

People with Disabilities and Disasters

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While considerable research has been published on the effects of disaster on other marginalized groups, studies on the experiences of individuals with disabilities have been limited (Alexander, Galliard, & Wisner, 2012; Kelman & Stough, 2015a; Mileti, 1999; National Council on Disability, 2009). Several elements appear to have inhibited research in this area. Foremost, research on marginalized populations experiencing hazards came to full fruition just 30 years ago (see Bolin & Bolton, 1986; Blaikie, Cannon, Davis, & Wisner, 1994; Peacock & Ragsdale, 1997) and only recently has included individuals with disabilities as a group of concern (see Peek & Stough, 2010; Phillips, 2015; Stough & Mayhorn, 2013). In addition, many researchers have limited expertise as disability studies did not emerge as an academic discipline until the 1980s and coursework addressing the social, cultural, and historical aspects of disability has been scarce (Society for Disability Studies, 2017). As a result, people with disabilities have been overlooked as a significant minority group by scholars despite the fact that more than 15% of the world's population, over a billion people, live with a disability (World Health Organization & World Bank, 2011). Lastly, people with disabilities are marginalized in most of the world's societies and such marginalization has occurred across millennia of history (Scheer & Groce, 1988; Stiker, 1999; Stough & Kang, 2016; Walker, 1981). Thus, the voices of people with disabilities have been only recently added to social justice movements around the world (Davis, 2006; Irvine, 2014; Shapiro, 1994).

The purpose of this chapter is to discuss research developed by several academic disciplines on the experiences of individuals with disabilities and to situate that research within the conceptual and definitional complexities inherent in disability studies.

Disability Defined

Research and practices surrounding disability must be carefully interpreted as the identification and labeling of disability is complex. Even within a named category of disability, individual functioning, intelligence levels, and behavioral competencies vary widely. Actually, the characteristics of people who have disabilities can be more disparate than similar (Alexander, Galliard, & Wisner, 2012; Kailes & Enders, 2007). Such diversity raises the question whether it is logical to consider people with disabilities as a distinct class of individuals.

Several strong arguments are in favor of conceptualizing people with disabilities as having a shared minority status. First, the historical and widespread discrimination and mistreatment of people with disabilities is an ongoing issue of human rights (Albrecht, Seelman, & Bury, 2001; Oliver, 1986; United Nations, 2006). Historically, and across cultures, disability has been stigmatized to the extent that people with disabilities have been discriminated against, institutionalized, and even killed (Nguyen-Finn, 2012; Scheer & Groce, 1988; Stiker, 1999), and are thus socially vulnerable. Second, individuals who evidence disability are commonly regarded with disfavor and conferred a different, usually lesser, status within their own societies and governments (Mitchell & Karr, 2014; Kelman & Stough, 2015b), again augmenting their vulnerability. While the inclusion and integration of people with disabilities has considerably advanced in some societies (see Stough & Aguirre-Roy, 1997), there remain many places in the world where education, employment, and civil liberties are withheld from individuals viewed as having disabilities (International Federation of Red Cross and Red Crescent Societies, 2007). Third, a phenomenon, such as disability, needs to be described to create a common discourse about the phenomenon. Pragmatically, the construct of disability must be defined and conceptualized so that inequities and barriers can be recognized and addressed effectively.

Disability is both a social construct and a cultural construct in that different societies conceptualize disability in different ways (Lauber & Rössler, 2007; Walker, 1981). For example, dyslexia is considered a learning disability in the U.S. but may not be identified nor problematic at all in South Sudan or Afghanistan, which have low literacy rates. Disability is also labeled differently across societies. For example, “learning disability” in the U.S. entails differences in learning not attributable to intellectual functioning, whereas in the U.K. the term “learning disability” is equivalent to the classification of “intellectual disability” as used in the U.S. Together, these differences in definitions and classifications affect the prevalence and incidence of disability reported across societies and time, as well as muddle the international conversation regarding disability.

Part of the current complexity has arisen due to changes from a deficit or “medical model” conceptualization to a “social model” of disability (Oliver, 2004; Shakespeare, 2006). In the medical model, disability is equated with illness, just as would be cancer or strep throat: The classification and severity of the disability is diagnosed and treatment recommendations follow the diagnosis. There are numerous counterarguments to the medical model perspective including that disability cannot be cleanly equated with illness, that treatment and education should follow function rather than diagnosis of disability, and that variation within classification of disability is considerable, rendering traditional labels inadequate. In contrast, the “social model” of disability argues that society itself creates physical, economic, educational, and cultural barriers that give rise to the experience of disability (Oliver, 2004; Shakespeare, 2006). For example, people with disabilities face barriers when using most transportation systems, in finding accessible housing, and in seeking employment (World Health Organization & World Bank, 2011). Disability is thus

viewed as arising from the interplay between the environment and the individual, not as an individual abnormality, which is the perspective of the medical model.

The World Health Organization (WHO, 2001) uses perhaps the most encompassing definition of disability, the International Classification of Functioning, Disability, and Health (ICF), which is more aligned philosophically with the social model. In the ICF definition, disability is conceptualized as the result of the interaction amongst impairment in body structure or function, limitations in specific activities, and resultant restrictions in social participation (WHO, 2001). Nevertheless, the definition is complex, presents measurement challenges, and is not consistently used across countries (Imrie, 2004; Wiegand, Belting, Fekete, Gutenbrunner, & Reinhardt, 2012).

Elsewhere around the world, a large number of classification systems for disability exist in addition to the previously described WHO definition and include; the American Psychiatric Association, the Australian Disability Discrimination Act of 1992, the Law of the People's Republic of China on the Protection of Disabled Persons of 1990; and the Indian Persons with Disabilities Act of 1995. Each of these organizations or acts define, classify, and count disability differently. Given that differences in classification exist not only across countries, but also within national boundaries, an individual may be considered to have a disability under one of these definitions, while not qualifying under another (WHO, 2011).

Adding to the definitional challenge is the emerging usage of “individuals with functional and access needs” within the emergency management field in the U.S (Davis, Hansen, Kett, Mincin, & Twigg, 2013). The functional needs-based approach, first defined by Kailes and Enders (2007), uses a five-part taxonomy of disaster-related needs in the areas of communication, medical health, independence, supervision, and transportation and is referred to

as the C-MIST definition of functional and access needs. The C-MIST was adopted by the U.S. Federal Emergency Management Agency [FEMA] (2010) in the National Response Framework (FEMA, 2010) wherein FEMA defines “Functional Needs Support Services” (FNSS) as “services that enable individuals with access and functional needs to maintain their independence.”

The FNSS approach encompasses not only the needs of people labeled as having disabilities, but others as well (Davis, Hansen, Kett, Mincin, & Twigg, 2013; Kailes & Enders, 2007). For example, ramps into shelters assist elderly people who cannot use steps as well as assist parents using strollers. Augmented communication systems support people who are deaf and additionally those who are hard of hearing but who do not use hearing aids. An advantage of the FNSS definition is that it pragmatically focuses on the environmental and social barriers which must be eliminated to ensure equitable treatment of individuals with disabilities in disaster. The conceptualization also aligns theoretically with the social model of disaster.

There are several difficulties with the use of the FNSS definition. As the definition covers additional populations, such as the elderly, children, and prisoners, the particular needs and experiences of individuals with disabilities can be obscured. Moreover, the FNSS definition has not been adopted by governments outside of the U.S., nor is the definition used outside of emergency management circles within the U.S. The definition thus has had limited utility for disaster researchers as the construct does not pertain exclusively to people with disabilities. Thus, existing demographics or research on disability cannot be simply equated to apply to FNSS populations. However, it is a highly pragmatic approach in that it focuses on the actions emergency personnel must take during disasters to accommodate people with disabilities and others with functional or access needs.

Despite the challenges of defining and classifying disability in most countries people with disabilities make up between 10 and 20 per cent of the population, depending on how disability is classified and registered within that particular country (WHO, 2011). Disability prevalence also increases with age: For example, in 2010, 36.7% of those 65 or older in the U.S. indicated a disability impacted their activities of daily living (Houtenville and Ruiz, 2011). Age is also associated with functional activity measurement in that as adults age they are more likely to report needing assistance with personal needs (Administration on Aging, 2013) as well as in processing information about disasters (Mayhorn, 2005). However, age cannot be used as a proxy substitute for disability measurement without qualifiers as some elderly adults are quite able to take independent actions in disaster, while others might need substantial support in order to do so (Fernandez, Byard, Lin, Benson, & Barbara, 2002; Stough & Mayhorn, 2013).

Research on Disaster and People with Disabilities

Few studies examined the needs of people with disabilities in disaster before the 1980s. Over the following several decades, relevant research emerged from within several different disciplines, but with little overlap between these disciplines. To illuminate these distinct lines of research, this review is divided into the following sections according to academic genesis areas; 1) disaster-focused research, 2) mental health, 3) epidemiology and public health, and 4) disability studies. Within these subsections, several seminal studies are summarized in detail.

Disaster-focused Research. Disaster scholars have repeatedly commented on the scarcity of research on people with disabilities, despite the evident vulnerability this population has to hazards (see Alexander, Gaillard, & Wisner, 2012; Meleti, 1999; Tierney, Petak, & Hahn, 1988). Disaster research which included disability status as a variable did not emerge until the mid-1980s and was led by sociologists. In an early study, Tierney et al. (1988) examined the

effects of earthquake hazards on individuals with disability. The authors noted that, prior to their study, “both researchers and those responsible for natural hazards policy and planning have virtually ignored those millions of persons whose physical capabilities differ from those of the general population” (p. 1). A lack of accessible building egress routes was reported in the 1983 Coalinga, California earthquake. The researchers argued that individuals with disabilities should be able to cope adequately with earthquakes given appropriate modification of the built environment and an increased level of personal emergency preparedness. Towards this goal, the researchers introduced the concept of “functional challenge” (a concept which June Isaacson Kailes would later expand upon) as a basis for describing various barriers which individuals with disabilities face during disaster.

In another early study, Parr (1987) investigated the effect of disasters on individuals with disabilities in New Zealand. Civil service agencies reported having limited knowledge and little urgency about preparing for the needs of individuals with disabilities in disaster. Conversely, members of organizations working with people with disabilities reported that emergency planning was of great necessity for their clients. None of the individuals with disabilities interviewed in the study reported having emergency preparedness plans, although they expressed concerns about their safety in emergencies.

A study of survivors of the 1989 Loma Prieta earthquake in California found that people who had restrictions in physical movement did not experience increased exposure to earthquake hazards. During the earthquake, more than two-thirds of the respondents took protective action (Rahimi, 1993). Respondents were well aware of their home environments and potential obstacles that had to be negotiated within them. In another study, Rahimi (1994) conducted simulation experiments on the abilities of manual versus motorized wheelchair users in

negotiating earthquake-related obstacles. Users of powered wheelchairs (which are larger) had more difficulties negotiating obstacles and their users often had to seek alternate escape routes.

Wisner (2002) examined the intersectionality of disaster and disability, pointing out that disasters often cause disability, as well as casualties among people with disabilities. He took issue with the biomedical model of disability, which ignores the barriers created in built and social environments. Wisner (2002) also explained that recommendations for people with disabilities were typically aimed at caretakers, rather than towards individuals themselves, further contributing to the perception of people with disabilities as passive recipients of care, rather than potential participants in disaster risk reduction.

Van Willigen, Edwards, Edwards, & Hesse (2002) focused on the experiences of individuals with physical disabilities, mobility impairments, and sensory impairments during Hurricanes Bonnie, Dennis, and Floyd. Households of people with disabilities were found to be less likely to evacuate in advance of hurricanes and reported needing more assistance. Some respondents with disabilities lived alone and had either hearing or visual impairments and evacuation orders were not communicated in a way that were accessible for them. Some respondents also believed public shelters did not have needed disability-related accommodations, which disaster scholars confirm is often the case (Twigg, Kett, Bottomley, Tan, & Nasreddin, 2011). Respondent households with disabilities also were found to experience greater housing losses and suffer more costly damages to their properties.

In a study of the 2011 Tokoku-oki earthquake and resultant tsunami, Brittingham and Wachtendorf (2013) examined differential impacts for people with disabilities in three Japanese prefectures. They found disparate information, material disaster resources, and disaster-related services at different shelters and temporary housing environments. Displaced survivors housed in

general population shelters had better access to information and material resources than did people with disabilities staying at social welfare shelters, which were designated for people requiring specialized care or services. Even when individuals with disabilities were housed within a general population shelter, resource disparities persisted, for example, mats and toilets were often not accessible for people with disabilities and service providers often did not have training to appropriately assist people with disabilities. Finally, people with disabilities had difficulty in reconnecting with their social services post-disaster.

In sum, research conducted by disaster researchers has explored how construction, evacuation, emergency response, and sheltering differ for individuals with disabilities. Without exception, this work has identified inequities in dealing with disaster and how these inequities differentially and negatively affect people with disabilities. Research questions, designs, and sample sizes have varied greatly from study to study and thus this body of research is markedly scattered in focus.

Epidemiology and Public Health Research. Epidemiologists and public health researchers have conducted data analyses on large data bases to identify how people with disabilities are differentially affected by disasters. Most saliently, people with physical disabilities, limited mobility, or mental illness have been found to die at higher rates in disasters (Chou, Huang, Lee, Tsai, Chen, & Chang, 2004; Osaki & Minowa, 2001). Chou et al. (2004) found individuals with physical disabilities had higher mortality risk during the 1999 Taiwan earthquake, although after adjustment for other socioeconomic variables, mortality differed only in individuals with moderate physical disabilities. The researchers suggested that individuals with more severe disabilities tended to receive care in nursing homes or long-term care facilities, which have stricter housing codes in Taiwan. Also noted was that physical disability, mental

illness, or poor health status might have prevented individuals from effectively evacuating after the earthquake. The Osaki and Minowa (2001) study found people with “physical handicaps,” including bedridden elderly, physical disabilities, and intractable diseases, were 5.6 times more likely to die in the 1995 Great Hanshin-Awaji earthquake. These empirical studies are supported by reports from the field: For example, none of the 700 people with post-polio paralysis on an island in the Bay of Bengal survived the 2004 tsunami as they were unable to evacuate to a safe place in the hills nearby (Hans, Patel, Sharma, Prasad, Mahapatra, & Mohanty, 2008). Among the deaths related to Hurricane Rita in 2005 were 23 nursing home residents in the U. S. with mobility, health, and communicational disabilities who had evacuated in a bus, which caught fire. The driver and six staff members, none with disabilities, all survived (Houston Chronicle, 2005).

A number of studies by public health researchers have examined emergency and evacuation preparedness in individuals with disabilities. Several of these studies have used data from the Behavioral Risk Factor Surveillance System (BRFSS), which collects data annually from over 400,000 U.S. residents regarding health-related risk behaviors, chronic health conditions, and preventive services use, making it the largest continuously conducted health survey system in the world. An analysis of data from respondents to the 2006-2007 BRFSS survey (Smith & Notaro, 2009) found only 25.8% of people with a disability believed they were “very prepared” for an emergency while 20.7% reported not being prepared at all. Another study based on BRFSS data found those with fair to poor health were less likely to have emergency preparedness items than others, yet were more likely to have a 3-day supply of medication (Bethel, Foreman, & Burke, 2011). However, the same study found individuals who used special equipment, such as canes or wheelchairs, were more likely to have an emergency evacuation

plan in place. A study of BRFSS data from the greater New Orleans area collected before Hurricane Katrina (McGuire, Ford, & Okoro, 2007) found almost one-third of individuals aged 65 or older had a disability, as well as lower income and education levels, and tended to rate their health as only fair or poor. The results illustrate that multiple categories of social vulnerability often intersect with disability, an observation also made by other scholars (e.g. Peek & Stough, 2010; Phillips & Morrow, 2007).

Other studies on evacuation behaviors of individuals with disabilities have focused on specific geographic locations, but with relatively smaller samples. Spence, Lachlan, Burke, & Seeger (2007) found individuals with disabilities who had evacuated from Hurricane Katrina were more likely to prepare an evacuation kit in advance of the storm, but less likely to have an evacuation plan in place. Individuals with disabilities engaged in less information-seeking about the ongoing disaster than others, although they relied on much the same informational sources, for example, television, telephone, and personal contacts. A study of Southeastern Pennsylvania households which included a person with a disability (Usher-Pines, Hausman, Powell, DeMara, Heake, & Hagan, 2009) similarly found these households more likely to have an evacuation kit prepared, identify an emergency shelter, and to have an arranged meeting place should evacuation become necessary. While these households were equally as likely as households without disabilities to have an evacuation plan, the authors point out that, given the additional support needed by family members with disabilities, a greater percentage of these household should have had emergency provisions in place. An investigation of the relationship amongst mental health, physical health, disability status, and disaster preparedness in people in Los Angeles County (Eisenman, Zhou, Ong, Asch, Glik, & Long, 2009) found individuals with poorer levels of health and with mental illness were less likely to have household preparedness

plans or emergency communication plans. The study found no significant difference in personal preparedness or communication plans between individuals with and without disabilities. In sum, these four studies suggest that individuals with disabilities tend to be just as, or in some aspects, more prepared for evacuation than are people without disabilities.

Over 20% of individuals with a disability require assistance with activities of daily living (Brault, 2012), usually from a paid home health care aide or unpaid family member. However, a survey of home-care aides in New York found most (57%) would be unwilling to report to duty at their client's home during a disaster, while 62% reported having competing obligations that would make reporting to duty difficult (Gershon, Magda, Canton, Riley, Wiggins, Young, & Sherman, 2010). In a second survey, people with cognitive and/or physical disabilities who received personal assistance services from a paid provider were interviewed (Gershon, Kraus, Raveis, Sherman, and Kailes (2013). Few had talked with their personal assistant about what to do in the case of an emergency. Although most of the sample had previously experienced a large-scale emergency, less than a third had made basic emergency preparations, such as a go-bag or emergency supplies, and less than half had an emergency plan at all. Similarly, a study of disaster preparedness among older Japanese adults with long-term care needs and their family caregivers who had experienced the 2011 Great East Japan Earthquake found the majority had no concrete plans for evacuation and those caring for adults with dementia were less likely to have a plan (Wakui, Agree, Saito, & Kai, 2016). Together these studies illustrate that leaving evacuation preparedness in the hands of family members and caretakers is not a panacea for people with disabilities in disaster: Even those caring for individuals with significant needs might fail to prepare.

Some promising practices for changing levels of preparedness in caregivers have been documented. For example, Bagwell, Liggin, Thompson, Lyle, Anthony, Baltz, Melguizo-Castro, Nick, & Kuo (2016) provided parents of children with special health care needs with disaster supply starter kits and educational materials on disaster preparedness. Six to ten weeks later, a significant number of caretakers reported they had added supplies to their kit, completed an emergency information form for their child, a fire escape plan, arranged a meeting place outside the home, and communicated with their power company the need for quick return of electricity in the event of an outage because of their child's special needs. However, more research needs to be conducted on interventions effective in increasing the preparedness of individuals with disabilities and their families.

Mental Health Research. A large and growing number of studies from the disciplines of psychiatry and psychology have studied the mental health effects of disasters, foremost the development of posttraumatic stress disorder (PTSD), depression, or anxiety following disaster. A more limited number have examined the effects of disaster on people with preexisting mental health disabilities. In an early study, Bromet, Schulberg, and Dunn (1982) assessed outpatients with preexisting psychiatric illnesses living near the Three Mile Island nuclear facility during the 1979 disaster. When the group's post-disaster mental health status was compared with a group of similarly diagnosed individuals living near an unaffected nuclear plant, no differences in occurrence of anxiety or depression was found between the two groups. Three studies have examined clinically diagnosed pre- and post-disaster mental health in institutionalized populations with preexisting mental illness exposed to disasters (Stout and Knight, 1990; Godleski, Luke, DiPreta, Kline, and Carlton, 1994; Bystritsky, Vapnik, Maidment, Pynoos, & Steinberg, 2000). Findings suggest that individuals with preexisting mental illness do not acquire

new disabilities following disaster, but the studied individuals were receiving ongoing psychiatric care in therapeutic environments, suggesting ongoing psychological treatment may be effective in preventing the occurrences of new mental illnesses. Findings from two community-based studies have similarly suggested that ongoing psychological treatment may prevent additional pathology in individuals with preexisting severe mental illness following disaster (Lachance, Santos, & Burns, 1994; McMurray & Steiner, 2000).

Posttraumatic stress disorder (PTSD) is the most prevalent new mental illness found in populations without preexisting disorders following exposure to disaster (Norris, Friedman, Watson, Byrne, Diaz, Kaniasty, 2002; North, Oliver, Pandya, 2012). Unlike other mental illnesses, the criteria for diagnosis of PTSD is conditional in that requires individuals be exposed to a defined event, specifically “to actual or threatened death, serious injury or sexual violation either through directly experiencing or witnessing the traumatic event or through learning that the event occurred to a close family member or close friend” (American Psychiatric Association, 2013). Repeated or extreme exposure to viewing the effects of disaster, such as by first responders or medical workers can also lead to a diagnosis of PTSD (American Psychiatric Association, 2013). Several large scale studies have examined how preexisting mental illness contributes to PTSD post-disaster (North, Kawaskai, Spitznagel, & Hong, 2004; Robins, Fischbach, Smith, Cottler, Solomon, & Goldring, 1986). These studies suggest that new psychological disorders, with the exception of PTSD, rarely develop following disaster in people with preexisting mental illness. But, a pre-existing history of mental illness is a predictor for developing mental disorders after disaster, so the prevalence of post-disaster psychiatric illness in a given population will be highly dependent on pre-disaster levels of mental illness (North, Oliver, & Padya, 2012).

The terrorist attacks of September 11, 2001 led to a number of studies which examined PTSD in populations with preexisting mental illness receiving institutionalized or outpatient psychiatric care (see DeLisi, Cohen, & Maurizio, 2004; Franklin, Young, & Zimmerman, 2002; Riemann, Braun, Greer, & Ullman, 2004; Taylor & Jenkins, 2004). No significant increase in morbidity or occurrence of new symptoms was found between patients who did or did not view the destruction. However, the patients in these studies were not at physical risk during these disasters, nor directly impacted by the event, and were at substantial distance from the sites where the attacks occurred. What is important in considering the validity of disaster studies on PTSD is the level and type of exposure to the event. While PTSD can and does occur following disaster, the disaster-affected person or a close loved one must have been exposed to actual or imminent physical danger, which is not the case for some survivors of disasters. Moreover, while feelings of distress or sadness are common after experiencing disaster loss, the majority of people exposed to disasters in actuality do not develop mental illness (North, 2014).

In summary, studies on individuals with preexisting mental illness suggest that higher rates of PTSD occur in these individuals than in those without preexisting disorders, that the development of new psychiatric disorders unrelated to PTSD is rare, and that continuity of psychological supports appear to mitigate the negative psychological effects of disaster. However, as individuals with disabilities are more likely to be exposed to hazards, psychological effects are more likely to be evidenced in this population as well as more severe post-disaster (Stough, Ducey, & Kang, 2017). Research also suggests that instrumental and social service supports are of particular concern for people with mental illness post-disaster and that disruption of pharmacological and therapy treatments can exacerbate the mental health status of individuals under treatment (National Council on Disability, 2009). An important line for future research is

the extent to which personal, social, and disability-service systems are disrupted for individuals with preexisting mental illness following disaster (Stough, 2009).

Disability Studies Research. Hurricane Katrina in 2005 spawned an increase in the study of disaster by U.S. disability researchers - and also marked a genesis of research reporting direct narratives from individuals with disability. Work from these scholars was often based from a social justice stance and advocated for change in emergency management practices. Notably, a significant proportion of these investigations were conducted by individuals, including June Isaacson Kailes, Barbara White, and Glen White, who themselves have disabilities. Leading these studies was the Special Needs Assessment for Katrina Evacuees (SNAKE), which was conducted in shelters, community based organizations, and emergency operation centers throughout the affected states of Louisiana, Alabama, Mississippi, and Texas during Hurricane Katrina (National Organization on Disability, 2005). Numerous barriers and inequities in response and recovery services were reported, which affected people with a wide range of disabilities. Many shelters were found to be inaccessible, not only entrances to the shelters themselves, but also toilets, showers, cots, and public communications. In addition, individuals with disabilities were often redirected to medical special needs shelters which usually did not permit their family members to accompany them. Some households reported that they had delayed evacuation, knowing that shelters and transport were unlikely to accommodate the disabilities of their family members. The SNAKE Report noted that mental health services were not consistently available across shelters and that some individuals with visual disabilities were separated from their assistance dogs or canes during evacuation. The Deaf or hard of hearing population was identified in the report as being the most underserved group in shelters following Hurricane Katrina, the majority having no access to the vital flow of information about the

unfolding disaster. The study drew attention from disability rights advocates, policy makers, as well as funding agencies which later supported additional research in this area.

The Nobody Left Behind project at the University of Kansas, led by Glen White, has focused a series of studies on the effects of disaster on individuals with physical disabilities (Fox, White, Rooney, & Cahill, 2010; Fox, White, Rooney, & Rowland, 2007; Rooney and White, 2007; Rowland, White, Fox, & Rooney, 2007). One major challenge noted was the lack of emergency personnel training on, guidelines for, and interest in the needs of individuals with disabilities in disaster. People with disabilities identified (1) a lack of evacuation plans in their worksite or community, (2) being left behind when people without disabilities were evacuated, (3) inaccessible shelters and temporary housing, (4) disaster relief personnel unaware of disaster relief options for people with disabilities, (5) inadequate infrastructure post-disaster, such as power, public transportation systems, and elevators, and (6) difficulties returning to daily routines. Respondents suggested that their survival depended most on preplanning and preparedness measures, personal networks, and help from first responders. Individuals with disabilities reported how they built upon personal strengths to cope with disaster, rather than compensating for weaknesses associated with their disabilities.

Christensen and Holt together with their colleagues, (Christensen & Sasaki, 2008; Christensen, Blair, & Holt, 2007; Christiansen, Collins, Holt, & Phillips, 2014; Koo, Kim, Kim, & Christensen, 2013; Manley, Kim, Christensen, & Chen, 2011) examined emergency egress from buildings and other public spaces by individuals with mobility impairments. While their empirical research has been conducted with simulations, rather than in actual emergencies, their scholarship points out that the construction of buildings does not consider the wide range of differences in how people mobilize and how quickly they are able to do so. These scholars point

out that evacuation barriers for people with physical disabilities are compounded by building designs that require that everyone have the ability to descend stairs, exit windows, or open doors.

Of note is the work of Barile, Fichten, Ferraro, and Judd (2006), who surveyed survivors of the 1998 ice storm in Montreal, Canada. Most of the 15 research participants with disabilities were stuck in their houses throughout the entire ice storm and most had no electricity for over two days. Others endured the discomfort of having to negotiate shelter environments that were inaccessible and over-crowded. Tragically, in one case, a woman with polio spent four days alone in bed at home and without electricity before being taken to a rehabilitation center, where she died a few days later.

Few published articles exist on the experience of individuals with sensory impairments during and following disaster, in part because of the relatively low incidence of sensory impairments in the general population. Barbara White (2006) provides an autobiographical narrative of her experiences in a shelter in Houston, where she was assisting individuals with hearing impairments, then as a Deaf evacuee in anticipation of Hurricane Rita. White emphasizes the inequitable access to communication experienced by the Deaf community, for example, hurricanes announcements were only available on selected television stations, translators were not available in shelters and information from FEMA and Red Cross was not communicated in sign language or in another accessible manner. In a study of adults with visual impairments, Good, Phibbs, and Williamson (2016) interviewed people who experienced the Christchurch, New Zealand earthquakes and aftershocks during 2010 and 2011. Participants described concerns regarding communication, safety, and orienting themselves in the post-earthquake environment. Participants who used guide dogs reported needing to retrain them when landmarks changed and having to calm them during aftershocks. Familiar landmarks often disappeared

post-disaster, causing a decrease in independence in self-navigation and mobility. Participants also reported hesitance in using evacuation shelters as they perceived a lack of accommodations and potential loss of independence within the shelters.

Stough, Sharp, Decker, & Wilker (2010) interviewed disaster case workers following Hurricane Katrina. Case workers reported individuals with disabilities required more intensive case management and often had multiple support needs during the recovery period. In a second study, they interviewed individuals with disabilities who had been displaced by Hurricane Katrina to determine the barriers which hindered their recovery process (Stough, Sharp, Resch, Decker, & Wilker, 2015). The results suggest that disability status enhanced the challenges that participants experienced in negotiating disaster recovery services related to housing, transportation, employment, and health.

Despite the informed focus that disability researchers have brought to the disaster field, the underpinning of much of this research has been one of advocacy rather than theory building. Disability scholars seem to agree that there are consistent inequities in disaster service delivery but their work, to date, has been on calling attention to the needs of people with disabilities. While research for change is a laudable objective, to move the disaster field forward disability scholarship needs to develop theoretically and to expand methodologically.

Research on Youth with Disabilities. Empirical research on children and adolescents with preexisting disabilities in disaster is particularly sparse (Peek & Stough, 2010; Ronoh, Gaillard, & Marlowe, 2015). Most of this work comes from the disciplines of psychiatry and psychology and focuses on the mental health of children with disability in disaster. Two of these studies were conducted on children with autism spectrum disorders and found some evidence of PTSD resulting from trauma (Mehtar & Mukaddes, 2011; Valenti, Ciprietti, Egidio, Gabrielli,

Masedu, Tomassini, & Sorge, 2012). Both of these studies also reported behavioral problems and regression in social interaction skills following earthquakes or other trauma. A clinical psychiatric study of children with a wide range of disabilities, including cognitive, motor, hearing, visual, and seizure disabilities, reported significantly elevated levels of aggression and enuresis one year following the 1988 Bangladesh flood disaster, but these behaviors did not significantly differ from those displayed by children without disabilities. (Durkin, Khan, Davidson, Zaman, & Stein, 1993). Two studies from the field of disability studies (Christ & Christ, 2006; Ducey & Stough, 2011) have examined the role of schools in supporting children with disabilities post-disaster. Both found the role of the special educator to be particularly salient as these teachers had in-depth knowledge of students' pre-disaster behavioral and academic functioning and provided important emotional and social supports post-disaster. These few studies suggest that youth with disabilities may exhibit behavioral problems post-disaster but that their reactions to disaster may be challenging to interpret (Stough, Ducey, & Kang, 2017). The role of teachers may be particularly of assistance to students with disabilities post-disaster. The chapter in this volume on children in disaster (Peek, Abramson, Cox, Fothergill, & Tobin-Gurley, 2017) further explores the roles of teachers and schooling.

Disaster as a Cause of Disability. While the review of literature above has focused on the experiences of individuals with preexisting disabilities, disasters can and do cause new disabilities (Alexander, 2015; Kelman & Stough, 2015b). Major injuries which may occur that can lead to lifelong disabilities include amputations, traumatic brain injuries, spinal cord injuries, and long bone fractures (Reinhardt, Li, Gosney, Rathore, Haig, Marx, & DeLisa, 2011). Earthquakes and tornados, when accompanied by building collapse often lead to crush injuries followed by amputation or traumatic brain injuries. Hurricanes, tsunamis, and floods are

associated with lacerations, soft tissue injuries, and bone fractures. Extended droughts can lead to famine and malnutrition, which has particularly devastating effects on the cognitive development of children. Landmines not only cause death and head injuries, but are a major cause of amputations both during wartime and when not removed following conflicts (Alexander, 2015). Collectively, disaster can be a major cause of disability, for example, Duyan & Karatas, (2005) reported that nearly 10% of people living in the earthquake-prone area of Sakarya, Turkey obtained their disability as a result of an earthquake.

Research indicates that physical injury incurred during a disaster also increases risk for subsequent psychological distress (Briere & Elliott, 2000; North, Nixon, Shariat, Mallonee, McMillen, Spitznagel, & Smith, 1999). Other types of support may be required: A study of individuals who had health or disability-related limitations following Hurricane Ike in Texas in 2008 needed immediate assistance with mental health and with social service needs, such as for housing, employment, or financial support (Norris, Sherrieb, & Galea, 2010). Kett and van Ommeren (2009) point out that individuals with mental illness warrant high priority during humanitarian action as they are at risk of abuse or early death during crises. While direct exposure to disasters can lead to increased incidence of PTSD it should be noted new cases of other types of mental illness rarely occur as a consequence of disaster. For instance, an epidemiological study by of the suicide rates in the years immediately prior to and following the 1994 Northridge earthquake did not find an increase in suicide rates (Shoaf, Sauter, Bourque, Giangreco, & Weiss, 2004).

Limitations of Research on Disabilities in Disaster

Collectively, research across academic disciplines reveals consistent limitations. First, disability is frequently treated as a homogeneous demographic group: Few studies have

examined the experiences of people who share the same functional and/or access needs. Second, while studies have found differences in mortality rates, preparedness, evacuation behaviors, and services post-disaster in particular disasters, for robustness these findings would need to be observed in other disaster settings. Third, most research to date has been focused on data and reports gathered at a single point in time, rather than following the long term experiences of people with disabilities across time. As research suggests that recovery from disaster is more complex and requires additional support (Stough, Sharp, Decker, & Wilker, 2010; Stough, Sharp, Resch, Decker, & Wilker, 2015), investigations of recovery are particularly of interest. Fourth, limited work has been done on how people with disabilities enact disaster risk, despite evidence they can create disaster risk reduction strategies which are not only personal and local, but structural and systemic (Stough & Kelman, 2015). Finally, as discussed at the beginning of this chapter, multiple definitions and conceptions of disability are used across disciplines and across researchers, making recommendations for people with specific functional needs problematic.

As documented in this review, research on people with disabilities has emerged from different disciplines which have different epistemological assumptions about disability and the origins of disaster. Researchers within these disciplines infrequently cross the boundaries of their own discourse communities and vary in their level of knowledge about disability as a social and cultural construct. As such, there is not yet a coherent theory underpinning most disaster and disability research. While there are advantages to the multidisciplinary examination of a phenomena, such as disaster and disability, the fragmented nature of research has yet to coalesce into an ongoing interdisciplinary academic discussion. Investigative challenges certainly exist in conducting disability-related research, however given the disproportionate impact of hazards, increased attention from scholars towards this population is merited. Davis and Phillips in their

report for the National Council on Disability (2009) provide additional recommendations for research across preparedness, response, recovery, and mitigation, as well as for research which specifically informs practice and policy.

Social Vulnerability and Disability

A theoretical approach used by disaster researchers for other marginalized populations has been social vulnerability theory which, to date, provides perhaps the most promising explanatory theory for the disproportionate effect of disasters on people with disabilities (Kelman & Stough, 2015b). Social analyses demonstrate that vulnerabilities to disasters emerge from a combination of factors, some due to individual choices but most due to wider social forces at work which create and perpetuate the vulnerability which particular individuals, groups, and communities experience (Hewitt, 1983; Lewis, 1999; Wisner, Blaikie, Cannon, & Davis, 2004). Research from scholars using the social vulnerability perspective (e.g. Morrow, 1999; Phillips, 2015; Wisner, Blaikie, Cannon, & Davis, 2004) have pointed out that disasters disproportionately affect some individuals who are poor, elderly, very young, migrants, minority-language speakers, and single parents. Disability status appears to stretch across these other social vulnerable categories, leading to a “layering” of vulnerability factors (Hemingway & Priestly, 2006; Peek & Stough, 2010). This view aligns with the social model of disability, which addresses the barriers which give rise to disability status (Oliver, 1986). The intersection of social vulnerability theory and the social model of disability emphasizes both that disaster vulnerability is socially constructed and that disability arises from barriers and inequities constructed by society. As a result, individuals with disabilities subsequently share a larger burden of this vulnerability not only in disasters but in other social milieus. Altering these conditions, which include poverty, unemployment, lower levels of education and medical care,

and substandard housing will require broad systemic change (Kelman & Stough, 2015a; Phillips and Stough, 2016).

Future Directions

Research from disability studies separately notes that perceived disability status is often associated with stigma, creating a separate and unique barrier across societies and across cultures, which we argue augments disaster vulnerability. From interviews (Barile, Fichten, Ferraro, & Judd, 2006; Good, Phibbs, & Williamson, 2016; Kailes, 2015; White, Fox, Rooney, & Cahill, 2007) and narratives (Ducy, Stough, & Clark; 2012; Kelman & Stough, 2015a; White, B., 2006; White, G., 2015), people with disabilities have identified stigma, discrimination, systemic barriers, and ignorance as leading to their exclusion from disaster risk reduction. Recent international human rights policy has made promising strides to recognize the marginalized status and needs of people with disabilities, but changes in practice continue to lag behind (Alexander, 2015; United Nations, 2006; World Health Organization & World Bank, 2011).

An important element in reforming practice is changing perceptions that people with disabilities are passive actors in disaster risk reduction. Scholars have documented the importance of individuals with disabilities as participants in their own preparedness, disaster risk reduction, disaster response, and disaster recovery (Alexander, Galliard, & Wisner, 2012; Ducy, Stough, & Clark, 2012; Kelman & Stough, 2015a; Rooney & White; 2007). Views of people with disabilities as helpless are the result of societies and environments that are not inclusive and which place ownership of disability on the individual rather than removing systemic physical, communicative, and attitudinal barriers (Hemmingway and Priestly, 2006). Disability researchers and practitioners assert that people and communities need to take control of their own disaster-related activities, integrating them into development and livelihoods even if external catalysts

and resources are needed for doing so (Lewis, 1999; Twigg 1999-2000; Wisner, 2002). At the forefront of the movement advocating for preparedness are researchers who themselves have disabilities (see Kailes, 2015; White, 2015). Further research is needed as part of a wider disability studies agenda on integrating people with disabilities into typical, everyday activities- of which disaster risk reduction is one. Many practitioners around the world (Disability Inclusive Disaster Risk Reduction Network, 2017; Sagramola, Alexander, & Kelman, 2014; Texas Disability Taskforce on Emergency Management, 2017) are successfully implementing training and action for emergency services working with people with disabilities. However, the effectiveness of these initiatives and how to introduce and translate for use in other countries, from Afghanistan to Zimbabwe, is yet not fully known.

A key part of disability and disaster research is exploring how people with disabilities can implement disaster risk reduction for specific hazards. Climate change impacts on hazards is a realm with few investigations on people with disabilities despite evidence they may be disproportionately at risk (Boon, Brown, Tsey, Speare, Pagliano, Usher, and Clark, 2011; Johnson, 2015). For instance, how can wheelchair users best drop, cover, and hold in an earthquake or find safe places in tornadoes when in a public space (e.g. a mall or gym) or protect their wheelchairs so they are mobile immediately afterwards? How does the wildfire evacuation policy “Prepare, stay and defend or leave early” (Bushfire Cooperative Research Centre, 2017) apply to people with different disabilities? What types of cognitive support do people with intellectual disabilities need both during and following disaster? (Takahashi, Watanabe, Oshima, Shimada, & Ozawa, 1997). Tailoring disaster risk reduction advice for specific hazards and specific disabilities is a significant area of further research to break assumptions of homogeneity about people with disabilities and how they experience disaster.

Research on disability and disaster should be used to inform policy. Two key international policy documents are the Sendai Framework for Disaster Risk Reduction (UNISDR, 2015)—frequently mentioning disability including the important statement that people with disabilities should be involved in disaster risk reduction activities (Stough & Kang, 2015)—and the Convention on the Rights of Persons with Disabilities (United Nations, 2006). The World Report on Disability (World Health Organization and World Bank, 2011) provides implementation guidelines for CRPD, but country-specific practices and policies vary (Stough, 2015). The CRPD has influenced disability-related disaster guidelines through *The Sphere Project* (Kett & van Ommeren, 2009; Sphere, 2011) in which people with disabilities are a “cross-cutting theme.” This guidance highlights the importance of family and community supports and of avoiding separation from these supports. *The Sphere Handbook* (Sphere, 2011) notes that, following disaster, communities should be rebuilt for everyone, including people with disabilities. Further implementation advice comes from the Council of Europe’s Toolkit (Sagramola, Alexander, & Kelman, 2014) detailing legal and ethical considerations underlying disaster risk reduction alongside seven steps toward successfully implementing “design for all,” including individuals with disabilities. Policy points in these documents are typically supported by research, even if the direct research-policy connection is not always strong.

Conclusion

Researchers concerned with individuals with disabilities in the context of disaster and disaster risk reduction have, to date, focused on the inequities and disparities experienced by this group. Attention by disaster scholars to these experiences has come mainly in the last two decades, distinctly later than similar research conducted on children, ethnic minorities, women, and the poor. This limited work, while fragmented by discipline and focus, has collectively

established that disasters affect people with disabilities and their families disproportionately and negatively. We contend that both disaster and disability are constructed phenomena that societies have created - and hence which societies can likewise un-create. When the vulnerability of one part of the population is addressed, the resilience of society as a whole is enhanced. Ensuring that people with disabilities can contribute to disaster risk reduction and disasters themselves, both through community design and the design of disaster-related services, will increase the rights and safety of all.

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