond power needed for medical equipment, power may also be needed to keep food cold for individuals with dietary-related AFN. Based on such deficiencies, there may be reasons to rethink public sheltering in order to be more inclusive of AFN.

As mandated by federal law, public shelters are to be inclusive. However, these same shelters may not be accessible for those with certain types of mobility impairments. The preparation of the interior space requires organizers to recognize people are able to support themselves with the correct accommodations. A person with limited mobility may come to a shelter, but find the cots arranged too closely together, prohibiting a mobility device from moving easily between rows. Or, in the instance of someone using a wheelchair, an assigned cot may be in the middle of the room without a wall to brace against in the event of a wheelchair-to-cot transfer, a potentially serious problem. Without something to brace the cot, it will, in all likelihood, slide across the floor. The person is able to transfer from a wheelchair to a bed without assistance in his or her own home, but in a public shelter, the cot is not accessible without help from someone else. Suddenly a person with a disability or AFN who is independent in his or her own space must rely on others in a shelter.

The way to overcome these inequalities is to be inclusive in sheltering practices (Clive et al., 2010; Twigg et al., 2011).

Not fully understood are the effects of prohibitive costs and concerns about available services at the destination locations on AFN. Further, even with the strides in providing necessary services and resources at public shelters, there is no guarantee people will utilize the shelters when they decide to evacuate. However, many changes in federal policies have encouraged inclusive sheltering for individuals with AFN.

Trends and directions related to access and functional needs

Even with limited research on disabilities (Kett, Lang, & Trani, 2009) and AFN in disasters, community plans must include AFN. Recent trends in emergency management recognize planning for functional needs is paramount in ensuring equal access to services and resources. Many community members are willing to work with emergency managers in the planning process to ensure disaster-related resources and practical solutions are available to meet individuals' needs. Focusing on the needs of the community involves adopting a "whole community" approach to emergency management. Planning for needs of individuals rather than for groups of people means community members and emergency management entities can work together to determine the community's needs and how best to address them (FEMA, 2011a). To create inclusive disaster plans, it is necessary to have people with disabilities and AFN help plan rather than allow emergency management professionals to lead without input and buy-in from the community at large (Barnes & Mercer, 2006).

Planning for functional needs includes five areas to consider. Parson and Fulmer (2007) note maintaining independence, supervision, medical care, communication, and transportation as functional needs to address in planning and response. To maintain independence, substitutes for support structures vis-à-vis supplies and assistance affected by a disaster must be available and may include durable medical equipment or attendants. A disaster may interrupt the supervision some caregivers provide, such as in cases of young children or individuals who experience age-related dementia. Supervision should therefore be available to meet the needs of people who may require it. The provision of medical care for individuals who require assistance with medical-related tasks and are not self-sufficient or who are without support from caregivers should be addressed. Communication dissemination must occur in accessible and usable formats to meet people's needs. Finally, transportation should address the needs of people who are without a personal or accessible vehicle, or who are unable to drive. Further, information should be available as to the location and availability of evacuation mass transportation (New Jersey OEM, 2006).

While emergency managers have the responsibility to coordinate preparedness and response to disasters on a community level, individuals are responsible for personal preparedness. To that end, some organizations have reached out – in this case specifically to the disability community – to help individuals create personal preparedness plans. The

University of Delaware's Center for Disabilities Studies received an emergency preparedness grant to assist different groups and individuals with disabilities plan for disasters. Utilizing planning material to facilitate the creation of personal disaster plans, participants were encouraged to think through challenges they could face in evacuation and sheltering scenarios (Center for Disabilities Studies, n.d.).

Other institutions, such as Temple University's Institute on Disabilities, also engage in emergency preparedness for people with disabilities. The Institute collaborates with a range of groups, from local communities to national organizations, as well as the City of Philadelphia and other local communities to assist with emergency preparedness. Creation of a plan and emergency kit for the household is encouraged in order to prepare for emergencies.

A recent court ruling in New York following a lawsuit filed after Hurricane Irene highlights problems people with disabilities faced while preparing for and responding to the disaster. Although the emergency management structure in New York City has, in many ways, fulfilled their responsibilities both planning and responding to disasters, the court found “the City’s plans are inadequate to ensure that people with disabilities are able to evacuate before or during an emergency; they fail to provide accessible shelters; and they do not sufficiently inform people with disabilities of the availability and location of accessible emergency services” (Brooklyn Ctr. for Independence of Disabled v. Bloomberg, 2013, p. 5). Each of these deficiencies highlights a lack of accessibility for people with disabilities. During and after Superstorm Sandy, people with disabilities faced many of the same issues described in the court’s ruling. A lack of accessible egress routes due to inoperable elevators or too many flights of stairs trapped too people with disabilities (Santora & Weiser, 2013). Further, if a person with a disability was able to evacuate their residence, there were an inadequate number of accessible public transportation options to meet evacuees’ needs (Santora & Weiser, 2013).

Evacuation plans increasingly take into account the fact that many people may not have their own transportation. Plans have identified key assets to assist in wide-scale evacuations. Assets include buses that can transport large numbers of people who are without personal vehicles, as well as accessible transportation for people with mobility impairments. In some areas, National Guard resources are available to move a large number of people who do not have the monetary resources or a personal vehicle, in addition to having specialized transportation and medical personnel to help with medical needs.

The Transportation Research Board's Transit Cooperative Research Program (TCRP) provides a toolkit on communicating transportation options to community members. Communication to vulnerable populations is crucial when three sectors — public, private, and nonprofit — evaluate the available disaster transportation options. The TCRP describes the necessity of determining who may need to know about emergency

transportation and how to best communicate with individuals about their options. Identifying public agencies and community partners to become part of a network that will communicate and organize to reach out to community members about transportation helps fulfill a communication-related functional need. Networking and collaborating among entities share the responsibility of inclusive outreach to vulnerable community members (Transportation Research Board, 2008).

Public shelter plans have also evolved to take into account people with disabilities and AFN. On March 15, 2012, new standards went into effect that guide alterations to existing public facilities and new construction that will accommodate those with disabilities (U.S. Department of Justice, 2010). These standards benefit those who seek out public shelters during times of disaster, as the buildings should be more accessible. Buildings that currently serve as public shelters are not necessarily accessible.

In the United States, the Robert T. Stafford Disaster Relief and Emergency Assistance Act of 1988 prohibits public shelters from refusing access to those individuals who identify with having a disability during presidentially declared disasters (FEMA, 2011c). Individuals should not be relocated to another shelter if the shelter does not appear to be able to handle their needs. Such a forced relocation would be considered a direct violation of their civil rights (ADA, 2009). As a result, people with different needs reside in the same shelters.

FEMA's Functional Needs Support Services (FNSS) guidance outlines steps for all people to access general population shelters and maintain their independence through the provision of appropriate medical goods and services and making reasonable modifications to structures (FEMA, 2010b). The design of this guidance, however, is not to create new obligations (Robinson, Gerber, Eller, & Gall, 2013). The FNSS sets forth ways to support current disaster shelter management. While not creating new obligations, the FNSS sets out practices for managing disaster shelters that "create an *implicit* standard for accommodating residents with functional needs" (Robinson et al., 2013, p. 318). During times of disaster, the buildings used to shelter the population are more accessible to all, while affording people with disabilities and AFN equal access to services and resources.

Conclusion

Incorporation of AFN in disaster plans is necessary to ensure that there are available services and resources for people who may need them. Legal protection is given to individuals who meet the ADA's definition of disability, but not everyone who has a disability will have an AFN in a disaster. A person may address their particular need(s) or the disaster prompts a specific need with which the person does not identify. Chronic conditions not covered by the ADA can cause the individual to have AFN during a disaster. Still, other people can have AFN without a health condition. When a disaster disrupts the environment in which the person lives, the available services and resources affect whether people have AFN.

Inclusive disaster planning among people with disabilities and individuals with AFN, community organizations, and emergency management helps identify functional needs. This allows for equal access to services and resources for members of the community.

A PRACTITIONER'S PERSPECTIVE

Introduction

As emergency management programs started to develop formal organizational structures and mature professionally, people with AFN continued to remain underserved, excluded, or denied access to disaster-related services. There were varying reasons for this: rejection of the notion that accommodations should be made for persons with access and functional needs, perception that the planning issues were too big or too complex to manage, unfamiliarity with how to develop strategic partnerships with AFN stakeholder groups, and lack of awareness or misperceptions about the different types of AFN, accessibility requirements, and/or resources to aid accommodations.

Fortunately, disaster policy and practice related to the inclusion and integration of people with AFN into emergency management programs is evolving, and continues to improve. This section discusses the state of practice regarding AFN inclusion into emergency management programs, with emphasis on disaster planning, response, and recovery. The discussion will focus on the needs of individuals with AFN who are living in community-based settings.

The most effective planning strategies involve multidisciplinary approaches that are inclusive of individuals with AFN, a triad of key government agencies (human/social services, health, emergency management), transportation providers, and service-providing agencies. When a multidisciplinary approach is not used, or when emergency plans are found to be inadequate, equality and inclusion remedies are sought through the legal system.

Communities Living Independently and Free (CALIF) vs. City of Los Angeles is often characterized as a “landmark” lawsuit in terms of its implications for emergency planning officials. The February 2011 ruling held that “the City of Los Angeles violated the Americans with Disabilities Act by failing to meet the needs of its residents with mobility, vision, hearing, mental, and cognitive disabilities in planning for disasters. A court order followed requiring the City to revise its emergency plans to include people with disabilities (Disability Rights Advocates, 2013).” The City and County of Los Angeles were both brought into the suit, with different courses of remediation. In addition to the plan reviews, the settlement agreement required Los Angeles County to hire an AFN Coordinator, maintain accessible formats on its websites, engage community-based organizations in the planning process, and be subject to monitoring over a six-year period.¹

In November 2013, the U.S. District Court, Southern District of New York, issued a wide-ranging Opinion and Order regarding *Brooklyn Center for Independence of the Disabled vs. Bloomberg* (United States District Court, 2013). The Court validated many elements of the City’s response capabilities and aspects of its emergency plans. However, it found for

the plaintiffs in areas covering nearly all phases of disaster planning, including public information messaging, accessibility of shelters, loss of accessibility during power outages, “ad hoc” reasonable accommodations, debris removal, pre-disaster outreach, and other significant disaster functions. As of this writing, the remedies portion of this legal action is still pending.

A proactive, inclusive approach to emergency planning – following the “spirit” not just the “letter” of the law – results in a more effective and reality-based emergency plan. It serves to build better pre-disaster professional relationships and increases understanding about the needs of people with AFN and the capabilities – and limits – of first response agencies.

This section offers insights and resources regarding the mechanics of access and functional needs planning: obtaining knowledge about people with AFN and what their needs are, evaluating resources available to meet those needs, identifying strengths of the key stakeholders and how they contribute to a holistic planning effort, and methods to fill gaps and increase potency where there are weak areas of community AFN planning.

Identifying Needs and Services

An essential question for emergency planners is: “Who is the person with access and functional needs, and what does this mean in terms of emergency planning and response?” First and foremost, a person with AFN is a community member with moral and legal rights to equally access all services that emergency management programs provide. This community member, like all others, also has the responsibility to plan for their own safety, to the best of their ability and personal resources.

Common misperceptions about AFN were rooted in the widespread use of the term *special needs planning* – a description that lacked both clarity and dignity regarding the individuals to be included in the planning process. FEMA’s adoption of the term *access and functional needs* ultimately provided enhanced meaning regarding how individuals with communication, independence, medical, transportation, or supervision needs function in a pre- and post-disaster environment, and what support systems are needed in order to ensure their survival.

The concept of “access and functional needs” also allowed emergency planners a better understanding of individuals with AFN, because it established the narrative that people with AFN are a part of the community. Almost everyone knows someone with an access and functional need. How does this increased understanding improve disaster-related outcomes for people with AFN? It required emergency management agencies to adopt a macro and a micro approach to AFN planning.

The Macro Approach

Macro approaches focus on organizations, management systems, and policies at the jurisdictional (state/county/municipal) level of emergency planning. When FEMA announced its Whole Community initiative (FEMA, 2011a), it provided validation to local jurisdictions regarding their macro approach, or commonly used operating strategies. FEMA's Whole Community approach is based on the following principles:

- Understanding and meeting the actual needs of a population
- Engaging and empowering all parts of the community to deal with the consequences of threats and hazards
- Strengthening what works well on a regular basis

The development of emergency plans starts with a hazard assessment and a community profiling process. The U.S. Census and other data sources such as Cornell University's Disability Statistics website (2013) and the U.S. Centers for Disease Control and Prevention's (CDC) (n.d.) Snapshots of State Population Data website help emergency planners provide insight into the scope and size of the populations with AFN.

In some communities, social vulnerabilities such as poverty, limited English proficiency, dependence on electricity for medical equipment, and risk factors for health may cause AFN-related needs to apply to nearly 50% of the population. Commonly recommended household emergency planning strategies such as stockpiling food and supplies becomes extremely difficult for those who are living in challenging economic conditions. Local government officials should plan to address basic needs of these individuals during a disaster, for a substantial period of time.

One example of this type of planning might include the Illinois-Indiana-Wisconsin Combined Statistical Area's "Gear Up, Get Ready" Community Preparedness Toolkits for emergency planners, featuring AAFN information. The toolkit provides advice on ways to engage the communities of individuals with AFN, how to use demographic research to identify AFN groups, how to market preparedness messages to audiences with AFN, and methods for incorporating social assessments into the community's risk and hazard analysis (Regional Catastrophic Preparedness Planning Team, n.d.).

One of FEMA's macro planning initiatives involved a 2010 Memorandum of Agreement with the National Council on Centers for Independent Living (CIL) (FEMA, n.d.) which are cross-disability service agencies. The agreement formally allowing CIL's nationwide access to the disaster recovery process and Disaster Recovery Centers (DRCs) also acknowledged the benefits of CILs' participation.

During the response to the May 22, 2011, Joplin, Missouri, tornado, the benefits of this pre-disaster agreement became evident. Stephanie Brady, Director of Programs for the

Independent Living Center (ILC) in Joplin, spoke about the experience during a May 2012 FEMA “Think Tank” conference call (FEMA, 2012). On the call, Brady explained how national and local level efforts enhanced response for people with AFN.

- **Pre-event:** The Joplin ILC established relationships with the local Community Organizations Active in Disaster (COAD) prior to the event. The Joplin ILC provided disability awareness training to Red Cross volunteers about a month prior to the event.
- **During the event:** The ILC provided durable medical equipment and helped with shelter transportation.
- **Post-event:** A disability and senior disaster resource committee met weekly to ensure that the needs of people with AFN were being met, including housing. The ILC hosted a mobile DRC. FEMA staff were invited to the ILC’s social event, which increased opportunities for networking and inclusion.

FEMA also entered into an Agreement with the National Disability Rights Network in 2011, to further strengthen emergency management collaboration (FEMA, 2011b).

The Micro Approach – Focus on the Individual

Micro approaches to emergency planning involve engagement with the individual with AFN, and potentially the family or other support systems. The role of individuals with AFN in emergency planning can be viewed within a number of contexts. Messages about emergency preparedness that are based on empowerment, rather than fear, are most effective.

“Not about us, without us” is a rallying cry often used by disability advocates who favor independence and self-determination over patronizing approaches toward disability policy on the national social service, health care, education – and most recently – emergency planning agendas. Planning strategies should be based on the assumption that individuals with AFN can and do provide leadership in the emergency management arena. Individuals with AFN should prepare for a disaster based on the assumption that their usual support networks, and local emergency response organizations, will likely be overwhelmed and negatively impacted by the event and unavailable to help them. Government agencies can also provide frameworks for consumer-focused preparedness activities.

FEMA’s Ready.gov website (FEMA, 2014) created in partnership with the Ad Council, offers substantial preparedness information for people with AFN, in a variety of accessible formats, including American Sign Language, languages other than English, and captioned videos. The Texas Department of Public Safety (2011) also offers accessible content regarding emergency preparedness on its website, including voice versions of preparedness topics.

Individuals with AFN should not be characterized only as passive receivers of assistance. The Progressive Center for Independent Living (PCIL), a Center for Independent Living located in Mercer County, New Jersey, provides several examples of emergency management leadership, rooted in the disability community. The first is PCIL's Emergency Preparedness Spokespersons Program, which connects individuals with disabilities with opportunities to attend the American Red Cross Community Disaster Educator's Course. The PCIL's team of spokespersons with disabilities then conducts emergency preparedness training for the individuals with disabilities at convenient times and locations. This strategy has the added benefit of placing people with disabilities in the roles of trusted spokespersons and peer mentors. Reaching out further to engage emergency responders and enhance their disability awareness, the goal of the PCIL's Adapted Vehicle Training Program is to train emergency responders who will aid individuals with disabilities during evacuations, and train them on how to work with accessible or specialized vehicles during more routine traffic accidents, or smaller-scale emergencies. The PCIL has also partnered with the AmeriCorps Program and a statewide developer of accessible housing, Project Freedom, on an Emergency Go-Bag Distribution Program.

The New Jersey Council on Development Disabilities has developed a training program aimed at individuals with development disabilities who are living in group home settings. The training content focuses on the changes that occur when disasters happen, letting the residents know that their community may look, feel, or even smell different after a disaster happens, and that different helping organizations – National Guard soldiers and other emergency personnel – will be visible, helping to keep them safe.

Using the multidisciplinary approach to provide information for individuals, the Oregon Office of Disability and Health (2009) has produced the "Ready Now! Emergency Preparedness Toolkit for People with Disabilities" in conjunction with the Oregon Institute of Disability & Development (OIDDD), the Center on Community Accessibility (CCA) and the Oregon Health & Science University (OHSU), a project funded by the CDC (Grant # GCDRC0164).

An Oregon woman, Nickole Chevron, shared her successful shelter-in-place experience (a preparedness topic that typically receives less attention than evacuation planning), on the CDC website, with advice for people with AFN. The event was a 2008 winter storm that buried Portland under more than a foot of snow. She reported being stuck in her home for eight days.

Chevron employs a caretaker and uses a wheelchair to maintain independence. She credits Oregon's "Ready Now ! (2009) – an emergency preparedness training program developed through the Oregon Office of Disability and Health (2014) – for giving her the tools and knowledge necessary to create a backup plan, and fostering a feeling of empowerment: "When I heard the snow storm was coming, I emailed all

my caregivers to find out who lived close by and would be available. I made sure I had a generator, batteries for my wheelchair, and at least a week's supply of food, water and prescription medication." Chevron added that understanding the limits of first responders during disasters is helpful in planning. Her additional tips can be found on the CDC website (2012).

The micro approach to AFN planning would not be complete without a discussion of “special needs registries,” a topic that is often surrounded by controversy. Registries are lists of individuals with AFN in a specific jurisdiction. The information is provided voluntarily by the registrant. Methods for keeping registries are wide ranging; and the type of information collected about individuals often varies in content and scope. Some communities use technology to manage registries, deploying “off- the-shelf” software applications provided by vendors. Others have developed their own in-house applications. Some registries consist of Excel spreadsheets, paper files, or return mail cards.

Fairfax County, Virginia’s Special Needs Registry Program (2013) allows individuals to register online or by mail; eligibility is limited to those needing to be in a medical needs shelter during evacuations. Fairfax County also offers registration opportunities for service-providing agencies to receive disaster-related information from the County. The State of Rhode Island’s Department of Health and its Division of Emergency Management have partnered to offer an online registry, with a paper form option (State of Rhode Island Department of Health, n.d.) The State of Utah offers online registration, paper registration, and a call-in registration option through a partnership with 2-1-1 (Utah Special Needs Registry, n.d.).

The State of Florida (FloridaDisaster.org, 2002) maintains an extensive website and uses registries and county-based special needs shelters to serve Florida residents with medical needs. The Florida Department of Health serves in a leadership role, in coordination with representatives from the disability community, to execute the state’s Emergency Operations Plan (EOP) and operate and staff special needs shelters:

Identification of individual need is also available through commercial services such as “Smart911 (2013).” Jurisdictions subscribe to the service, which allows free access to residents. Residents complete a safety profile, which can be viewed by public safety telecommunications during incidents. The vendor also offers a “Smart Prepare” application to aid public safety officials in AFN planning for specific areas, or community-wide.

At this writing, there is mainly anecdotal evidence both for and against the use of registries. Proponents stress the importance of having specific awareness and information about persons with AFN in the jurisdiction. Proponents also state the necessity of being able to conduct outreach before disaster strikes, and conduct welfare checks after impact. Registries are a tool that, if managed and maintained properly, could enhance AFN planning for some jurisdictions. Individuals who perceive less value in registries assert that they are

notoriously difficult to update and maintain, they are inconsistently managed, and registration establishes increased and unrealistic expectations about being rescued, without the individual having to develop a personal emergency plan. Registries are a complex solution to the ongoing concern of integrating persons with AFN into a community's emergency planning and response operations. Disaster experiences and technology have influenced the format and governance of registry programs. Registries continued to evolve as preparedness tools to address the disproportionate number of deaths of persons with AFN, such as occurred during Hurricane Katrina and, most recently, Superstorm Sandy.

However, registries have not turned out to be the perfect solution to this emergency planning process. In response, FEMA has produced guidance suggesting that by working with community organizations and agencies, a "list of lists" can be developed that contains aggregate data on disability numbers (FEMA, 2008). When an emergency occurs, however, aggregate data will not be enough to find individuals needing assistance, and registries also may not have all community members requiring assistance registered. The New Jersey Office of Emergency Management (2006b) uses a commercial software application for its "Register Ready" program. Outreach and messaging around the program include radio advertising, Internet banner advertising, and communications about the program to the AFN communities by trusted sources. While have been in place in many communities for several years, it is difficult to find research delving into whether registries are used by emergency managers for decision-making purposes. A recent survey was conducted to address this question (Donny, 2013). Three different areas of the United States were surveyed to gather data on the use of the registries by emergency managers. The survey returned clear results revealing that a majority of emergency managers use registry data both for planning and operational purposes. For those not using their registry for decision-making purposes, reasons provided included a lack of understanding of the purpose of the registry, a lack of training on the use of the registry, and a lack of resources to conduct outreach in their community to raise the profile of the registry (Donny, 2013).

It is through public outreach and partnerships that emergency managers can increase participant numbers and develop robust data that will enhance their decision making during emergencies. While registries are imperfect tools, they can be part of the emergency management equation to help safeguard the welfare of persons with AFN during times of emergencies.

Inclusive Emergency Planning

Inclusive emergency planning is guided by federal policy, such as the ADA and other key legislative initiatives. Inclusive emergency planning is led on the ground by coalitions, advocacy strategies, and multidisciplinary endeavors. People with AFN, government agencies, and services providers must work in partnership to ensure that policy translates into effective practice.

Community emergency planning is a government responsibility that often involves multidisciplinary planning committees of emergency response agencies, government officials, and external partners. Emergency plans should reflect an inclusive process that accounts for AFN considerations and allows AFN stakeholder groups a seat at the planning table. A major planning challenge is resisting the inclination to “annex” the needs of AFN populations onto a completed EOP. Planners should integrate AFN resources into plans, annexes, or emergency support functions, whichever format is being used. Accessible transportation for example, should be reflected in Emergency Support Function (ESF) #1 (Transportation) or the Evacuation Annex to the jurisdiction’s EOP. Shelter resources to meet accessibility requirements should be included in the either ESF #6 (Mass Care) or the Shelter Annex to the EOP.

Some jurisdictions establish planning committees for the purpose of enhancing AFN planning. The New Jersey Group for Access and Integration Needs in Emergencies and Disasters (NJ GAINED) (NJ Office of Emergency Management, 2006a) “acts as an advisory board to the New Jersey Office of Emergency Management (NJOEM) and the NJ Office of Homeland Security and Preparedness (OHSP) regarding issues affecting people with access and functional needs (AFN) in New Jersey before, during and after an emergency or disaster.” The group consists of over 50 members from across the emergency response and AFN spectrum.

Together Prepared offers another example of an inclusive planning organization. Together Prepared is a Kansas partnership launched in 2007. The coalition includes the Lawrence-Douglas County Health Department and Douglas County Emergency Management, together with the University of Kansas Research and Training Center on Independent Living (RTC/IL), and various community-based organizations serving AFN populations (University of Kansas Research and Training Center on Independent Living, 2012). Together Prepared conducted preparedness surveys, found individual and agency disability preparedness lacking, and explored the reasons why. It launched a series of training and education forums around the topics of business continuity, hazardous weather preparedness, pandemic planning, agency/first responder expectations management, and household preparedness.

FEMA’s (2010a) “Comprehensive Preparedness Guide 101 v.2” (CPG) outlines the planning process and recommended structure for emergency plans. The CPG states specifically that “it is essential to incorporate individuals with disabilities or specific access and functional needs and individuals with limited English proficiency, as well as the groups and organizations that support these individuals, in all aspects of the planning process” (FEMA, 2010a, p. 14). CPG 101 v.2 (FEMA 2010a) incorporated a section on AFN aimed at the broader planning effort. CPG 101 v.2 specifically states the need for planning jurisdictions to engage external partners, and employ social and demographic assessments in the hazard analysis. It recommends that jurisdictions identify a leading agency for the

AFN-related components of the EOP, and outline the mechanisms for successful evacuation support. It offers a productive strategic model for applying the skills of people with AFN as subject matter experts for the EOP. It also proposes that emergency planners devise means for information collection about macro and micro needs of community members with AFN, with the goal of ensuring that disaster-related needs are addressed.

The ADA is one of the most influential public policies to influence emergency planning; ADA requirements are underscored by the U.S. Department of Justice in its guidance to emergency management agencies. Prior to the issuance of the CPG 101 v.2, and prior to the adoption of the term *access and functional needs*, FEMA (2008) issued “CPG 301-Interim Guidance Regarding Planning for Special Needs Populations.” It served as a basis for outlining planning issues post-Katrina, but was ultimately replaced by FEMA’s guidance on shelter support, and was later rescinded.

Inclusive mass care planning became a specific challenge for many emergency planners, who were faced with the issue of whether or not they needed to establish “special needs” shelters. Planners also had additional concerns about the target population to be served at these facilities. More questions arose: What medical conditions would be treated? What type of staff could perform certain services? Who had responsibility for the operations? What was the role of the American Red Cross?

A U.S. Department of Justice (2008) guidance document “An ADA Guide for Local Governments – Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities” served as a “how-to” guide for local government planners regarding making an emergency management program accessible to people with AFN. The guidance addressed alert and warning, transportation and other planning concerns, but more specificity on mass care was needed.

FEMA’s (2010b) “Guidance on Planning for Functional Needs Support Services in Mass Care Shelters” offered solutions regarding the shelter client and related services to be provided. Focus was clearly on consumer independence, access, integration, and inclusion, and the need for these shared values when engaging in emergency management planning for diverse communities. This guidance incorporated the Department of Justice guidelines, as well.

Functional Needs Support Services (FNSS) are defined as services that enable individuals to maintain their independence in a general population shelter. FNSS includes:

- *reasonable modification to policies, practices, and procedures*
- *durable medical equipment (DME)*
- *consumable medical supplies (CMS)*
- *personal assistance services (PAS)*
- *other goods and services as needed*

Children and adults requiring FNSS may have physical, sensory, mental health, and cognitive and/or intellectual disabilities affecting their ability to function independently without assistance. Others that may benefit from FNSS include women in late stages of pregnancy, elders, and people needing bariatric equipment. (FEMA, 2010b FNSS, p. 8).

FEMA's FNSS guidance also eliminated the perceived need for stand-alone "special needs shelters," advising local mass care officials that individuals with AFN could not be turned away from general populations shelters or automatically placed in a segregated and restrictive environment such as nursing homes (FEMA, 2010b FNSS, p. 9). The FNSS guidance offered resource lists, how-to's, legal guidance, and key considerations regarding operating an inclusive shelter. The guidance still allows for the operation of Medical Needs Shelters for those who need medical care from licensed or certified medical professionals. Most jurisdictions will address FNSS in general operations shelters and/or operate medical needs shelters using a variety of resources (e.g.,, Medical Reserve Corps volunteers, service-providing contractors, Community Emergency Response Team Volunteers, Disability Rights and Advocacy Groups, and contracted personal care assistants). Many jurisdictions either employ, or are exploring, co-located facilities (general mass care/medical needs/pet shelters) on a single campus, intended to serve a regional geographic area.

In 2013, the National Fire Protection Association (NFPA) launched a web page with fire safety education materials for people with disabilities. The NFPA's (inclusive) Fire Safety for People with Disabilities Task Force ensures that fire safety messages reach people with disabilities. The NFPA's Evacuation Planning Guide (2014) "provides information on the five general categories of disabilities (mobility, visual, hearing, speech, and cognitive) and the four elements of evacuation information that occupants need: notification, way finding, use of the way, and assistance. It also includes a checklist that building services managers and people with disabilities can use to design a personalized evacuation plan, as well as government resources and text based on the relevant code requirements and ADA criteria."

Technology offers individuals with AFN, and emergency planners, the opportunity to increase the level of accessibility to emergency management information during all phases of a disaster. Emergency management professionals should be cognizant that high- and low-tech approaches to communications accessibility will reach the widest audience. There is a digital divide: individuals who cannot afford expensive assistive technologies or access to the Internet, or individuals who do not have a comfort level with high-tech communications approaches. Power outages will factor into the availability of communications technology.

The U.S. Department of Justice (2007) toolkit on accessible emergency planning strategies offers a section on communication requirements. It directs government authorities to ensure that "whatever is written or spoken must be as clear and

understandable to people with disabilities as it is for people who do not have disabilities.” The ADA toolkit provides advice to emergency management officials on assistive technologies, American Sign Language interpreters, face-to-face and written communications, and other facets of accessible communications.

At the individual level, people with disabilities that affect their expressive speech capabilities, or people with limited speech, should consider their disaster-related needs. The Assistive and Augmentative Communications Rehabilitation Engineering Research Center (AAC-RERC) (2014) functions as a collaborative research group dedicated to the development of effective AAC technology. Augmentative and alternative communication (AAC) refers to ways (other than speech) that are used to send a message from one person to another.” The Center has developed a wide range of disaster preparedness materials for people with limited speech, advice for emergency responders who will need to communicate with people with limited speech, and a section for advocates on disaster-related self-empowerment.

Behavioral Health and Access and Functional Needs Planning

Individuals with mental illness and cognitive impairments should be integrated into AFNANAFNANAFN preparedness efforts. Planning for individuals already engaged with the mental health system must take place *in addition* to planning for the disaster responses crisis counselors who will deploy after an event to assess, and address, the emerging mental health needs of disaster survivors.

There are a number of disaster-related issues present for individuals with mental illness (MI), including the event triggering symptoms of an earlier post-traumatic stress diagnosis, feelings of grief and loss, or depression and anxiety. People with MI may struggle with medication compliance, maintaining their recovery from substance abuse, or safety in mass care shelters, if they are evacuated. Individuals with cognitive or memory impairments may not be able to achieve a full understanding of the incident and its associated hazards.

The U.S. Department of Health and Human Services Substance Abuse and Mental Health Administration (SAMHA) (2013) offers comprehensive disaster planning guidance for service providers: the *Disaster Planning Handbook for Behavioral Health Treatment Programs* (2013). The guidance contains information on agency tasks such as preparing the client, service continuity planning, medication management, and organizing a preparedness program, with planning worksheets. The Yale Center for Public Health Preparedness’s 2008 bulletin “Disaster Preparedness for People with Serious Mental Illness” is still relevant. It characterizes mental health consumers as partners who can contribute to preparedness efforts if they are provided outreach and disaster preparedness information in an empowering context.

The Alzheimer's Association offers several resources for caregivers of persons with dementia and other memory disorders. The Association's checklist includes tips for helping a loved one with dementia through all phases of a disaster, with emphasis on Alzheimer's-related behaviors and symptoms. It reminds caregivers that the disaster may change a patient's routine or place them in a new, stressful environment, and offers suggestions for reducing agitation and continuing to meet physical medical needs. The Alzheimer's Association (2007) also offers a paid service -- Alzheimer's Safe Return® --- for patients whose symptoms include elopement.

Roles for Service-Providing Agencies - Response and Recovery

Agencies that serve people with AFN have insight into their abilities, needs, accommodations, disability status, family and supportive relationships, etc., and should be included throughout the planning process. However, these organizations generally tend to be overlooked as a resource. Additionally, service-providing agencies may serve as first responders or even become victims of the disaster themselves.

Nongovernmental organizations, primarily private nonprofit social services providers, typically provide services to AFN populations on a day-to-day basis: case management, personal care assistance, in-home medical care, counseling, substance abuse services, child welfare, and services for the aged, among others. When disaster strikes, these agencies often react, reorganize, and redirect staff and resources to meet the impacts of the disaster faced by their clients. The agencies are critical partners in the long-term recovery process, because they are aware of their clients' needs and possess the cultural competency needed to interact successfully with them.

According to the Mississippi Center for Non-Profits, after Hurricane Katrina, service providers in the Biloxi/Gulfport/Pascagoula area had these experiences: 67% lost volunteer or paid staff, 77% sustained major building damage, and 93% lost programs or services (Lampkin & Auer, 2006). The Louisiana Urban Institute reports that 50% of the agencies outside New Orleans served 73% more clients than before the storm (Lampkin & Auer, 2006). Faith-based groups and service agencies sheltered as many people as the Red Cross, in four times as many shelters. Some reported severe financial stress, s there was a lack of clarity how to access federal reimbursements for disaster-related services. Others had no or very limited clients left to serve, due to evacuations and relocations (Lampkin & Auer, 2006).

This situation is not limited to natural disasters. After the Deepwater Horizon Oil Spill, the Louisiana Association of Non-Profits (2011, pp. 3-4) reported that "39% of nonprofits saw 'noticeable changes' in client numbers or services needed after the oil spill...40% of nonprofits reported needing additional resources because of an increased demand for services [and] ... 32% of nonprofits reported that the oil spill had a direct impact on their employees" (Louisiana Association of Non-Profits, pp. 3-4).

Emergency management personnel should focus on encouraging service-providing agencies to improve their disaster resiliency and assist them with continuity of operations strategies. The private nonprofit sector is often overlooked regarding business continuity planning; yet they are in the business of helping others on a daily basis. If the agency is assisting the client in maintaining independence during non-disaster situations, it surely needs to do so in the post-disaster environment. Agencies can also serve as trusted spokespersons regarding alerts and warnings, risk communication, or disaster preparedness messages.

The New York City Office of Emergency Management (n.d.) deploys its “Advanced Warning System” for service-providing agencies, “to alert individuals with special needs to various types of hazards and emergencies in New York City that may affect their independence and their daily lives.” Registration is required, and participating agencies “receive public preparedness and emergency information designed for used by individuals with special needs. Agencies can then relay this information to their clients and contracted agencies.”

The NJOEM conducts a “Business Continuity Planning for Service Providing Agencies” training program, adapting FEMA’s Ready Business model to address the needs of the nonprofit sector. In partnership with the NJOEM the Rutgers University School of Social Work’s School of Continuing Education has included Disaster Planning for Agencies in its continuing education curriculum.

The California Department of Social Services (2007) engages service providers in its Functional Assessment and Service Team (FAST Team) program. FAST Teams “provide staff to conduct functional assessments of PAFN [people with AFN] who are in shelters. This assessment will evaluate the needs that people with access and functional needs may have, and determine whether they can be supported within the general population shelter.” The teams consist of “trained government employees and CBO [community-based organization] personnel ready to respond and deploy to disaster areas to work in shelters. FAST will work side by side with shelter personnel and other emergency response workers to assist in identifying and meeting essential functional needs so PAFN can maintain their health, safety and independence during disasters.”

The California FAST Team Training Program is standardized statewide and has been endorsed by the U.S. Department of Homeland Security. Guidelines are being developed to develop a mechanism for reimbursing community based organizations that perform essential community services when disasters strike (FAST. n.d.)

A U.S. Department of Health and Human Services Katrina/Rita Research Brief from December 2008 supports early engagement with agencies in its “Lessons Learned” section (p. 8): “traditional models of disaster relief are not equipped to deal with the deep and sustained injuries of disaster victims....[S]eek out the best performers with track records in

addressing complex or challenging needs....[T]ap connections before disaster strikes.” When established, the Incident Command System should include resources directed at AFN populations. A FAST Team is essentially a human services strike team, or AFN services may be considered a Branch under the Operations Section. The ability to provide access, integration, and inclusion of all community members impacted by the disaster is the true measure of how successful government is at managing an emergency disaster or catastrophic event.

The University of Massachusetts Medical School Eunice K. Shriver Center for Emergency Preparedness and Response Initiative, Cornell University, and the University of Connecticut offer examples of how academic partnerships can help foster Whole Community engagement. The Shriver Center (kim26stephens, 2013) has developed a number of products and toolkits related to disability preparedness. There are information sheets aimed at specific audiences, a disaster toolkit for families who have children with disabilities, training opportunities, and consultation for emergency management exercises. The Cornell University Employment and Disability Research Institute Northeast ADA Center (2014) highlights the issues of disability disaster preparedness in the work environment, continuity planning for service-providing agencies, and individual preparedness on the website and throughout its training curriculum. The University of Connecticut’s University Center for Excellence in Development Disabilities, in partnership with the Connecticut Council on Developmental Disabilities and the Connecticut Office of Protection and Advocacy for Persons with Disabilities (2005) produced “A Guide for Including People with Disabilities in Emergency Planning,” which advocates that people with disabilities maintain a voice in the planning process.

Conclusion

Emergency management professionals can easily access official guidance and standards related to inclusive emergency planning for individuals with AFN. This guidance has been informed by federal laws and standards, and produced with input from the community of people with AFN. Applying the standards – finding the right AFN contacts, ensuring a cross-disability approach, examining AFN needs across the lifespan, engaging local service providers, evaluating the extent of local resources, identifying the trigger points for accessing regional or higher-level resources – is where the real work begins and will continue.

Expectations management on the part of all stakeholders is key: how can the community of people with AFN inform the planning process, what are the limits of local responders and resources in an emergency, and how does a community leverage time, personnel, and other assets to ensure an inclusive response?

Timing and accessible communication tools are key when trying to maintain the systems that support independence. Early warning strategies and remaining engaged on the topic of disaster preparedness require almost constant focus.

Successful AFN planning requires stakeholders to move outside of the “comfort zone.” Emergency planners will need to look beyond the usual first response agencies with which they are engaged: who are key contacts in the field of human services, public health, and the community and faith-based service-providing sector that interact with the AFN community on a daily basis? Likewise the willingness to learn about, understand, and prepare for the true conditions of a disaster – taxed emergency response units, long-term power outages, infrastructure damage, less-than-perfect shelter conditions, complicated long-term recovery processes, and an overall disruption to the systems that provide services to people with AFN – is necessary.

Endnotes

¹ <http://www.dralegal.org/sites/dralegal.org/files/casefiles/noticeofproposedsettlement.pdf>

BRIDGING THE DIVIDE

Introduction

Practitioners and researchers must address AFN in all stages of the disaster cycle. Addressed in this section are the following issues: the ongoing evolution of terms and concepts that surround AFN, implementation of policies and frameworks, collective and individual responsibilities, organizational involvement, and knowledge regarding outreach and preparation. Within each of these five areas, practitioners' and researchers' perspectives are explored, highlighting consensus, conflict, and tension between different views.

Terms and Concepts

The term *AFN* encompasses functional needs to be addressed in disaster planning and response. These functional needs involve communication, transportation, supervision, medical care, and maintaining independence. Planning for AFN respects the abilities people have, rather than assuming certain groups of people will automatically require additional, specialized assistance. Practitioners and researchers agree AFN are present in all communities and are not limited to specific groups.

AFN terminology moves away from umbrella terms that categorize everyone as special or vulnerable. Previous terminology utilized *special needs* to describe groups of people assumed to be more vulnerable to disasters. Putting all the groups included under this term together, *special needs* described 50% of the population. The term lacked dignity, and presumed that a person with a characteristic having a "special needs" designation automatically needed assistance or was more vulnerable to a disaster.

The shift in focus to AFN was part of a larger dialogue within the disability community to stress the ability people have to be independent. The perception that people with disabilities are automatically more vulnerable to disasters compared to people without disabilities is not true. This is, in part, because any member of the public might have AFN, while an individual with disabilities may not. Moreover, the number of individuals with AFN can increase during disasters due to disruptions in services and resources. Planning for needs rather than people is an area of agreement between practitioners and researchers because plans must reflect the capacity to deal with fluctuating numbers of individuals with AFN.

However, it is questionable as to how many states are making the move to AFN terminology and practice. Some plans explicitly use AFN terminology and planning assumptions based on FEMA guidance. Some plans use terms such as *special needs* and *vulnerable populations*, often in addition to AFN.¹

Finally, there is consensus between practitioner and researcher that people with disabilities are a part of the community with legal and moral rights to services. The Department of Justice utilizes the phrase “people with disabilities and access and functional needs.” The phrase refers to a legally protected class of people with disabilities and the wider group of people who have functional needs.

Implementation of policies and frameworks

The implementation of policies and frameworks varies between entities. State and federal governments implement federal policies, and individual states also create their own policies and plans applicable only to their state. The variation between states in implementing federal policies and the difference between states’ policies and frameworks means state plans use different language and describe different practices for disaster planning.

The ADA of 2008 protects the civil rights of people with disabilities. The act prohibits discrimination toward people with disabilities and mandates equal access. The values of the ADA include equal opportunity, integration, and full participation (Devlyder, 2013). People with disabilities should “not be denied the benefits of programs, activities, and services, such as public transportation, provided by public entities, and, in many cases, by private entities providing public accommodation” (Banks, 2011, p. 29). Practitioners and researchers are in agreement that disaster planning and response activities should, without exception, incorporate the ADA to ensure equal access and protection for people with disabilities. However, recent court cases in Los Angeles² and Brooklyn³ highlight problematic implementation where services and resources made available may not have been compliant with the ADA.

The practitioner and researcher agree public shelters should adhere to the ADA to ensure equal access. Government agencies (e.g., emergency management, Department of Education) work with nongovernmental organizations (e.g., American Red Cross) to pre-select accessible shelter sites. Site selection should include accessible buildings, although that is not always the case in practice. Some buildings constructed before the implementation of the ADA of 1990 are not accessible, and, in the time since the ADA law was signed, have not been remodeled, meaning they still may not be accessible. Under FEMA’s FNSS approach, reasonable steps toward accessibility should be conducted by planners (Robinson et al., 2013). Planners should use strategies described in the FNSS to ensure that disaster shelters are more fully prepared to accommodate functional needs (FEMA, 2010b).

A shared concern of practitioners and researchers involves the shelters opened by community-based organizations (CBOs) or faith-based organizations (FBOs) independently of those opened by emergency management entities. CBOs or FBOs may open shelters spontaneously because of a wish to do something for the community. Compliance with the

ADA is not necessarily taken into consideration, limiting access to services and resources for people with disabilities.

Collective versus individual responsibility

The responsibility for preparing for and responding to disasters has collective and individual components. Disaster plans and responses are often the responsibility of a designated emergency manager at the state or local level. There is a limit to the efforts practitioners make, and then it is up to individuals to take responsibility for their own preparedness pre-disaster and for their own care post-disaster. However, when a disaster occurs, not all people take appropriate actions to keep themselves safe and prepared.

The practitioner and researcher agree that ideally people should be prepared to meet their own needs if they evacuate to a public shelter. The function of shelters is to provide temporary lodging to individuals who are unable to stay in their own homes. Meals are served three times a day, but may not be designed to meet the special dietary requirements of some individuals. Shelters are not a hotel away from home with extra amenities. In fact, it may be that people are more comfortable staying with family or friends, as is often the case when people evacuate. There are potential conveniences available at the homes of family or friends not offered at public shelters. Additionally, there is not an assumed cost associated with staying in a private home as there would be for staying at a hotel. Individuals who identify with AFN should assume that most of what they would require is not easily available in a public shelter. Therefore, when it is possible and safe to do so, they should plan to bring anything they may feel is important for their AFN with them, regardless of where they seek shelter.

There is tension between practitioner and researcher regarding the individual or collective responsibility toward AFN services. Identification of both the types and levels of services needed during a disaster must occur. Although emergency managers do their best to have services available for those who need them, many of these services will be provided in a broad fashion. If services are being provided as written in the plan, but are not those that would best serve people, who bears the responsibility of maintaining the independence of the person with an AFN? For example, opening a general population public shelter is a service provided before and after disasters. Typically, individuals reside in a common area, such as a gymnasium. Crowding or loud noise in such a situation may result in an increase in the number or severity of some AFN. It is unclear if accommodations can be made available for that type of AFN. That is, would other rooms in the building be available for a person with an AFN meeting that description, or would they be able to use different accommodations?

Evacuation of people with AFN is another source of tension between practitioner and researcher. It is the responsibility of individuals to prepare, and this includes planning a personal evacuation strategy involving the type of transportation (e.g., personal vehicle,

public transportation, etc.) as well as the evacuation route. However, there is a collective responsibility toward citizenry with transportation-related AFN to help them evacuate, if necessary. There are situations that lead researchers to have concern about evacuation assistance. For example, assume a hurricane is approaching and a mandatory evacuation order of particular coastal counties is enacted. Forty-eight hours before landfall, someone ordinarily unable to leave home because of a medically related AFN and without a personal vehicle calls his/her local emergency management agency to notify the agency of the need for assistance in evacuating to a public shelter. He/she was unable to arrange for any other transportation, and lives outside of the mandatory evacuation zone. The emergency management agency indicates there will be a fee assessed for specialized transport to take the person to a shelter. The person is unable to pay for a ride due to economic constraints. What would happen if the person lived within the evacuation zone? Would help be sent? Is there a community responsibility to evacuate the person given they live outside the evacuation area? There is no way to be sure if a hurricane will affect a larger or different-than-predicted area. If the hurricane affected the area where the person lived and he or she needed to call for help during the hurricane, first responders could be put in jeopardy. Researchers are concerned that such scenarios need to be considered when individuals' responsibilities for evacuation ties into the collective responsibility of assisting people to evacuate.

A discussion of collective versus individual responsibility must look beyond service provision and its associated logistics. Certainly, these are important planning tasks; however, integration and inclusion of people with AFN involves the establishment of pre-disaster personal relationships and support systems; there is no substitute for interpersonal relationships as a means for an individual with AFN to increase his/her chances of surviving a disaster. In "Personal Relationships – Who Are Your People?" Kahn and Pearpoint (2007) addressed disability advocates and emergency planners after Hurricane Katrina, calling for each group to begin building bridges, and increase understanding of the other's needs, capabilities, and situation. They ask:

What if we act on approaches that connect us? Our isolation from one another creates profound loneliness and despair. This is the greatest disability for any of us. What if we reframe and reorganize our energy? What if our actions engage and support folks with disabilities to share their gifts, including their capacity to bring people together?

The person with AFN viewed as a contributor, a community member, is highlighted again in a 2010 research study titled "Disaster, Evacuation and Persons with Disabilities – An Assessment of Key Issues Facing Individuals and Households. This study also makes a statement about the roles and responsibilities of service providers:

A richer social network, even when part of that network results from membership in voluntary organizations, is a good predictor of evacuation behavior. A social network with family, a caregiver, and voluntary organizations facilitates the decision to evacuate. The influence of use of a caregiver for assistance with daily activities was found to be particularly important in facilitating evacuation. These results suggest that provision of a personal care assistant from disability services organizations, particularly during an evacuation, is likely to help persons with disabilities to accurately perceive disaster risk and have the capacity to evacuate in a disaster. Disability services organizations with personal care assistance programs should be carefully examined to determine how the personal care assistant facilitates the evacuation of persons with a disability and their household. (Gerber, Norwood & Zakour, 2010, p. 10)

An additional key question is how do we better reach individuals in the community who are not connected with services from outside the home, who risk isolation from disaster warnings and preparedness information? There are many families in which a spouse or other family member is the primary caregiver, and where emergency management officials cannot rely on a third party such as a community agency and caseworker to amplify emergency management messages.

Organizational involvement

Organizations are regularly involved with providing services and resources to individual with AFN. Providers of AFN services work with the AFN community regularly. Practitioners and researchers agree these organizations know the needs of the citizens they serve. Providers are called upon to be part of disaster plans in order to continue services. In many instances, emergency managers incorporate community organizations into plans and detail what services and resources they might provide. However, regular service providers have varying levels of success in being part of disaster plans.

Community organizations may indicate they will be able to provide services during times of disasters. However, there may not be an accurate sense of the number of staff members available to provide services. Additionally, staff may be overstretched. Although research suggests role abandonment does not occur in the rates conveyed by the media (Trainor & Barsky, 2011), organizations are concerned about their staff being able to come to work during a disaster. Staff who are not required to work have a legitimate right to follow possible orders to evacuate, and may do so with their families. The staff who are able to work may find themselves stretched by trying to provide regular and additional services at multiple, possibly distant locations. There may also be an increase in the number of people with AFN during and after a disaster. Hence, more individuals who receive services are depending upon a single employee.

The issues noted above have evolved to some degree because of a lack of sustained disaster-related funding for the human services sector. A successful AFN disaster response involves participation by three sectors of government: emergency management, health, and human services. Deployment of behavioral health professionals for disaster crisis counseling is a common practice, which is funded by FEMA and other federal agencies. However, disaster planning, training, and exercising – the preparedness fundamentals – are generally unfunded or underfunded for the human services sector. Public health has benefitted from being able to access pandemic, bioterrorism, and other hazard-based federal grant programs for preparedness and planning. These resources have not been as available to the human services sector, which is most likely to address the needs of AFN populations. This is particularly problematic, as human services professionals are involved with AFN populations during all phases of the disaster life cycle.

Outreach and preparedness knowledge

An aspect to fulfilling AFN is outreach and dissemination of preparedness knowledge. Outreach may be in the form of emergency managers or other entities, such as nonprofits or non-emergency management agencies, going into a community to educate on preparedness. Preparedness education is an important function in informing citizens of what they should do before, during, and after a disaster.

The University of Delaware's Center for Disabilities Studies (CDS) had a grant through the U.S. Department of Health and Human Services to help people with disabilities prepare for disasters. One element of outreach included making personal preparedness plans that documented specific information, such as type of disability/disabilities, medications and dosage (if applicable), and an up-to-date contact sheet. The plan was for the individual to use, but it served a second purpose of compiling this information to provide to emergency management personnel or shelter volunteers if necessary. The planning sessions revealed people with disabilities and caregivers had very little, if any, knowledge about emergency management strategies. Those in the disability organizations with whom planning sessions were conducted had not received information from or interacted with emergency management entities. This was despite the interest in preparing for disasters evidenced by inviting the CDS researchers to present on the topic of personal planning. This suggests there are many additional people with disabilities or caregivers in the community who are not exposed to emergency management principles that could assist them in preparing for disasters.

Outreach is also done by practitioners. However, individuals who benefit from emergency management agency outreach may be the same people engaged with nongovernment entities. There remains a challenge in reaching the large number of individuals not connected to traditional outreach activities, as they may remain unknowledgeable about preparedness.

For outreach, one benefit of AFN terminology is to limit the stereotyping and labeling that often places people with disabilities and older adults in a negative context. This is timely, as there is more recognition needed regarding the disaster-related needs of older adults. Age in and of itself does not equal a need for assistance; each individual has his/her own needs and abilities. Disability statistics present a challenging reality, however, in the later decades of life. A look at changing demographics and social trends regarding older adults will challenge emergency planners to make sure plans are more inclusive of specific AFN needs.

An older adult may or may not self-identify as “disabled,” or consider him or herself a person with “access and functional needs.” Hence, he or she may or may not perceive preparedness messages aimed at these communities as relevant. States’ choices regarding the use of aging-related resources are trending toward older adults remaining in a community setting with support services, rather than moving to congregate settings. What will this mean as emergency planners attempt to keep individuals connected with support services during adverse conditions? Aging-in-place communities, many in larger cities with deteriorating infrastructures, will continue to evolve. What will this mean for those involved in evacuation planning, shelter accommodations, or temporary housing? There is more emphasis placed on people with disabilities rather than older adults in current policy discussions and planning guidance.

Certainly, actions taken to foster preparedness for people with AFN enhance the whole community, but older adults also present with specific issues. These issues may include significant and prior losses pre-disaster, reluctance to evacuate, fear of institutionalization, vulnerability to fraud and abuse, sensory deprivation and adverse physical effects related to extreme weather conditions (R.I. Hope, n.d.). The CDC does offer an emergency preparedness portal that serves as a good basis for additional information sharing between the aging services sector and emergency management agencies (CDC, n.d.).

Future directions for related research

There is limited research on AFN; however, the collection of promising practices at the state, county, and municipal levels continues to accrue. Further research into this topic would be beneficial in providing information regarding preparing for and responding to disasters, especially in situations that require information be communicated on evacuation and sheltering. Understanding how AFN affect people can help form key insights. This knowledge informs practitioners and researchers about the types of services and resources regularly used during normal times and should be planned for during a disaster.

Future directions for certain academic institutions involve schools of social work, psychology, counseling, and other human services professions incorporating disaster-related topics into their curriculums. Except for the topic of Post-Traumatic Stress Disorder, students

pursuing degrees in the human services professions typically receive very little exposure to disaster-related topics during their educational experience. Yet, chances are likely they will encounter a disaster survivor in their therapeutic experiences, while providing casework management, or in other settings. Many students pursue an administrative track in their studies, or move on from direct service to management of an agency. Education and knowledge about where and how human services professionals fit into the disaster life cycle, and how they can apply their knowledge and skill-sets to address the needs of the AFN – and the larger community - is needed. For instance, the Rutgers University School of Social Work’s School of Continuing Education is now offering Disaster Business Continuity Planning classes for social work professionals seeking Continuing Education Units (CEUs) (Rutgers School of Social Work, 2010).

There is also a role for schools or institutes of technology. Technology has allowed for increased independence and enhanced quality of life for people with AFN, especially in the areas of communications, health monitoring, mobility, and essential life functioning. However, disasters can result in long-term power outages of several weeks or more, and consumers find these essential, assistive technologies interrupted. The service interruption causes a person to lessen or lose independence, in some cases causing death. Improved options for individuals who are technology-reliant may offer opportunities to remain in their home, or their community, and avoid public shelters. There is a trend toward communities establishing “charging stations/areas” with water, snacks, and a rest area, but not full shelter capabilities, for this purpose. If technology schools could advance developments related to assistive technology and charging options, the larger community would benefit.

To more fully understand the services and resources needed to address AFN, specific research should include the following:

1. Identifying with AFN – Do people identify with AFN? What might this mean for planning?
2. Planning for AFN - What are best practices for different types of functional needs?
3. Trends related to AFN - Are there patterns in the population of people with various types of AFN? Are there trends in requirements for services versus resources to address AFN?
4. Privacy concerns - Are people not sharing information regarding AFN because of privacy concerns?
5. Inclusion of people with AFN – Are programs designed with the assistance of people with AFN? Are organizations with expertise on AFN helping in the design of policies and plans?
6. Best practices - What elements of projects influence the characterization of these practices as “promising?” What do “best” practices mean in the field of emergency management of AFN populations?
7. Responsibility for AFN - Where is that responsibility best addressed within the planning framework, that is who “owns” it?

8. Tried-and-true recommendations for emergency preparedness (get a plan, have a kit) – Are they adequate for individuals with AFN?
9. Registries - What is the true effectiveness of registries, and what are the specific situations when registries are best used?
10. Preparedness - Many people with AFN are still unprepared for disasters. Why?
11. Evacuation barriers - There is research regarding why individuals will not or cannot evacuate. How can we remove those barriers?
12. Social factors - Are there social factors, such as poverty, joblessness, or technology's digital divide, that influence people with AFN preparedness and response?

Conclusion

Practitioners and researchers agree on the new AFN terms and concepts, and support the movement away from the phrase *special needs* to *access and functional needs*. Some states have adopted AFN terminology in their plans in conjunction with the phrases *special needs* or *vulnerable populations*. Even with plans that utilize outdated terminology, there is agreement that the phrase *access and functional needs* is more respectful and conveys a more meaningful message of independence for individuals. Federal policy creation and implementation uses the phrase *access and functional needs*. There is concern by researchers who see the variation in plans across states as potentially problematic to equal delivery of services and resources.

Nonetheless, practitioners and researchers feel individual responsibility for services and resources is the first step in disaster preparedness. Individuals should not solely rely on federal, state, or local policies and plans in the event of a disaster. Government agencies and community organizations will be available to assist in times of disaster, but there is the possibility of large service disruptions. Practitioners and researchers agree that community providers should, and must, be active partners in disaster preparedness and response. These organizations are an integral part of preparing for and responding to disasters. Nonemergency management agencies and organizations that interface with the AFN community are familiar with who requires specific services and resources. Familiarity with the community allows knowledge to pass to practitioners about the best ways to address AFN in disaster and response.

Endnotes

¹ See, for example, emergency operations plans from California, Delaware, Florida, Mississippi, and North Carolina.

² *Communities Living Independently and Free (CALIF) v. City of Los Angeles*

³ *Brooklyn Center for Independence of the Disabled v. Bloomberg*

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