

Chapter Twenty-Five

Exploring and Exchanging (Dis)ability and (Dis)aster

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Exploring Narratives

Among other individual and collective characteristics, disaster vulnerability is gendered (e.g., Enarson and Chakrabarti, 2009), racialized (e.g., Bullard and Wright, 2009), and age-related (e.g., Bourque et al., 2006; Peek and Stough, 2010; Norris et al., 2002), with each characteristic's level of influence being contextual (see also "layered vulnerabilities" from Phillips and Morrow, 2007). Little research, however, documents the experiences of people with disabilities (Stough and Mayhorn, 2013). Additionally, the existing literature principally consists of statistical surveys (e.g., McGuire et al., 2007; Metz et al., 2002), responses collected on undifferentiated groups of people with disabilities (Stough et al., 2010), or is authored by people without disabilities. These chapters differ not only in being written by and with people with disabilities, but also in that these voices are unfiltered and individual, rather than combined in a manner that obscures the contextual nature of how disaster affects people with disabilities. As such, these narratives allow for deep examination of how each person's individual experience has been affected by, and has had an impact upon social and environmental factors. Collectively, these narratives combine to paint a picture of what it is like for people with disabilities and their families to encounter, consider, respond to, and prepare for disaster.

Perhaps, for some, the most surprising aspect emerging from these narratives is what does not exist: passivity, helplessness, and a lack of resilience. These authors report how they assessed difficulties, calculated risks implicitly or explicitly, took action, and moved forward, continually striving toward inclusion for themselves and others. We did not select these authors to represent these particular viewpoints; we simply asked them to contribute a chapter. As such, their writings

counter the stereotypical view of people with disabilities as passive and vulnerable in disaster situations. Deviating from traditional perspectives, these authors rarely assign blame to personal characteristics as the cause of vulnerability in disaster. Rather, they focus on the environmental and social factors that hinder them from preparing, participating, evacuating, and responding as independently as they desire.

We were initially taken aback about how relatively little these authors wrote about disabilities in the first drafts of their chapters. In fact, we usually had to request that authors include “something about how disability is a factor in your narrative” or “this book will focus on disability and disaster, could you write a bit about that intersection?” We even had authors decline to write as they were uncertain how to include disability in their disaster-related narrative. Finally, we came to see that disability formed only a small part of their self-identity—irrespective of the perspectives of others around them. Thus, these narratives are not about disability as a central organizing theme or focus of their life, but are about how people negotiated life along with disasters that were sometimes part of that life. Hardinger writes, “I can do anything just like anybody else. It may take me a minute to figure it out, but I will . . . I just adapt.” And, likewise, much of what these authors write about is adaptation to environments in which barriers sometimes exist for them.

Exchanging Narratives

Together, these chapters can be seen as a Critical Disability perspective of disaster, in that they challenge typical, preconceived assumptions about people with disabilities (Ducy et al., 2012). While we sought to produce a book on disability and disaster, our authors simply wrote about their lives and how disasters affected—or might affect—them. They present themselves as active, powerful, self-directed agents, disputing the prevailing view of individuals with disabilities as “acted upon” during disaster. The existing literature, while pointing out the disproportionate effect disaster has on people with disabilities, has overwhelmingly portrayed people with disabilities as passive victims of disaster who must depend on others. The authors here dispute this view in their self-portrayals as actors and responders both in disaster and in life in general.

Just as examining disaster through a Critical Disability lens lends a new perspective, so too does examining disability through a Critical

Disaster lens. A commonly used definition of disaster is “A serious disruption of the functioning of a community or a society involving widespread human, material, economic or environmental losses and impacts, which exceeds the ability of the affected community or society to cope using its own resources” (UNISDR, 2009). Likewise, disability can be reconceptualized as a state in which personal capacity is easily exceeded within a societal system that is unprepared to support individuals who differ. Similarly, as is found in disasters, when the social structure and physical infrastructure are not prepared, people are placed at risk.

While social vulnerability theory highlights social and structural factors, this approach does not typically address the individual agency, resources, and direction that individuals in disaster bring with them. Thus, the individual experience is sometimes overshadowed in the social view of vulnerability. However, chapters written here by people with disabilities and their family members reveal the control and proactivity that supposedly vulnerable individuals have, and their surprisingly active roles in dealing with disaster.

Exploring Commonalities in the Narratives

These individual narratives are linked by common themes, which is rather astonishing given that they originate from authors from six different continents with a wide range of ages and first languages, portraying varied experiences with disaster, and representing different manifestations of disability. Together, these narratives express how disability is perceived and reacted to by others, usually negatively, patronizingly, and inaccurately. They challenge viewpoints of others that label them as sick, strange, or fragile. The authors take issue with insinuations that they are inferior, unable, or to be pitied and object to exclusionary attitudes that frequently lead to their treatment as invisible, actively avoided, or deliberately forgotten.

Contrasting with how others view them is how the authors of these narratives describe themselves, especially in terms of preparing for and responding to disaster. While we asked these authors to write about the intersection of disability and disaster, they do not write about how their individual characteristics limit them, rather about how the environment around them limits them. They address how barriers, both environmental and social, prevent them from being fully included in

their communities and from participating in disaster risk reduction. They speak about inclusion as a human right and as an equitable expectation. Their narratives display strength, self-determination, and identity, with much being about self-definition, even self-redefinition. They are actors and anticipators, powerful, agential, and often proactive during disasters.

Self-determination and independence were common themes across the narrative chapters. Inge Komardjaja of Indonesia writes that barriers are “not so much about the inconvenience of being helped, but a matter of being at liberty to make a choice and decide by myself what I choose.” From the other side of the globe, June Kailes of California states “independent living does not mean doing everything without assistance, rather it is being in control of how and what things are done, whether or not one employs the services and assistance of others.” Anonymous describes the “potential personal disaster” of falling or being walked into something when walking with her guide dog and concludes, “Is it risky? Yes. Is it scary? Always. I hug the dog whenever we get back to our gate safe and sound. Is it worth it? Heck, yes. Being blind doesn’t mean you can’t have a life.”

Self-determination and independence here are not simply abstract goals; they have specific and tangible ramifications. If individuals are able to maintain their independence and choose their own outcomes, then their need for external assistance is minimized, thus placing fewer demands on the emergency system before, during, or after disaster. In fact, Kailes identifies independence as being at the heart of planning for the needs of people with disabilities in arguing, “Independence is the steady state that an individual seeks to maintain in an emergency.”

Authors here also write about intolerance and exclusion from everyday life, and the ramifications of social distancing. Christoplos writes, “Sometimes I feel like my wheelchair is actually invisible, as otherwise they might be expected to recognize that they are excluding people like me and feel embarrassed” while Mrs. KB, heartbroken, states, “My husband would like me to die a natural death so that he gets all the sympathy, but it is most unfortunate that I am still alive but of no use. Now, the cattle are better treated at home than how I live—in a dirty bed.” Komardjaja explains, “Many people treat me as if I am inferior. They may feel threatened because they do not want to appear less than me.” Rincon Ardila feared her disability put her at risk of being jailed by military forces as “if they saw my injury, they would think that I was

a guerrilla [belonging to the enemy forces].” Mataiti gives us a revised perspective of this social distancing: “Some points I want to raise . . . are ignorance, looking down on people with disabilities, calling names, and much more. So I will categorize that this behavior is a disaster for people with disabilities within their families and their communities.” Many of these narratives expose the everyday disasters that these societal attitudes create for people with disabilities.

The needs of people with disabilities should be built into society as the usual state of affairs, not as an extra, add-on, or specialty. That means designing societal infrastructure so that negotiating daily life, in addition to extreme situations, is successful for everyone. Instead, barriers are often institutionalized. These authors give myriad examples of structural exclusion, which makes navigating their daily lives difficult. “On a small scale,” Anonymous states “given our condition, we are all one (mis-)step from (personal) disaster.” Similarly, Simon notes that “emergency is a part of my daily life, each time I am handled in a stair, in any crowd, and potentially all nights I spend in a hotel.”

These barriers are particularly troubling to these authors as they decrease independence and force them to rely on others for assistance. Komardjaja says, “Disaster is an inconvenient condition where I need people’s help.” Kailes suggests that, as additional effort must be made to navigate these barriers, “some people that live with disabilities are doing all they can to just manage. Some live their lives in a constant, heightened state of emergency preparedness and response because of daily barriers encountered in the environment . . . It’s all about plotting and planning and for some people it’s all they can fit in—they can’t add more than that. Some of these folks they have reached their preparedness threshold, their maximum ability to prepare.” For many of these writers, personal disasters are daily phenomena they must anticipate and deal with, leaving them less energy for dealing with less frequent hazards.

Some chapters point out that disasters can also lead to disability, from Ferreira losing her leg in a nightclub fire to Mr. HP and Mrs. KB experiencing the Gujarat earthquake in India. Violent conflict can result in disability, such as in the case of Rincon Ardila’s leg amputation due to a landmine and Thanh who acquired spinal cord injuries while evacuating within wartime Vietnam. Komardjaja points out that disability can occur at any time for any of us, and disaster and war certainly give rise to conditions that cause disability.

Given practices of exclusion and the diversity of people, emergency services are not always prepared to handle all forms of disabilities (WHO, 2013). White reports that emergency managers do not usually receive training on the needs of people with disabilities, nor do they know how many people with disabilities live in their jurisdiction—or any other details about types of disabilities. Some espouse the view that they can only deal with a limited number of people, and are thus aware that they focus on the majority, meaning others are left behind. For example, people requiring regular medication or medical check-ups are at risk during evacuation and sheltering. Johnson worries, “I wonder how long I and others can go without a treatment or infusion of some kind.”

So that they may be successfully included in disaster-related activities on their own, independent terms, people with disabilities may require accommodations or modifications. Being evacuated is disorientating when familiar surroundings, travel routes, and routines are changed. Disasters can also destroy physical and social infrastructure designed to reduce barriers. Such changes in the environment can reduce the level of independence of people with disabilities during disaster. Josefsen argues, “Only if we all receive the same warnings and opportunities to respond can we protect our own safety, health, and life—just like everyone else.” Thanh expresses his dislike for reliance on others during evacuation, “Not because I was afraid or that the system did not work. But I did not like the fuss around me and my things to take me and my dog down a winding staircase, hindering many of my colleagues from escaping the building.” Roth points out, “In the face of a disaster, we are all vulnerable, we are all at risk. The needs of our communities will be best served by planning and practices that are inclusive. We will all be stronger as we succeed.”

While disaster-related systems certainly should include everyone, it is also the case that everyone, including people with disabilities, must take some responsibility for their own disaster risk reduction and disaster response. In writing about the actions that they would take and have taken during disaster, these authors present solutions both small and large, as well as structural and personal. Barquero Varela recounts reassuring the household maid during an earthquake, taking protective action, and then waiting for the tremors to pass as “out on the street, the danger was greater as power lines could fall.” White describes building a tornado shelter into the design of his home, while Cox

explains the emergency procedures that he reviews and rehearses with his family on a regular basis. Simon's hotel roommate, who is blind, navigates a dark hotel hallway during a fire, leading them both to the exit staircase. Stenersen's sister's preparedness strategies include being with others during storms and checking her weather forecast application regularly. The diverse strategies that these individuals put into place illustrate their awareness of hazards that might affect them and their families.

At the same time, Kailes somewhat cynically cautions, "a lot of the emergency world says, 'well if you would just prepare, it wouldn't be a problem.' Translated, this means 'if you people with disabilities would just plan better and prepare then we emergency professionals would not have to do as much to include people with disabilities and others with access and functional needs in our planning.'" While preparing is part of what we individually should undertake, the responsibility of society remains that people with disabilities must be included in disaster preparedness, recovery, and mitigation.

Bhadra writes that part of the disaster rehabilitation process involves re-establishing "a sense of place" that "consists of attachment, familiarity, and identity coming together," painting a stark portrait of Mrs. KB's death when she no longer is given an identity within her family. We see the importance of family, friends, and helpful others in these narratives—but as interdependent, not as one-way relationships. Indeed, Rincon Ardila is not only rescued, but also sheltered by others following the landmine explosion in which she lost her leg. Thanh says, "Life has been very kind to me in many ways and I meet mostly kind and helpful people everywhere. Without this kindness, I would not survive. I am in debt to all of them." Ferreira affirms, "Through my faith and prayers from family and friends (which are many), and from people whom I do not even know but trust and believe in me, I have stood up from the big fall I had. So many people have been by my side, offering a hand and the support I need to stand up and remain up." Simon reflects that evacuating along with his blind roommate demonstrated for him "the interdependence of human beings." These authors are connected to others who support them and who are also supported by them.

The Everyday of Exploring and Exchanging

We have been encouraged by, and have learned from, attitudes that extend beyond the authors providing narratives, to those who have supported us in putting this book together. One reviewer wrote of our book proposal, “Including this range of speakers telling their own stories not only exposes the reader to the tremendous diversity of challenges members of this group face, but it humanizes a population who are far too often seen by emergency responders as a burden or a problem to be solved—or more frequently, ignored or seen as someone else’s problem to solve.” In contrast, others clutch old paradigms. A publisher refused to publish this manuscript as it was judged to consist of unscholarly narratives and inquired, “Who would want to read all those stories?” While we disagree, we leave it to others to debate the scholarly value of people’s experiences in their own words. We see these words as having value in their own right, and have learned much through the generosity of people from around the world, many of whom we have met only via email.

Our professional interactions, friendships, and e-relationships with our authors reinforced the falseness of the assumption that disability inherently and always inhibits. In fact, some of these narratives are mundane, simply reporting on daily lives. For example, although Thanh encounters mobility difficulties, he lives life happily and so far without recently encountering disasters (as most of us do). However, his daughter, who does not have a disability, has been near the center of three major disaster-related incidents. From wanting to wear highheeled shoes in Brazil to being a sister in Norway, these narratives center on the thoughts and actions of people living everyday lives.

Disaster is not commonplace, but the vulnerability that leads to disaster is, sadly part of the chronic condition that marginalized groups face all the time. Disability is commonplace, but society makes living with differences require special care and treatment, unusual, an oddity. As Christoplos implies, it is nothing special that he uses a wheelchair—except for the barriers “which I face every time I have to drag myself up steps into an embassy, or reschedule an interview to a nearby café since I cannot even get into the office of the defenders of human rights that I am supposed to meet.” Removing the “dis” from disaster and from disability means reducing vulnerabilities and accepting that abilities are expressed differently across the broad human spectrum.

Beyond (Dis)aster and (Dis)ability

In these narratives, at the intersection of disability and disaster, are unexpected explanations of how disasters and disability coincide. At this intersection, we find broader issues that underlie how society deals with people. First, is the theme of intolerance and discrimination wielded against a particular segment of the population. Kihungi writes, “Such people suffer a double tragedy—the disaster and then not being treated the same as others. To me, the lack of an all-inclusive policy is a disaster by itself since we could ensure equality and adequacy for persons with disabilities if we tried.” Kihungi’s point could refer to a number of groups who disproportionately affected in disaster, including people who are poor, prisoners, people who are elderly, homeless, and children.

Also at this intersection, we find a desire for equity and equal treatment. Roth states, “No one wants to be special during an emergency. They want to receive the same services as everyone else, and they should.” These narratives advocate, not for specialness, but for equality. If we are offering these services to some, then why not to all?

Several writers point out human rights implications. Dr. Bhadra states “It is evident that the violation of human rights is common and not enough effort is made in this area.” and Christoplos points out the disconnect between “grand declarations about human rights and resilience” and the reality of how people with disabilities are excluded from these very initiatives. But, at the intersection of disability and disaster, the issue of human rights becomes muddled when we consider the extreme poverty that exists in some locations. Thanh writes, “Even if they could now use crutches, braces, and a wheelchair, they will always need to renew or repair these things. They will also need other day-to-day medical equipment and medicines. How do we get these in a country that was extremely poor and with an ongoing disaster in the form of a war? How will a wheelchair user survive in the countryside without such facilities as running water, toilets, and electricity?” We question, how can disability rights be upheld when basic human rights are ignored?

Underpinning the above points is the intersection of insiders (with disabilities) and outsiders (without disabilities) in constructing these themes. A primary reason for eliciting narratives from people with disabilities was to understand disaster and disaster risk reduction from that perspective. Christoplos points out that people with disabilities can

more readily identify the lack of commitment of governments and organizations in following existing laws as they directly experience the results of such hypocrisies. In partnering with members of disenfranchised groups, such incongruities may thus be identified and lead to improved disaster preparedness.

A joint and inclusive effort is necessary to resolve the social and environmental barriers that confront people in disaster. White is optimistic about the potential for these changes in the United States: “We have observed [increased] efforts to better meet the needs of people with disabilities before, during, and after disasters. Progress is even being made at the county level as emergency managers are becoming more aware of the importance of including people with disabilities into their planning and emergency response following emergencies and disasters.” It is up to society to provide equity, access, and resources, so that everyone can be involved as much as feasible in taking disaster responsibility for themselves. Measures should go much further than they do today and be much more about working with, rather than for, people affected by disaster.

No reason exists to wait. As Rincon Ardila lyrically writes, “One who wants to do something finds the way. One who does not want to do a thing, finds an excuse.” More succinctly, Komardjaja (and we along with her) question “If not now, then when?”

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