

Disability and Disaster Readiness Initiative – Policy Overview & Recommendations

Marsha Saxton & Alex Ghenis
World Institute on Disability
June 2019

Contents

<i>Abstract</i>	3
The Balance of Government, NGOs, and Individual Action	5
Climate Change as a Disaster Readiness Issue.....	8
Disability’s History.....	9
Contrasting Models of Disability.....	10
<i>Disasters as a Threat to the Social Model of Disability</i>	12
What Is “Dependence”? What is “Vulnerability”?.....	13
Intersectionality and Vulnerability.....	14
Existing Conditions, Barriers and Programs.....	15
Relevant Laws and Regulations.....	16
Emergency Registries: Good in Concept, Questionable in Practice.....	18
What Are First Responders Taught?	21
Barriers for Individuals with Paralysis in Disaster Readiness Planning.....	23
Independence	24
Social Policies and Practices That Tend to Discriminate	26
Emergency Safety Practices	26
Poor or Prohibitive Access in Shelters	27
Recommendations	28
Overarching Principles	28
Recommendations for Disaster Management Agencies	29
Recommendations for Disability and Related Services Agencies	31
Planning for Individuals and Families	33
Conclusions	35
Authors.....	35
References	35

Abstract

People with paralysis conditions are affected uniquely in environmental disasters of all kinds. The social context of disability, which includes attitudes about disability, societal infrastructure and public policy related to disability is considered an essential frame for exploring and understanding how to assist people with paralysis to survive and thrive during a disaster and afterwards, in the recovery phase. This paper discusses the range of crucial factors that affect this population and offers recommendations for action and further research and policy development.

Disaster Preparedness, Disability and Paralysis

Communities all around the world must focus on preparing for disasters, be they caused by natural or human-influenced factors. Recent Atlantic hurricanes, extreme cold on the East Coast and disasters in western states (forest fires, flooding, and mudslides)—with dramatic impacts on people with disabilities (PWDs)—have raised awareness among disability leaders and disaster managers alike. The impact upon people with paralysis specifically has been striking, as individuals lacked access to appropriate emergency transportation and shelter, faced interruptions in vital medical care, and became separated from the caregivers and family that support their independence. PWDs also have lower incomes, on average, compared to people without disabilities, which raises additional barriers for those with paralysis to manage and recover from disasters.

Occurrences of disasters impact specific communities and populations differently depending upon needs, geography, economic factors, etc. The National Preparedness Goal, issued by the Federal Emergency Management Agency (FEMA),¹ calls upon all to take on a sense of responsibility for our country's, our local communities', our own personal and our family's safety from all manner of threats, natural or man-made.

The disability community is affected uniquely by any environmental impact. The clear evidence from past and current natural disasters (as well as all other kinds of environmentally compromised circumstances, such as in refugee camps and forced migration) show that people with paralysis have a low survival rate, and in many situations are even neglected or left to die (Weibgen, 2015). Comprising a significant 10%–15%² of the global population, people with disabilities are uniquely affected by environmental devastation.³ One in fifty people in the U.S. live with paralysis defined “as a central nervous system disorder resulting in difficulty or inability to move the upper or lower extremities,” representing about 1.7% of the population or over five million people in total.⁴ Disasters can result in food and water insecurity, storm-related injuries and mortality, damage to transportation infrastructure,

¹ https://www.fema.gov/media-library-data/1443799615171-2aae90be55041740f97e8532fc680d40/National_Preparedness_Goal_2nd_Edition.pdf

² World Health Organization (2017). Many estimates are higher, for example, up to 19.8% of the U.S. (Brault, 2012).

³ These population numbers will undoubtedly increase worldwide with such forces such as disaster change impact and terrorism.

⁴ “Paralysis in the U.S. Reeve Foundation Policy Brief.” <https://www.christopherreeve.org/living-with-paralysis/stats-about-paralysis>, retrieved 1.20.19.

violent conflict (IPCC), forced migration, and other challenges. The disability population overlaps with a wide array of mobility, sensory (visual, hearing), developmental, intellectual, and emotional impairments, as well as chronic health conditions and other forms of paralysis. Individuals will experience social or medical factors differently, depending on their race, gender, culture, language, nationality, and other identities. Dismissing these factors exposes, and causes, the neglect of the population of people with paralysis worldwide. Disasters impact this population at a disproportionately greater level compared to those without paralysis.

The specific impacts on people with paralysis include, but are not limited to:

- *Individuals may be unable to evacuate the building they are in (their own home or otherwise).* Elevators may become inoperable, requiring individuals to be carried down the stairs or left behind; falling objects may block pathways for wheelchairs; individuals may be unable to transfer out of bed at all or in time to reach safety; and other factors may impede evacuation.
- *Individuals may not have accessible transportation for evacuations.* This is especially true for persons reliant on public transportation, paratransit and/or taxis—which may stop operating before, during, and after disasters—as well as those who own a vehicle but cannot drive on their own, if they cannot locate a driver in time to evacuate. Transportation barriers are present both in rapid evacuations (e.g., fast-moving forest fires) as well as in situations with advance notice (e.g., hurricanes). The former poses immediate dangers of personal safety, while the latter means that people with paralysis risk being left behind to “ride out the storm” (with or without companions) even when they would prefer to travel away from a disaster’s anticipated path.
- *Individuals may leave behind vital medical and personal care supplies when evacuating.* The medical and personal care supplies needed by people with paralysis go far beyond the contents of a regular “go bag” emergency kit (which may contain flashlights, first-aid supplies, non-perishable food, and a week’s worth of medication, among other items). People with paralysis may use a multitude of other resources on a daily basis, such as vinyl gloves, commode chairs, catheters, bowel care supplies, orthopedic boots or braces, transfer lifts, etc. Losing access to these resources can seriously jeopardize health and, in some cases, survival. The process of recovering supplies, especially durable medical equipment, can also be prohibitively costly or lead to financial struggles beyond those usually associated with recovering from disasters.
- *Individuals may become disconnected from caregivers and other support networks.* People with paralysis work with an array of caregivers in order to maintain health and independence, especially outside of institutions. Some caregivers are paid privately, others receive funds from government or agencies, and others are “informal” or “unpaid” caregivers; their tasks range from preparing meals to dressing and transfers to personal care and medical supports. Should people with paralysis lose caregiving supports, their health may suffer and/or they may end up in nursing homes or other institutions when they otherwise could live independently.
- *Disaster shelters or other evacuation areas may not be fully accessible.* Accessibility includes many factors, such as wide-enough doors and pathways, barrier-free entrances, accessible restrooms and bathing facilities (e.g., roll-in showers), and the availability of beds/mattresses that prevent skin breakdown and are an appropriate height for transfers to/from wheelchairs.

Although laws such as the ADA dictate accessibility requirements, the frantic nature of emergency response and shelter management often creates related shortcomings. Shelters also may not provide the “reasonable accommodations” necessary for health and comfort, as staff may not be able to give direct care due to experience, available time and/or legal constraints.⁵

- *People with paralysis may face many barriers related to post-disaster recovery.* Individuals may have difficulty repairing homes, replacing damaged property, etc., both because PWDs have disproportionately low average income and savings relative to people without disabilities and because certain disability-specific items (e.g., wheelchair-accessible vans) are costly. People with paralysis who are forced to move may have difficulty finding accessible housing (or affording housing modifications), securing government benefits (including for caregivers), and finding employment. There are many other difficulties related to post-disaster recovery, which vary depending on personal circumstance and the characteristics of a given disaster. Individuals often encounter additional barriers when moving to a new state, given that many programs and regulations (e.g., Medicaid services and SSI rates) vary from state to state and may include wait times before applicants receive services.
- A recently released federal report highlights the trend of involuntary institutionalization of disabled individuals during and after disasters with significant long-range impact on the quality of life for these individuals. The study notes conflicting guidance from the range of federal agencies that address disability issues.⁶

The Balance of Government, NGOs, and Individual Action

As noted above, people with paralysis face a multitude of social, economic, and logistical barriers to maintaining health and safety during disasters. These barriers are caused through incomplete disaster readiness, response and recovery by three main actors: government stakeholders, non-governmental organizations, and individuals. In an ideal world, all parties will have comprehensive plans, appropriate funding and supplies, and mutual communication and support as needed. The primary responsibilities of these parties include, but are not limited to:

- *Government actors* include policy-makers, planning agencies, and direct responders. These stakeholders must analyze disaster-related dangers (e.g., hurricanes and heat waves in the southeast, tornadoes and flooding in the Midwest, or forest fires and earthquakes on the West Coast), priority population groups, and existing plans, vulnerabilities, assets, and opportunities. Relevant reports can then be used to reduce vulnerability (e.g., by improving infrastructure’s resilience), plan direct disaster responses (e.g., by designating shelters, staff responsibilities, and priority response areas), and communicate with NGOs and the public on their best actions (e.g.,

⁵ Some agencies have established "Functional Assessment Service Teams" (FAST) that deploy to disaster shelters and coordinate shelter accessibility, delivery of necessary supplies (e.g., elevated beds), and connecting shelter residents with temporary caregivers. However, FAST has limited capabilities and shelter residents still face barriers.

⁶ Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters.

<https://www.prnewswire.com/news-releases/federal-report-highlights-trend-of-involuntary-institutionalization-during-and-after-disasters-300856426.html>

Ready.gov campaigns for personal preparedness). Staff and agencies have responsibilities during disaster response and recovery, such as evacuating residents, managing shelters, distributing supplies, and rebuilding infrastructure. Government has the responsibility to regulate NGOs to ensure appropriate pre- and post-disaster services—and that services provide equal support to all groups, including people with paralysis—especially when government “outsources” services such as operating and managing shelters. Government can provide NGOs and individuals with funding for disaster readiness, response and recovery (e.g., grants/loans for housing retrofits, distributing “go bags,” training NGO staff, or helping individuals rebuild or relocate post-disaster). A related responsibility is developing high-quality government services for individuals with paralysis, such as healthcare, personal care, and income supports; location-based services should be resilient and responsive across states and counties, in case individuals evacuate from disasters and must re-apply in a new location.

- *Non-governmental organizations (NGOs)* range from community-level nonprofits to national or international organizations; some for-profit businesses also provide valuable disaster-related products and services. Community-level organizations are often well positioned to assist with individual disaster preparedness, such as distributing “go bags,” helping individuals secure loose furniture, developing personal preparedness plans, and running public awareness campaigns through emails, flyers, events, etc. Larger nonprofits may undertake similar efforts (on their own or in coordination with local NGOs), while some—most notably the Red Cross, which is arguably the best-known disaster-related NGO—manage disaster shelters and support communities through post-disaster recovery. A few NGOs advocate for PWDs (or specific disability groups) in disaster readiness and response: Advocacy will range from partnering with government and NGOs on projects to filing lawsuits under the ADA addressing inclusive disaster response to raising public awareness through reports, articles, documentaries, social media, etc.⁷ Finally, some for-profit companies provide valuable products and services; these may include housing retrofits, disaster kits and related supplies (e.g., “MRE” (Meals Ready to Eat) nonperishable meals or emergency generators). Disability-specific supplies may include slings for transfers and carrying individuals down stairwells, portable “evacuation chairs,” smaller-than-usual medical devices, etc. For-profit companies sometimes provide products and services at-cost, for free, or somewhere in between for especially under-resourced groups and/or during crises (rather than charging full-price with a profit margin).
- *Individuals (those with paralysis and their friends, families, caregivers, etc.)* should develop personal disaster plans and provide mutual support in planning, response and recovery. Individuals with paralysis should develop personal disaster plans—both for sheltering in-place and evacuating as needed—and err on the side of caution when doing so. Comprehensive

⁷ Some examples of disability-specific advocacy groups include the Partnership for Inclusive Disaster Strategies (“The Partnership”), which hosts regular disaster management conference calls and has released critical reports on disaster response efforts by government and nonprofits; the Pacific ADA Center, which hosts training webinars on disability-inclusive disaster management; the Disability Rights Education and Defense Fund (DREDF), which has filed several civil rights lawsuits around government and NGO shortfalls; and Rooted in Rights, which produces short documentaries on many topics including disaster response (including “The Right to be Rescued” about Hurricane Katrina and its aftermath — available at <https://www.youtube.com/rootedinrights>).

personal disaster plans should include assembling an emergency kit (“go bag”) of easy-to-grab supplies that will last at least one week and preferably longer (this paper addresses “go bags” elsewhere); coordinating transportation; having a document explaining one’s disability-related needs (to give to emergency responders, healthcare workers or shelter staff); identifying the nearest accessible evacuation shelter and/or a friend’s house away from a vulnerable area; securing a network of nearby friends, neighbors, family, or caregivers to check on one’s home; and purchasing communication devices (e.g., battery-powered two-way radios) to connect with those friends, neighbors, family, or caregivers. The network of friends, neighbors, family, and caregivers can assist with disaster preparedness (especially tasks the individual with paralysis cannot accomplish, such as moving and securing heavy furniture); help to identify fully accessible shelters and/or offer their home in an emergency; ensure that they check on the individual with paralysis and provide immediate support (e.g., transfers, grabbing a go-bag, and driving); and advocate during the recovery process⁸. Individuals of all kinds may also advocate for effective disaster readiness by government and/or NGOs, e.g., by attending local disaster planning meetings or coordinating with other advocates. They may finally take initiative to assist others with paralysis through teamwork, friendly advice, etc.

The current situation, as demonstrated through research and experience (both distant and recent), is that all categories of stakeholders do not plan to the best extent possible and are often under-resourced for adequate preparation and recovery. In general, there is insufficient communication and coordination between government, nonprofits, business, and the public (with and without paralysis), resulting in poor preparation and heightened vulnerability when disasters hit. Recovery does not fully address the needs of people with paralysis, leading to potential health complications, extended homelessness, and excessive economic struggles. Turnover of regulations, initiatives, and stakeholders at government and NGO levels can only exacerbate these problems—as can the patchwork nature of regulations, laws, services, etc., across the U.S.—and future turnover is surely inevitable. Given the above, planning must factor in realistic assessments of the situation at hand and strike a balance when providing recommendations to, and supporting the actions of, stakeholders at all levels.

Fortunately, there is momentum to improve planning, response and recovery. Awareness about the experience of PWDs and those with paralysis during disasters has risen in recent years. Photojournalism showing the impact of Hurricane Katrina in the southeast U.S. in 2005 documented this impact with tragic photos of dead people in their wheelchairs as crowds of other displaced people streamed by; evacuees with disabilities in the Superdome likewise provided dramatic imagery. Stories of people

⁸ Unfortunately, people with paralysis (among others with disabilities) are frequently discounted or ignored throughout society, and especially in times of crisis. Stories abound of PWDs being “pushed aside” in disaster shelters and not receiving vital access, personal care, and care for medical needs. Ingrained social ableism also often leads shelter managers, service providers, etc. to insufficiently respect the needs and requests of PWDs. Individuals with paralysis may benefit from a companion who advocates for their well-being, as “two advocates are better than one” and a person without paralysis may just be listened to more than somebody with a notable disability. Of course, it is important to not let a companion-advocate reduce the personal agency of the person with paralysis.

trapped in flooded nursing homes revealed a lack of planning for people whom disaster preparedness leaders had failed to consider. A 2015 documentary by Rooted in Rights, “The Right to Be Rescued,” highlights the experiences of people with disabilities affected by Hurricane Katrina (Rooted in Rights, 2015); other recent journalism, such as coverage of California wildfires showing that a disproportionate number of victims were seniors and/or had disabilities,⁹ is raising yet more awareness. Videos, journalism, and related disability activism intend to educate the public and policy-makers about the need for planning for this population. This is fostering a push for widespread personal preparedness, plus changes from government agencies and disaster responders to better address the disaster needs of people with paralysis and other disabilities—which includes supporting individuals in their personal preparedness.

Climate Change as a Disaster Readiness Issue

Climate change must be addressed in the context of disaster readiness. As average temperatures continue to increase, the impact of climate change is being felt all over the globe.¹⁰ This impact includes severe weather, flooding, sea level rise, heat waves, droughts, desertification, impacts on agriculture, increases in disease and insect infestation, melting of glaciers and increasing extinction of species. While each of these impacts is damaging in its own right, their interaction with each other exacerbates immediate and long-term disruptions (e.g., higher ocean levels make storm surges of stronger storms more damaging). Even with strong efforts to reduce carbon emissions, the Earth will continue to warm to some extent in the coming decades, which will bring along more frequent and dramatic disasters. It is thus essential to increase resilience to climate change, including through improved disaster readiness and response at all levels (national, regional, local, individual, etc.).

The trajectory of climate change is another crucial factor as we revise and improve disaster readiness, response and recovery plans. Assorted locations already have experience with certain types of natural disasters and their related intensities (e.g., wildfires in California, hurricanes in the Gulf Coast, tornadoes, in the Midwest, etc.), so we can learn from those disasters to prepare for similar, likely events. However, the increasing frequency and severity of these disasters is a strong reason to practice the “precautionary principle” and invest in robust, well-supported disaster readiness and response efforts. Climate change will also lead to a broader range of potential disasters in any one area,¹¹ so plans should be dynamic and able to respond to diverse climate impacts.

⁹ “Poor, elderly and too frail to escape: Paradise fire killed the most vulnerable residents” Los Angeles Times. February 10, 2019 (<https://www.latimes.com/local/lanow/la-me-ln-camp-fire-seniors-mobile-home-deaths-20190209-story.html>)

¹⁰ The International Panel on Climate Change (IPCC) is a well-recognized research body. Its website has multiple in-depth reports and more concise resources on climate change and its assorted effects, including increasing natural disasters. (<https://www.ipcc.ch>).

¹¹ For example, California is likely to experience more intense wildfires in summer and fall, heightened peak severity of winter “atmospheric river” storms, and flooding concerns on the coasts and inland Delta from sea-level rise. Historically, wildfires have been the state’s main concern, with destructive winter storms occurring less frequently. Multiple complex, intersecting climate change impacts will require dynamic disaster readiness and response plans.

Climate-related impacts frequently result in loss of human life and/or livelihood (e.g., extreme weather leads to injuries and deaths, droughts lead to higher food prices and poor nutrition, and most impacts damage real estate, infrastructure, and personal property); these losses will only increase in the coming years as average temperatures rise. Marginalized peoples, notably people with disabilities (including specific disabilities such as types of paralysis), are most severely impacted. The reasons are many, including but not limited to: living in more climate-vulnerable areas (e.g., deserts, low-lying islands, or inter-city “heat islands”), having fewer assets to prepare for and manage climate impacts, having pre-existing health vulnerabilities (e.g., some people with spinal cord injury [SCI] have difficulty regulating body temperature, which is dangerous during heat waves), and simply being de-prioritized or “discounted” during time of socio-economic crisis. Using the “equity framework” by reducing socio-economic inequalities and providing appropriate support to “even the playing field” of climate resilience is a key response to these disproportionate climate impacts. Considering this, climate change provides another strong reason to specifically support people with paralysis when preparing for, responding to, and recovering from disasters.

Disability’s History

All these issues justify an alert to the paralysis community to develop resources and seek guidance for advance disaster readiness planning. First, however, this article will briefly explore a broader frame on the societal circumstances of people with paralysis, to give context and detail to the challenges of disaster readiness.

For those newer to disability issues, exploring the reasons—the social, economic and other factors—behind the marginalization and exclusion of this constituency is essential to addressing solutions. Indeed, these factors have resulted in poor policy and ongoing mistreatment. We must consider how society has viewed disability and disabled people historically and explore newer models of disability and challenges to marginalization. Discrimination against people with paralysis has a deep history. Those with “disabled bodies” have been made to feel unwelcome, incapable, burdensome, unattractive, despised, and unworthy even of life itself. This phenomenon has been documented since earliest times in writings and artwork. For example, the Greeks and Romans celebrated able-bodied-ness; from infancy through old age, disabled human beings were ostracized, marginalized, vilified, or killed (Winzer, 1997).

Garland-Thomson (1997) asserts that functionality, attractiveness, and *normality* itself are defined in our culture on the basis of boundaries set by “aberrant” bodies. In the late nineteenth century, these attitudes were introduced into public policy through the Eugenics Movement. Understanding the values and practices of Eugenics ideology and its historical influence on public policy has become an essential focus of Disability Studies (Longmore & Umansky, 2001). Eugenics drew upon the notion of the *able body* as a cultural signifier of not only beauty and function but also of traits of “human goodness,” such as acceptability, normality, and worthiness (Baynton, 2001). Eugenics, initiated primarily in Britain and the U.S., then spread throughout the western world, sought to control human breeding in order to eliminate the “unfit,” who were thought to drain resources from white, non-disabled, middle- and upper-class people, whose procreation was favored (Baynton, 2001). The Eugenics Movement, which

began in the 1880s, targeted people with paralysis, as well as immigrants, people of color, and other “undesirables,” through public campaigns that included both institutionalization and systematic sexual sterilization, affecting over 70,000 people in the U.S. not finally ending until the 1970s (Kevles, 1985). This history still haunts us in the form of discriminatory attitudes, as well as persistent exclusionary policies and programs. People with paralysis must bear not only the experience of being turned away when public facilities and services are not accessible (Longmore & Umansky, 2001), but also of having to make do with fewer community resources (Gill, 1996). The deeper message that comes across—sometimes clearly and sometimes subtly—is that the needs of disabled people for access to community services available to others can be evaded or ignored. Titchkosky (2011) characterizes this act of drawing boundaries as making disability “essentially excludable.”

In recent years, the Disability Community has successfully fought this oppression and emerged as a powerful, worldwide movement of civil and human rights (Longmore & Umansky, 2001) that, over the past five to six decades, pushed for the enactment of public education and laws, such as the *Americans with Disabilities Act* (ADA) and the *United Nations Convention of the Rights of People with Disabilities* (UNCRPD). The creation of disability *inclusion*, via specific measures of *access and accommodations*, removes barriers to participation in the mainstream community (Iezzoni, O’Day, 2006). Examples of disability inclusion include ramps, assistive devices, technologies, and services that enable people with paralysis to participate fully in their community and the economy. Changes to government services, such as work incentives allowing people on Supplemental Security Income (SSI), Medicaid, and other programs to earn income and save money, are also becoming more available (although progress is gradual and often needs to be defended from policy challenges). This movement is led by people with paralysis and other disabilities, and supported by their allies: families, service providers, advocates, and policy-makers. The movement’s slogan, “Nothing About Us Without Us,” strongly asserts people with disabilities’ insistence in full participation in all activities that affect them.

Contrasting Models of Disability

Two models contrast in describing the “problem of disability.” The Medical Model, also referred to as the Deficit Model (Pfeiffer, 2002), operates on the assumption that an individual’s bodily limitations, their “impairments,” are the locus and cause of their difficulties in achieving social, financial, or personal success. A resulting assumption is that medical intervention and subsequent cure is the amelioration of such difficulties.

In contrast, the Social Model (Oliver, 2013) looks to *society*, to socially imposed barriers as the *crucial source of difficulties*. These include:

- *Attitudinal barriers*, including our society’s myths and stereotypes about people with paralysis, which are deeply rooted in ancient history (Winzer, 1997) and reinforced by current cultural practices, overlook or evade thinking about and planning for the inclusion of disabled people. Society’s attitudes about disability underlie additional, more tangible barriers.

- *Architectural or structural barriers*, which prevent or limit physical access to or mobility within and around buildings and other spaces (Longmore & Umansky, 2001), notably stairs and lack of ramps and/or elevators.
- *Programmatic barriers*, which prevent or reduce full participation in services and programs (U.S. Department of Health and Human Services, 2010).

These social barriers occur when systems, facilities, and services are created and operated without the needs of people with paralysis in mind (Longmore & Umansky, 2001). Various solutions emerge from this Social Model, such as community education, advocacy, legislative change, and the restructuring of the built environment through Universal Design.¹² For example, accessible transportation includes lifts on buses and level entrances to trains in stations with elevators and ramps, while reduced-fare programs address disproportionately low income and asset levels faced by people with disabilities. These physical and programmatic features facilitate not only physical mobility and participation in the community; they also transcend the low socio-economic status associated with disability (Longmore & Umansky, 2001), supporting disabled people to attend school, gain employment and income, and socialize and participate in the community just like everyone else.

The development of the Social Model of disability from the 1970s onward was a breakthrough in challenging exclusion of disabled people from opportunities to contribute and participate in the community. The Social Model challenges the most fundamental aspect of disability stereotyping that had justified exclusion for millennia: that the problems of disabled people are a result of the limitations of their bodies. Instead of focusing on the body, the Social Model places the responsibility for the existence and the removal of barriers on society and proceeds to require that social institutions make appropriate accommodations (e.g., ramps, technologies, assistance services) that enable access and participation.

This shift in perspective is profound: “Disability” does not *reside* in the person; it exists and operates in the rigid system of environmental and attitudinal barriers that have excluded people with disabilities for centuries. “Impairment,” the complementary concept and term, is employed in Disability Studies to describe the physically based condition as opposed to societal factors that may impose limits (Linton, 1998); it recognizes that people with disabilities may indeed have “atypical” bodies and may have atypical needs of various kinds. For the vast majority of people with disabilities, these needs can be accommodated with a range of resources and devices. As a result, the impairments—the bodily limitations—become minimized as “the problem” in terms of inclusion. Individuals with disabilities may

¹² Universal Design creates a framework for design of things, places, information, communication, and public policy for use by persons in the widest range of circumstances. This enables people with paralysis, as well as the general public to operate in spaces without “special” or separate facilities or services (as described by the Institute for Human Centered Design).

proceed to function in the social roles as community participant, employee, student, or parent, for example, with provision of accommodations and community access.

Disasters as a Threat to the Social Model of Disability

The concept of the Social Model is not just a wonderfully empowering philosophy that has changed society and the lives of many (though not yet most¹³) people with disabilities. The Social Model must be enacted in the real-world community through the creation of an extensive infrastructure of material resources and services. This infrastructure can offer a wide range of resources, such as roads, sidewalks, curb cuts and accessible transportation systems; provision of personal assistance services in the home and workplace; production and availability of assistive devices and technologies (e.g., wheelchairs, computers, and phones with screen readers and working cell phone towers). Each of these is generally designed to be resilient, but resilience varies, and nothing is invincible. When this infrastructure is threatened, through environmental disasters or degradation of any kind, the societal inclusion of people with disabilities is uniquely threatened.

The community of people with disabilities and our allies cannot take this infrastructure—this network of resources and services so central to the Social Model—for granted. Disasters, through both their immediate impact and aftermath, potentially undermine the requirements of the Social Model to operate in the real world. We have seen that what is revealed in circumstances of environmental destruction (due to extreme weather, conflict, pollution, or otherwise) can be described as a reversion to the Medical Model of disability. Under the extreme duress of environmental devastation, fixed infrastructure may be damaged and the provision of resources is greatly disrupted. Survivors with paralysis in environmentally compromised situations often are treated as “patients,” with little autonomy and self-determination, and extremely limited access to many physical areas as well as the customary array of disability- and, indeed, survival-related resources that people with disabilities had become used to accessing through established sources. In short, physical and programmatic infrastructure are cornerstones of building equity under the Social Model, but when that infrastructure is compromised during environmental damage, people with disabilities fall back to the troubling Medical Model with all its negative consequences.

Real enactment of the tenets of the Social Model requires much more than an empowered mindset to counteract the discriminatory implications of the Medical Model. It is an illogical notion that this issue can be postponed until other pressing priorities are addressed; to the contrary, widespread adoption of the Social Model will only accelerate progress on the many priorities of people with paralysis and other disabilities. Of course, this is a daunting challenge, given the magnitude of still-urgent challenges for the disability community, even for developed countries with disability laws implementing inclusion.

¹³ Implementation of the Social Model can only exist where countries’ laws and services offer and enable this. The United Nations Convention of the Human Rights of People with Paralysis (UNCRPD) offers hope but enacting this promise will be slow across the globe, where extremely limited financial resources among other barriers, can slow progress.

Challenging the Medical Model, especially in the context of disasters and their impacts, will require significant effort but have incalculable benefits.

What Is “Dependence”? What is “Vulnerability”?

Conventional thinking presumes that some categories of people are “dependent” and others “independent,” with the dependent category including babies, children, people with paralysis, people with other disabilities, and seniors. Disability awareness trainers enjoy challenging this notion, pointing out, for example, that people who can walk and who didn’t bring their own chairs to the workshop are dependent upon the facilities for this helpful resource and that sighted people require electric lighting. Everyone, everywhere, is highly “dependent” upon these common resources which have evolved over centuries. The clothes we wear, the beds we sleep in, the roofs over our heads, the food we eat, our vehicles, services, are all brought to us through an interwoven network of mutual dependencies. Yet often, people simply take such resources for granted because their everyday availability seems so normal. In many countries, people tend to forget or ignore that about 15% of the world’s population doesn’t have or can’t assume to have available electricity. (Indeed, at the time of this writing, Puerto Rico hasn’t fully restored electricity and other utilities two years after the Category-5 Hurricane Maria made landfall.)

In this sense, seating and electric lighting are almost universally available in homes and public venues, but it requires “*special*” resources to provide walkers, wheelchairs, and respirators. Moreover, these are then produced, purchased, and distributed through special methods related to disability. Labeling the aforementioned resources “special” creates a veneer of dependency unlike that of the “normal population,” even though these support resources are simply different rather than “extra” per se.¹⁴ These “special needs” may sometimes be regarded as a burden on the general (able-bodied) population, most frequently through taxation for government services or healthcare, and personal support for activities of daily living (ADLs), leading in the extreme to vilifying the disabled people with these needs (Longmore & Umansky, 2001). A stark reality check is that with the impact of disasters, the population of disabled people will likely increase, normalizing “special needs.”

Let us consider “vulnerability.” The population(s) of people with paralysis do indeed have untypical needs in relation to extreme environmental conditions, especially whenever *the social and architectural infrastructure* becomes compromised. These needs are specific to certain kinds of impairments and must be considered specifically, if they are to be addressed meaningfully, depending on disaster consequences and their related effects on humanity in general. For example, extreme weather creates infrastructure damage, storm-related injuries, separation from caregivers and more; drought can lead to water shortages, famine, and even violent conflict (Gleick, 2014). Dozens of other disaster-related consequences lead to direct and overlapping effects on existing systems and populations. Each of these

¹⁴ This phenomenon appears in many other categories: conventional health insurance (requiring employment, premiums and co-pays) versus means-tested healthcare (requiring disability determination, limited income and government funding), personal vehicles (requiring gas stations, well-maintained roads and auto mechanics) versus public transit (requiring public funding and facility for subways), etc.

many consequences must be addressed regarding *specific* disaster change impact on *specific* individuals and categories of people.

Of course, *everyone is vulnerable* in any kind of disaster or environmental degradation. The notions of “vulnerability” and “increased vulnerability” for certain persons were created in disaster research discourse (Fjord, 2015, p. 17) in order to encompass the circumstances of unique and distinct populations and their divergent relationship to disasters, in comparison to the *idealized survivor*. Such ideal survivors, if uninjured, would presumably be relatively able-bodied, facile, financially and logistically mobile, privileged persons, able to swim or jump into boats, or run from falling debris, fires or other dangers, endure extremes in temperature, as well as to gain access to, and survive on, minimal resources, and potentially offer assistance to others. This characterization is present in many instructional videos on managing disasters, as well as in popular media such as movies. People with paralysis, however, almost certainly do not fit into the portrayal of the idealized survivor—but they *certainly do* have the right to survive any disaster they may encounter.

Intersectionality and Vulnerability

The category “people with special needs” is appearing on lists of “vulnerable populations” in disaster preparedness media in ways that can homogenize, mask, or trivialize the potential impact of disasters. Well-intentioned services and policy-makers grasp that this diverse population needs something “special,” but it seems that simple mention of these lists can somehow allay concerns without actually addressing them. Disaster preparedness documents have begun employing additional terms, such as *people with access and functional needs*, and *individuals requiring additional assistance* (IRAAs). These terms must be carefully defined in ways that result in appropriate action.

Realistic consideration must include attention to specific, accurate approaches to assistance in extreme circumstances. *Impairment* is the term employed by Disability Studies to describe the physically based components of a condition, as opposed to societal factors that may impose limits (Linton, 1999). The impairments of people in the paralysis community include mobility, manifested through necessity of using mobility devices, such as wheelchairs, scooters, canes, walkers, crutches, and braces. Paralysis can affect upper and lower extremities. These impairments will range in type and severity, but may also include people with multiple impairments (so somebody with paralysis may also have a sensory disability, chronic health condition, psychological disability, or other impairment). Generalities about the broader population of “people with special needs” in this context ultimately do little to support people with paralysis in the context of disasters or any other aspect of life. Because of the diverse and intersectional characteristics of this population, intervention in disasters must provide resources, supports, accessibility, and accommodations that meet the needs of specific disaster victims and related situations. These may include, for example, approaches to feasible evacuation transportation for persons using plug-in respirators, who are unable to safely utilize standard evacuation methods, or effective approaches for alerting people with hearing impairments to evacuation measures. Preparation, evacuation, sheltering, and recovery must also consider and address other health impacts, including pressure sores, bladder and bowel complications and the potential for anaphylaxis.

All social intersectional factors are essential to consider, and attention must be directed to higher rates of disability in low-income populations; rural populations; incarcerated people with paralysis; and intersections with racism, ageism, sexism, and so forth. Each of these sub-populations is complexly impacted with respect to health and provision of assistance for survival before, during, and after disasters.

Disasters will uniquely affect individuals, groups and peoples, including women, children, older persons, indigenous peoples, minorities, migrants, rural people, persons with paralysis, and the poor. Such language attempts to capture the range of groups likely most impacted. But *lists* cannot encompass the overlapping and intersecting features of any of these listed groups. Each group potentially includes many of the others, adding to their “vulnerability.”

Addressing the complex nature of intersectionality and vulnerability before, during and after disasters requires focused responses by all stakeholders: governments, NGOs, individuals, communities, and more. It requires broad collaboration as well as appropriate delineation of rights and responsibilities among respective stakeholders. It’s no easy task—but if done right, it can save countless lives.

Existing Conditions, Barriers and Programs

Effective disaster preparation involves a vast network of stakeholders, infrastructure, regulations, resources, programs, communication strategies, and more. For our purposes, these must be coordinated to address the needs of people with paralysis before, during, and after disasters.

Many pieces of guidance have been assembled by legislatures, regulatory bodies, public service agencies, and non-governmental organizations at many levels. Some of these provide valuable, constructive guidance on how to address disability in disasters; some are constrained by the limited extent of existing legislation; and some present highly critical analyses of poor responses to disasters.¹⁵ Advocacy organizations have also pursued litigation resulting in court decisions that require government entities to better include PWDs in disaster readiness efforts.

The following section outlines relevant laws and regulations, concerns about disaster registries, and existing training for first responders on meeting the needs of disaster victims with paralysis and other disabilities. For individuals who would like to learn more, one especially useful website for documents around laws and regulations, guidance for individuals and disaster planners, worksheets and checklists, and other useful resources is the California Office of Emergency Services’ Access and Functional Needs (AFN) Library. The AFN Library has well over 200 links on ADA compliance, AFN populations, planning

¹⁵ "Getting it Wrong: An Indictment with a Blueprint for Getting it Right" published by the Partnership for Inclusive Disaster Strategies, is one such critical report. The website for the report describes it as follows: “This After Action Report is an unvarnished account of the devastation from poor planning and failed execution throughout the 2017-2018 disasters as reported by people with disabilities and allies with first-hand knowledge. The report also documents promising and good practices that can be refined, customized and replicated. Most importantly, it contains recommendations for “getting it right” before the next disasters strike.”

<http://www.disasterstrategies.org/index.php/news/partnership-releases-2017-2018-after-action-report>

guidance, communications, evacuation and transportation, sheltering, and smart phone apps; it can be found at <https://www.caloes.ca.gov/AccessFunctionalNeedsSite/Pages/AFN%20Library.aspx>

Relevant Laws and Regulations

Laws and regulations provide frameworks, guidelines, resources, responsibilities, and enforcement mechanisms to address the needs of PWDs and people with paralysis during disasters. U.S. Federal laws address the responsibilities of U.S. governmental agencies to serve people with paralysis in disasters, while the federal government provides guidance to state and local actors and distributes funding under assorted disaster- and disability-related programs. Most states also address these issues at the state level. State and federal laws and regulations sometimes set requirements for local programs and policies to meet disability-related benchmarks, and may or may not reimburse localities for any associated costs (thus delineating “funded mandates” and “unfunded mandates”).

Disability inclusion is referenced as a priority in federal laws and publications. The National Preparedness Goal, which outlines frameworks for addressing disaster preparedness throughout the U.S., specifically references “individuals with disabilities and others with access and functional needs” as a constituency which must be included in disaster preparedness and response. Other federal regulations of particular importance are provisions in the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA). These collectively ensure that federal programs do not discriminate against individuals based on disability (thus requiring the federal government to provide accommodations for PWDs to receive equal access to disaster services) and set regulations for states and private entities to likewise ensure equal access to physical and programmatic areas.

The web of federal, state, and local laws and regulations address many areas of disaster readiness, response and recovery, ranging from public communications to evacuation to sheltering. Some laws and regulations focus on one or two specific areas, while some are much broader. Certain statutes, such as the ADA, influence a multitude of government regulations which affect disaster management directly or indirectly. Statutes are frequently referenced in lawsuits calling for improved disaster planning which addresses the needs of PWDs or specific disability groups; some suits filed after disasters reference statutes when seeking compensatory or punitive damages for PWDs who were harmed due to a lack of proper readiness, response and recovery planning and actions. Thus, the entire legal framework has an array of mechanisms for enforcement and accountability, as well as creating progress (e.g., lawsuits can set precedent for improvements beyond the suits’ target areas or constituencies).

There are literally thousands of laws and regulations at federal, state, and local levels that affect people with paralysis during disasters. Though they are too many to list here, some notable areas of focus and types of laws and regulations include:

- *Broad-based federal statutes guaranteeing access to physical locations, buildings, programs and services.* The Rehabilitation Act, ADA, and IDEA are cornerstone statutes that have been used in various ways to support equal access, including in the context of disasters. Specific regulations

and guidance are provided by the federal government under these laws, and many are available online (e.g., through www.ADA.gov).¹⁶ Some guidance specifically references emergencies.

- *Federal disaster-related regulations, statutes and initiatives which specifically reference disability inclusion and accommodation.* As of March 2019, there are no federal statutes specifically addressing PWDs' needs during disasters; however, a proposed bill, the Real Emergency Access for Aging and Disability Inclusion in Disasters Act (R.E.A.A.D.I. Act), would address universal access, necessary services, engaging disability-related organizations, and more during disasters and emergencies.¹⁷ Certain federal agencies, such as FEMA, have released documents on best practices, recommended resources, and state/local requirements in meeting PWDs' needs during disasters. The Federal Emergency Management Agency (FEMA) has started to recognize the disability constituency's needs, creating a series of educational webinars for agency leaders and policy-makers, through FEMA's Office of Disability Integration and Coordination.¹⁸
- *State-level laws, regulations and initiatives that complement and expand the scope of federal statutes.* State-level efforts may establish specific departments or agencies to address access and functional needs; set requirements for localities to incorporate disability considerations into emergency plans and procedures; allow for communication and coordination (e.g., through emergency registries); or provide grant funding for statewide and/or local disaster readiness initiatives. Some laws, regulations, and initiatives are not explicitly disaster-focused but are still relevant: for example, transportation initiatives may address both disability access and emergency evacuation and can be leveraged to support people with paralysis in emergencies. Certain states provide trainings for government staff (at state and local levels), NGO staff, and interested community members who may deploy to disaster shelters and assist shelter residents with disabilities in attaining reasonable accommodations and through the recovery process.¹⁹
- *Local laws, policies, procedures, and best practices related to disability and/or emergency management.* Localities (cities, counties, etc.) generally have emergency management analyses and planning documents, and many states require localities to produce updated documents at regular intervals. Government entities may operate emergency registries, train NGOs and the

¹⁶ The nine most relevant federal statutes and Executive Orders are explained in detail in "Getting it Wrong," (The Partnership, Pg. 34). http://disasterstrategies.org/application/files/3615/2718/6466/5-23-18_After_Action_Report_-_May_2018.compressed.pdf

¹⁷ The bill is based on the R.E.A.A.D.I. Act introduced by Sen. Bob Casey in Nov. 2018 (<https://www.congress.gov/bill/115th-congress/senate-bill/3679>), which will likely address use of disaster funds and projects of national significance; it also establishes Training and Disability and Aging Technical Assistance Disaster Centers, a National Commission on Disability Rights and Disasters, and an oversight committee in the Department of Justice to review ADA settlement agreements related to disaster response activities. The updated R.E.A.A.D.I. Act includes some revisions, as well as an adjusted name. A finalized version is set to be introduced in 2019.

¹⁸ See "We Prepare Everyday Preparedness Videos," "Working Together to Assist Disaster Survivors," and "Training" at the FEMA disability homepage. <https://www.fema.gov/disability>

¹⁹ Notably, the Functional Assessment Service Teams (FAST) program, which began in California under the California Department of Social Services, is operated in partnership with the Red Cross. FAST programs are present in a limited number of states and localities; partly due to this, some of California's FAST members have deployed to shelters in other states, including for several weeks to North Carolina after Hurricane Florence in 2018. More at <https://www.cdss.ca.gov/inforesources/Mass-Care-and-Shelter/FAST>

public on best practices during emergencies, and designate staff to support PWDs in emergency shelters. Local city councils and governmental entities may pass resolutions, laws, or regulations to address PWDs and people with paralysis during emergencies. Because of the importance of local planning and response during emergencies, interested stakeholders should contact local governments, legislative bodies (city councils, county boards supervisors, etc.) and disability and/or emergency management commissions to understand current regulatory environments; local systems also provide valuable venues through which to advocate for progress.

Due to the array of laws and regulations that may affect people with paralysis during disasters, this report does not go into detail for each one. Rather, we recommend that interested agencies, organizations, and individuals research more based on their individual, organizational, and policy-related goals. This is an important stage in preparation, as understanding disability law and the current degree or lack of enforcement for disaster planning and implementation is a fundamental source of concern in readiness for our population.

Emergency Registries: Good in Concept, Questionable in Practice

One proposed method to address the “unique vulnerability” mentioned above is the development of a series of government registries of PWDs (and “special needs persons”) who, ideally, will receive priority outreach and assistance from emergency responders in advance of, during and after disasters. This was highlighted following Hurricane Katrina, when a report (U.S. House of Representatives, 2006) chastised Louisiana for having failed to develop a “registry of special needs persons” that could alert responders to seek out these individuals, especially if communications systems fail. The Department of Justice’s Civil Rights Division now recommends that states and local government develop these confidential emergency registries (DOJ 2008), and FEMA suggests that individuals contact local governments and sign up for those registries²⁰. However, it is unclear if such registries are always useful; some argue that they may do more harm than good. For example, when Hurricane Harvey made landfall in August 2017, around 70,000 Texans were registered with the State of Texas Emergency Assistance Registry (STEAR), which “allows people with disabilities and special medical needs to sign up to receive priority status for evacuations, shelters, wellness tracks, power and water shutdowns and information on support services”²¹ (Texas Tribune 2018). Many PWDs who were registered with STEAR felt that they could expect assistance with evacuation ahead of the storm, even though the STEAR website states that “[r]egistering yourself in the STEAR registry DOES NOT guarantee that you will receive a specific service during an emergency”²² (Texas DPS, emphasis original) and the registry is simply given to local disaster managers who use it to prioritize disaster response services (rather than being used by state-level officials or emergency responders). Houston and other localities were so overwhelmed during Hurricane Harvey, though, that they did not use the registry to any significant extent, leaving some PWDs wondering where their expected assistance was. Many felt abandoned—and although the list of

²⁰ <https://www.ready.gov/individuals-access-functional-needs> FEMA, accessed Feb 2019

²¹ <https://www.texastribune.org/2018/08/22/did-state-registry-help-people-disabilities-during-harvey/>

²² <https://www.dps.texas.gov/dem/stear/public.htm>

registrants is confidential, it is almost certain that some of Harvey's nearly 100 fatalities were signed up for STEAR. A properly managed and utilized registry has potential, but in this instance, the false sense of security provided by STEAR may have done more harm than good.

Ultimately, no research exists, so far as we know, to demonstrate the overall effectiveness of emergency registries for PWDs. The lack of any widespread use of consistently managed registries poses yet more problems with regards to policy analysis. Berkeley, CA, reputed to be the birthplace of and one of the most highly developed disability rights communities in the world (as well as being located in an area famous for its earthquake potential), has no such registry. No equivalent registries exist for other "vulnerable populations," such as families with young children, pregnant women, or seniors (in Berkeley or elsewhere). The community of people with paralysis in the U.S. has not asked for such a registry, and some activists have explicitly opposed registries out of concern for individual privacy and instilling a false sense of security. As Harvey showed, the notion of such registries or even identifying signs in windows (e.g., "disabled person here") is often thought to give false hope of promise of rescue.²³ Sadly, some fear that such signs could invite abuse, such as theft. Furthermore, PWDs should not be expected to *be at home* any more than other people, or to simply to wait for evacuation personnel going through a registry list. They should be allowed to evacuate if possible, but this may raise yet another conundrum. In the case that broad-based communications (cell phone networks, Internet, etc.) are off-line and emergency responders cannot contact registry enrollees to see if they need help—or enrollees don't have a way to "mark themselves safe"—emergency responders may spend valuable time and energy moving from one enrollee's home to the next, with no way to know what percentage need to be rescued.

The Partnership for Inclusive Disaster Strategies notes that:

Most, if not all, access and functional needs registries have systemic problems. A registry plan may sound feasible, but it may not be able to achieve its well-intentioned objectives for two reasons. First, the response capacity is not considered or calculated based on the size of potential events, and second, knowing where people live doesn't tell responders where individuals are located at the time of the event. The former presumes that there are enough responders available for mid-to-large scale events when there are not. The latter wastes critical resources and time as the limited number of responders look for people in the wrong places, which helps neither the responder nor the evacuee. - Getting it Wrong, pg. 96

Although state-level lists such as STEAR exist, few cities in the U.S. could begin to avail funds to create and maintain current lists and fewer still could meet the full evacuation, communication, and other related needs of all registrants in the case of a disaster. Therefore, any government entity seeking to

²³ As explained by the instructor in the CERT class on February 15, 2017. The authors were able to locate "Resources for Individuals with Access and Functional Needs" on the FEMA website, and various state CERT programs, but this was not mentioned in the class, nor are there as-yet consistent resources across state emergency programs.

establish such a list must weigh the costs and benefits of the realistic extent of its application, any downsides related to a “false sense of security,” PWDs’ concerns about privacy and safety, etc.

Some states have alternative methods to alert emergency responders to the location of individuals who may need extra assistance. Notably, California’s Welfare and Institutions Code § 10850.9²⁴ states that “an authorized employee of a County social services department may disclose the name and residential address of elderly or disabled clients to police, fire, paramedical personnel, or other designated emergency services personnel, in the event of a public safety emergency that necessitates the possible evacuation of the area in which those elderly or disabled clients reside.”²⁵ This allows for privacy safeguards and largely avoids concerns about PWDs having the “false sense of security” presented by conventional registries.²⁶ And while this still raises potential problems of emergency responders deploying to empty homes—or overlooking PWDs who do not receive government services and are not on County-level lists—it is better than having no policy at all, given that seniors and PWDs are at greater risk to be stuck at home during a disaster than are able-bodied individuals.

Despite their downsides, disability-specific lists can be useful for the purpose of *communicating relevant warnings and advice* to residents with paralysis and other disabilities. Information can be sent via text message, email, and/or automated phone calls/voicemails. A non-exhaustive list of potential information includes: geographic-specific disaster warnings (e.g., flash flood warnings, winter storm warnings, high-fire-risk conditions, etc.), advance notice of planned or potential power outages (especially important for individuals who use powered medical equipment or live in buildings with elevators), reminders to prepare evacuation supplies, locations of fully accessible disaster shelters, immediate evacuation orders, disability-specific evacuation reminders (e.g., contacting support networks and caregivers), a list of emergency or informational phone numbers, and online links to more detailed information about disaster warnings, disaster planning, evacuation methods, etc. Email and text message “listservs” can be operated relatively affordably and do not require the identifying information (type of disability, home address, etc.) that would otherwise dissuade people with paralysis from enrolling in conventional “special needs” registries out of privacy concerns. NGOs serving the paralysis community may even set up their own email/text listservs and provide this needed information, if it appears that government officials are avoiding that task or doing so insufficiently.

The FEMA website does offer fact sheets including lists of supplies and suggestions for advance planning for individuals and families to gather in preparing for disasters. Much more thought and planning is

24

http://leginfo.legislature.ca.gov/faces/codes_displayText.xhtml?lawCode=WIC&division=9.&title=&part=2.&chapter=5.&article=

²⁵ As of March 2019, a social service department employee must first receive a request for information from an emergency manager, then contact the federal government for approval to release individuals' addresses and/or other information. Due to concerns about urgency during emergencies, a proposed bill (SB 46, 2019-2020) would allow social service staff to release home addresses without federal approval, to the extent allowed by federal law. http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201920200SB46

²⁶ Most social service clients are not aware of this policy and will thus not expect that emergency responders will rescue them because they are enrolled in social services. This has a very different effect than voluntary registries with their implication that people will be prioritized in disaster response.

needed to link disabled people with community networks that realistically address real disaster preparation.

What Are First Responders Taught?

A multitude of stakeholders may provide direct emergency assistance during any given disaster. Stakeholders come from the federal government, state government, local fire and police departments, other designated government departments, licensed and trained NGO staff, and even volunteers from the community at-large. Collectively, they assist with outreach and communication, proactive and/or reactive evacuation, search-and-rescue, first aid, acute medical support, logistical help (e.g., with finding temporary shelter), and more. Involved agencies and their staff receive a range of training and education on how to assist individuals during disasters, and some agencies provide educational materials and training programs to other stakeholders.

An unfortunate reality—but a reality nonetheless—is that resources are limited during and after disasters. First responders are frequently instructed to follow the classical triage process for rationing resources and prioritizing victims during emergencies, especially when emergencies are life-threatening. Triage directs responders to rescue and/or treat those who are most likely to live and require the fewest resources to support; they may then move to victims who require more resources to treat and support post-disaster; finally, responders can try to save victims whose survival is uncertain and who require significant time, energy, and resources to support—but only if there is enough time, energy, and resources left over to do so. This ultimately de-prioritizes victims who require more support, whether due to pre-existing disability or injury acquired during a disaster, and persons with severe injuries who appear unlikely to survive may be outright abandoned in the most extreme circumstances.

In preparation for this work, authors of this piece enlisted in the CERT (Community Emergency Response Team) training programs, created by FEMA, offered in local communities to better understand the community responder mindset in addressing rescue operations. These classes are taught by a faculty of local firefighters and are an important community resource, staffed and attended by committed community-minded participants. The classes are revealing with respect to ways that “special needs” are considered in emergencies and compromised environmental situations. In the CERT training guide, a 200-page ring-bound textbook, reference to the phrase “special needs” was employed once, i.e., in the section on escape planning (p. 1-20), along with the sentence, “Consider the needs of children and individuals with disabilities.” Then, under “Additional Training for CERTs” (p. 1-38), several bulleted points indicated possibilities for training on issues such as Advanced First Aid, Animals in Disasters, and Shelter Management. “Special Needs Concerns” was also on this list. However, people with paralysis, or people with health issues or chronic illness, or any other reference to planning or rescue or anything related to disability was not mentioned anywhere else in this training guide. When the trainers, the chief and captain of the fire department, were asked if this “Special Needs Concerns” segment of “Advanced Training” was available, the instructors said they were not aware of this, though they readily agreed that it was important (and that it might be taught elsewhere). The authors were later able to obtain access to these Advanced Training documents, though it is unclear how widely distributed they are. The CERT

training films did not mention or include issues pertinent to persons with paralysis, though people newly injured from the disaster was a major focus.

Rescue of people with paralysis is, in fact, often indirectly or even explicitly de-prioritized in disaster response. An example comes from the evacuation attempts in February 2017 of nearly 200,000²⁷ California residents living downstream from the Oroville Dam, after its spillway became damaged due to unexpected water volume from persistent storms, in concert with long-ignored warnings from environmental engineers about increased weakening of dam supports. A resident, interviewed on National Public Radio, stated with dismay that his family “had to leave a disabled family member behind,” after they had tried to summon an ambulance for their family member, to no avail, due to the overwhelming limitations of community services to evacuate 200,000 residents.

In the CERT class, the training section described as “size up” explores considerations in assessing rescue potential for victims trapped in collapsed buildings or stranded by floods, for example. The instructor verbally reinforced the standard directive given to responders. The order of priority of whom to protect and, if possible, to rescue, is thus:

- First is the responder him- or herself, who, of course must be prioritized to be effective;
- Second is the responder’s partner, who could get help if the first responder is injured; and
- Third are, as the CERT trainer stated, “people easiest to rescue.”

The logic here appears to be that this category of “easiest-to-rescue” people, within the *triage mentality*, are those most likely to survive and then able to further assist in the project of rescue or evacuation. The slogan of the CERT program is “The greatest good for the greatest number.” Given this philosophy and practice, we need to ask, where does this leave people with paralysis in the project to rescue survivors? Likely low on the priority list. This raises complex, as yet, unaddressed questions. For example, how do emergency responders make distinctions between persons newly injured from the disaster and those previously disabled, but not newly injured? What assumptions are made in the triage “size up” regarding people who are not in need of emergency services yet may be more difficult for untrained responders to remove from compromised environmental circumstances?

These unanswered questions indeed help clarify “vulnerable” and illuminate the connection between disability oppression, eugenic ideology, and the “essentially excludable” stereotype that results in the low survival rates of people with disabilities in refugee and natural disaster situations. Triage logic is hard to argue with, and the pivotal question of who should survive to enable the greatest number of survivors raises even more questions. Will triage decision-making, regress, for example, to stereotypes under extreme duress of stressful situations, whether natural or man-made disaster? This triage logic may be influenced or, at best, complicated by disability discriminatory notions that people with paralysis are less worthy, non-contributory, and a burdensome barrier to the survival of the larger number of more worthy, and potentially more resourceful *able-bodied persons*. Decisions about rescue, allocation of resources, and distribution of scarce supplies will likely get made based on regressive notions of who

²⁷ https://www.washingtonpost.com/news/morning-mix/wp/2017/02/13/not-a-drill-thousands-evacuated-in-calif-as-oroville-dam-threatens-to-flood/?utm_term=.8eb2962d406f

is *valued by, and valuable to*, society and not necessarily on who is human and deserves to live and survive as much as anyone else.

There are a few programs working to address disability in a constructive manner during disaster readiness and response that can become relevant to disaster change impact. For example, the United Nations International Strategy for Disaster Reduction (UNISDR) addresses disability concerns during emergency situations, such as effective communication and interaction; ensuring accessibility and medical support in disaster shelters; organizing personal assistant care; and other areas of focus. Another valuable program is the Functional Assessment Service Team (FAST) initiative, under which professionals and community members are trained on how to support PWDs in Red Cross disaster shelters, including recommended actions to improve physical accessibility, provide reasonable accommodations, ensure privacy as needed, etc. While FAST is not flawless, and not yet widely disseminated and implemented,²⁸ it is a valuable model program that can be used as a framework for inclusive disaster response.

Disruption of social cohesion, the network of stable relationships in one's family and community, is especially significant to people with paralysis, whose lives depend upon such connections. A huge challenge facing displaced persons with paralysis is receiving appropriate assistance with activities of daily living (ADLs), the daily self-care activities, such as feeding, bathing, and dressing (Skinner, P. 39). Assistance for these kinds of tasks is typically provided through a range of close relationships, which can be greatly disrupted in disaster circumstances. Some significant disruptions include:

- Unreliable or nonexistent availability of medicines and supplies, such as durable medical equipment, or clean or sterile products (catheters, ostomy products, for example) in shelters.
- Loss of or limited access to government benefits, such as supplemental income, healthcare, or funding for personal care support, because they are generally tied to location and residency.
- Lack of accessible transportation to enable travel to safer or improved environments.
- Coping with predictably strained government budgets, imposed austerity, and cuts to disability services (among many other cuts to services for everyone).

Barriers for Individuals with Paralysis in Disaster Readiness Planning

Disaster planning isn't typically on the forefront of most people's minds, whether they have a disability, a disabled family member or neither. Disaster is an abstraction, something that many may consider sadly happened or could happen to someone else, or is simply something to be read about in the news. Denial that "it could happen here" is pervasive and leads many to avoid planning altogether. But beyond

²⁸ FAST was spearheaded by the California Department of Social Services (DSS) after Hurricane Katrina and DSS, Red Cross and partner organizations host multiple trainings each year for interested community members. Other states have started FAST programs, but the number is limited and FAST is not yet a national initiative. Some California team-members have even deployed to other states in times of need (e.g., North Carolina after Hurricane Florence in 2018).

this widespread denial, individuals with paralysis have several unique additional barriers to sufficient planning, or any planning at all.

The following section explains several barriers to effective planning for people with paralysis. This paper will provide recommendations for addressing these and other barriers.

Independence

Independence in the lives of people with paralysis is typically a significant goal. Many adults with paralysis grew up in an era where people with disabilities were expected and forced to be dependent upon family and medical professionals for decision-making and care-giving. This expectation of dependence with all its related value sets was widespread across society, as is explored in the earlier section on the Medical Model. For those who acquired paralysis later in life, this set of values had been present earlier in life, with the assumption that “Those people need help for everything — they can’t take care of themselves.” When many individuals acquired their paralysis, these values, inherent in the Medical Model, became directed inward right at the onset of disability.

Enter the remarkable era of Independent Living in the 1970s in the United States, along with the passage of disability laws in the late 1970s, *with Section 504 of the Rehabilitation Act*, setting the stage for the *Americans with Disabilities Act* in 1990. People with all kinds of disabilities were freed from the constraints of Medical Model thinking and began to take over control of their own lives for self-care, transportation, education, employment, for full self-direction, and for full participation in the life of the community.

This has been a liberating era for our constituency. There may be a cost, however. Some people with paralysis have acquired a rigid notion of “independence,” possibly in defiance of the former values of past eras. Few people with paralysis have been made aware that disasters may impose an old set of standards when the community’s infrastructure—the transportation and communication systems, power sources, community networks, cohesion of community assistance and so forth—potentially go down. People with paralysis may be rendered dependent upon basic help for well-being and even survival in critical times of instability and stress. This is very hard to face for those of us with the relatively recent and hard-won achievement of independence. The level of resistance to considering how one could plan and survive in environmentally compromised circumstances is understandably high. Reaching out to neighbors, family members, even close friends—to ask for help in planning for this abstract arena of a potential disaster—may bring up feelings of weakness, inadequacy, or loss by abandoning the core identity of an independent person with paralysis. Even more, going through the logistics of coordinating personal disaster preparedness with others may just seem too hard to take on.

Social connections are an important component of disaster preparedness. Experts recommend having emergency contact lists that include at least five friends, family members, or other trusted individuals to assist with evacuation and recovery; social isolation limits numbers of potential emergency contacts and thus the robustness of personal emergency preparedness. Unfortunately, people with the full range of disabilities may become socially isolated due to many factors. People with paralysis may not have

adequate transportation in their locales to have access to their communities and therefore to social relationships that people without paralysis can enjoy. Architectural barriers in towns and cities pose limits to local resources, such as restaurants, theaters and regional parks. Inadequate access to Personal Assistance Services (PAS) is a pervasive problem for people with paralysis, due to economic factors as well as a national shortage of workers available for this important resource. Additionally, government-supported PAS often requires that assistance be provided only in the home or at medical appointments, which further limits social interaction and reinforces isolation. Employment is yet another factor that furthers social interaction. Most people in the general population meet peers for friendships, and even meet their spouses, in their workplaces. So for people with paralysis who aren't employed, or are unable to work for disability-related reasons including employment discrimination, this factor limits sociability. Indeed, a 2013 publication by the Christopher Reeve foundation noted that "15.5% of individuals living with paralysis are employed versus 63.1% who are not living with a disability. Additionally, 41.8% of those living with paralysis indicated they were unable to work."²⁹ Social isolation from these factors and more limits the number of coworkers, friends, partners, and other community members that individuals can include in their disaster readiness plans—which ultimately reduces the effectiveness of any response when disasters strike.

A significant proportion of people with paralysis are low-income, due largely to the impact of disability discrimination—the constraints of disability benefits, employment discrimination, and lack of access to asset building and the potential for having extra cash for expenses beyond the basics. Approximately 28% of households with people who experience paralysis have annual incomes less than \$15,000.³⁰ The "asset limits" tied to many vital government benefits (SSI, Medicaid, and related programs almost all require that recipients have under \$2,000 in assets, or \$3,000 if married) lock a significant portion of the paralysis community into poverty and prevent them from saving enough to prepare for emergencies. Newer programs are enabling many people who receive social/financial benefits to acquire assets, purchase vehicles and homes, seek higher education and gain employment without losing basic medical coverage—but these programs are recent and may have limited eligibility and/or scope, and many people with paralysis haven't even heard of them yet.³¹

The connection between poverty and disasters is clear. Planning for disaster readiness, for some people with paralysis among other communities with limited means, may be financially out of reach. Even packing a "go bag" takes some disposable income, potentially unworkable for those on very limited incomes. The prospect of purchasing a generator, batteries, slings, stockpiling extra food, medication,

²⁹ <https://www.christopherreeve.org/living-with-paralysis/stats-about-paralysis>

³⁰ Paralysis in the U.S. Reeve Foundation Policy Brief. <https://www.christopherreeve.org/living-with-paralysis/stats-about-paralysis>, retrieved 1.20.19.

³¹ For example, ABLE Accounts allow qualifying individuals to save \$100,000 without losing SSI and \$300,000 or more without losing other means-tested programs, such as Medicaid. However, an individual must have acquired a disability before age 26 to be eligible to open an account. Just looking at eligibility for a few groups with paralysis: all individuals with cerebral palsy would be eligible for ABLE, while under half of individuals with spinal cord injuries and small fractions of those with multiple sclerosis or post-stroke paralysis would be eligible. Even with existing programmatic efforts at improving financial conditions, the paralysis community faces many barriers.

water, and so forth, isn't possible. Personal vehicles, which are invaluable for evacuation, may be prohibitively expensive—especially considering heightened costs of wheelchair-accessible vehicles and their modifications.³² Even an able-bodied person who could help to organize emergency supplies, secure furniture, etc. will likely charge for their services. Finally, paralysis-related costs (medical expenses, home modifications, etc.) are significant and often take priority over matters deemed “trivial” or “secondary”—labels sometimes assigned to disaster readiness.

Social Policies and Practices That Tend to Discriminate

Some of the most significant needs for planning and stored provisions may not be available to people with paralysis. One example is with medications. We are told by readiness planners to store and keep a few days' supply of essential medications. This may not be possible depending upon the health conditions, the medications, one's prescribing physician, and insurance coverage policies. Some insurance providers will allow advance prescriptions for travel, but have no provision for disaster readiness. This puts many people with paralysis at risk because it could encourage some to ration their current supply to enable a small excess for emergencies.

Disagreement about best practices among planners is not surprising, given that we haven't sufficient experience in disaster planning for any constituency or community. Should people with paralysis try to “register” with the local safety agencies, such as the fire department, or place signs in windows to anticipate that they will get priority assistance during an emergency? Recent disaster experiences around the country have not shown this strategy to be effective; as these agencies are immediately inundated with overwhelming communications and demands, “special needs” are not prioritized.

Despite wonderful stories of first responders rescuing people, experience has shown that individuals waiting, hoping or expecting to be rescued by local services isn't a workable policy. Individuals, families, groups of friends and neighbors planning and acting together in common human caring, in conjunction with local advance readiness programs, clearly seems the best policy.

Emergency Safety Practices

Power Shutoffs

Recent investigations have found that some Western wildfires were likely caused by power lines and/or electrical transformers coming into physical contact with dried-out trees—and thus igniting vegetation. In some states that are at higher risk for wildfires, power and utility agencies may have begun alerting the general customer population of the potential for “Public Safety Power Shutoffs” (PSPS) of electrical circuits. Downed power lines and other hazards may contribute to increased fire hazards. Thus shutting

³² New, converted wheelchair-accessible minivans cost around \$30,000 for a more affordable model, which represents a premium of several thousand dollars above non-modified units. Higher-end versions with motorized ramps, hand controls for driving, and other features can cost \$70,000 or more. Used accessible vans are often difficult to find and still carry a cost premium.

down power would reduce this risk. This PSPS practice may be implemented in the coming year, and could be enacted with little or no advance warning to consumers. This puts people with paralysis who utilize electric power for their wheelchairs, respirators, elevators, and other powered equipment at serious risk during a disaster.³³ These utility companies assert that they will monitor relevant conditions and intend to provide alerts. This situation does call to question the need for networks of vulnerable consumers with paralysis and other disabilities.

Damaged or Cancelled Transportation Systems

Public transportation systems of all kinds—trains, buses, paratransit, and so forth—may be damaged or cancelled before, during and after disasters. For example, transit agencies may stop bus and rail service several days in advance of an anticipated hurricane’s landfall; meanwhile, earthquakes may damage roads, affecting bus routes and resulting in shutdowns for days, weeks, or months. These and other shutdowns—with or without advance notice—can leave many people with paralysis (along with all others who may depend upon public transportation) stranded in dangerous situations. Transportation during disasters is a significant challenge for maintaining some degree of workable infrastructure and must become a major focus of disaster readiness for community planning for individuals, families and communities.

Poor or Prohibitive Access in Shelters

Disaster shelters in the U.S. are operated by a mix of government agencies and NGOs; these have an array of resources, rules, regulations, and responsibilities related to both general operation and disability access. Although the Americans with Disabilities Act (ADA) and other accessibility laws technically apply to disaster shelters, the chaos of post-disaster shelter management combined with limited resources and enforcement can result in inadequate accessibility and services for shelter residents with paralysis and other disabilities. Stories abound of inaccessible restrooms and showers, a lack of elevated beds/cots, actions barring service animals from entering shelters, and insufficient personal care supports of all kinds, among other unmet accommodations. PWDs may sometimes be directed to hospitals or separate “special needs” shelters, despite their right to reside in a general-population shelter wherever possible. Certain shelter operators (through the Red Cross, FEMA, and state-level agencies) are working to improve disability services—but much more needs to be done to ensure equal access to healthy, safe environments during and after emergencies.

³³ PSPS shut off power with the goal of preventing wildfire-related disasters – so if they are successful, the main concern for people with paralysis will be getting needs met without electricity, which is no small feat. However, wildfire may still occur even when power lines are turned off. This situation would require people with paralysis to evacuate taking into account all other disability-related factors, including those that are made worse due to the loss of electricity: for example, contacting friends/family/caregivers/drivers with no functional cell phone network or evacuating a building when the elevator will not work.

Recommendations

How do we approach this challenge to a community of people still greatly stressed from unmet needs for healthcare, discrimination, and marginalization? We must seek a balance between some urgency—as well as compassion, patience, and *connection* — and a sense of joining together in pride and responsibility to maintain the wonderful, yet still fragile gains we’ve made. Again, our call to the Paralysis Community is to educate and activate all stakeholders to develop strategies to safeguard people with paralysis before disasters take place; the sense of urgency is heightened as climate change unfolds.

As we noted, there are three main groups of stakeholders that affect disaster readiness and response for people with paralysis: government actors (agencies/officials/etc.), NGOs, and members of the paralysis community (individuals with paralysis, their families, friends, and so forth). With this in mind, below is our list of recommendations for research and action.

Overarching Principles

- Policy and pragmatic planning must include substantial input from people with paralysis in keeping with the tenet, “Nothing About Us Without Us.” This long-used mantra of the disability rights movement acknowledges that people with paralysis (or any specific disability) have unique insights that can support the development of practice and policy—and have the right to participate in matters that affect their lives.
- Plans must address the likely and potential effects of climate change, including changes to the severity, frequency and dynamics of natural disasters. Although many activists push for mitigation efforts towards limiting the Earth’s temperature rise to 1.5 to 2 degrees Celsius, mitigation alone is not enough and should not be the only priority. We must plan for adaptation to changing conditions that will affect everyone, including people with paralysis; adaptation should also harness the “precautionary principle” and pursue maximum resilience for conditions beyond 2 degrees Celsius wherever possible.
- Education, training, and coordination for all appropriate stakeholders related to disasters must address the needs of people with paralysis. This includes government agencies, disaster readiness organizations, disability rights organizations, and all related services agencies. Extensive searches will reveal emerging models and best practices among cities and states.
- Educational curricula for the disability community about disasters, alerts, and all relevant information must be made accessible and appropriate for the various sub-communities mentioned. The disability community is incredibly diverse with unique needs regarding accessibility and accommodations (e.g., accessible media for blind/low-vision individuals or physical accessibility for persons with paralysis). Information for persons with paralysis must likewise address the multitude of relevant conditions—such as cerebral palsy, post-stroke, multiple sclerosis, and spinal cord injury—as well as their extent and severity.
- Positive, encouraging messaging is crucial. Educators must strive to create educational models that don’t just employ scary scenarios. We can acknowledge feelings of fear and threat, but only

using these are not the best approaches to learning. Effective education must be fun, engaging, and hopeful. Ideally, it can connect, wherever possible, with theater, music, playfulness, and laughing—to motivate constructive action, not shut down learners with fear tactics. Throughout history, young people have shown adults that fun and connection works best. Young people, especially disabled young people, can help to lead us here.

Recommendations for Disaster Management Agencies

Many government stakeholders address disaster management and/or services for people with paralysis. These operate at different levels of government (through federal, state, county and local agencies) and may work on disaster planning, public health, social services, or other relevant topics. The patchwork nature of disaster management leaves holes in communication and coordination that must be addressed—and when government stakeholders connect with each other, they must ensure that disaster response supports people with paralysis and that disability services are resilient during disasters. Important actions include:

- Wherever possible, disaster management agencies should hire dedicated staff to address the needs of people with paralysis and other disabilities; if resources are limited, agencies may consider dedicating a portion of a staff member's time to inclusive disaster planning. Relevant agencies should also take efforts to increase the percentage of employees with disabilities, as those employees will bring valuable insight to support inclusive disaster readiness and response.
- Agencies that address the needs of other vulnerable populations, such as low-income and all marginalized communities, must address the needs of their constituents with paralysis. These intersectional populations are also struggling to organize and motivate their communities to action along with all other urgent needs. Coalition building is essential to garner resources and affect policies in ways that include everyone, including marginalized and intersectional populations.
- Research is needed which explores the health effects and survival implications of disasters upon the specific constituencies of persons with paralysis and recommendations for interventions and needed resources. Examples are mitigation of the effects of extreme heat on people with higher-level spinal cord injuries (who are unable to perspire); effective technologies for alerting people with hearing loss on evacuation instructions; and approaches to feasible evacuation transportation for persons using respirators, who are unable to safely utilize standard evacuation methods (e.g., buses). Government can pursue this research by using agency staff through partnerships with universities, or by establishing grant/funding opportunities for research- and policy-focused NGOs.
- Existing emergency infrastructure, including evacuation-focused transportation and shelters, must be assessed for current and potential accessibility for people with paralysis.
- A partial list of focus areas in shelters includes physical accessibility of entryways, restrooms, and bathing facilities; designated zones for privacy during dressing and personal care; availability of elevated cots or other bedding; and navigable pathways. Other disability-related considerations address dietary needs, accommodating service animals, providing medical

services (including prescription medication), coordinating with social service staff, and supporting transitions back to the community.³⁴

- Accessible transportation must be available to evacuate from disaster zones to emergency shelters or other temporary housing options. For disasters with advance warning (e.g., hurricanes), transportation agencies should engage all possible options including rail, buses, paratransit vans, and even private transportation operators, e.g., taxis, TNCs (Transportation Network Companies), etc. through partnerships. Post-disaster evacuation—from disasters with or without warning—must consider safe roadways, available drivers/operators, public communication and more. Relevant agencies and organizations should assess the number of wheelchair-accessible seating areas in available vehicles and coordinate transportation accordingly.³⁵ Agencies should also coordinate transportation in the recovery phase to bring people with paralysis from temporary shelters to more permanent housing, whether in a prior residence or a new home.³⁶
- Emergency managers can establish public information alert systems (for email, text message and other announcements) to warn of potential dangers or to give evacuation orders. Managers should advertise alert systems to people with paralysis and other disabilities so those groups can prepare and evacuate in a timely manner. Online or paper sign-ups can include the option to receive disability-relevant information, such as the location of accessible shelters or evacuation services. Given the past problems with disability registries, we do not recommend that agencies establish lists where individuals expect to be rescued based on their disability. Any website or paper sign-ups for emergency communications—especially ones that have markers for disability-specific alerts—should note that lists are for communications only and will not guarantee emergency rescue and/or prioritization based on disability.
- Cross-community connections (through newsletters, social media engagement, etc.) and mutual in-person and webinar trainings between disaster organizations and disability community organizations can introduce and engage these movements with each other for mutual benefit and action.
- Rulemaking and other policy efforts must seek input from individuals and organizations representing people with paralysis. Agencies may set up listservs to announce opportunities for input, then reach out to Independent Living Centers (ILCs), paralysis-focused community groups, and other stakeholders with opportunities to receive announcements.

³⁴ A detailed list of disability-related considerations is available from FEMA through its "Guidance on Planning for Integration of Functional Needs Support Services in General Population Shelters" document. The publication is from 2010, and presents a good starting point for shelter managers. However, true "universal access" will include even more factors beyond those in the FEMA guidance. <https://www.fema.gov/media-library/assets/documents/26441>

³⁵ For example, city buses generally have two wheelchair accessible seating areas, while accessible taxis almost always have one and paratransit vehicles range from one to a half-dozen or so.

³⁶ More detailed guidance is available through the Department of Transportation's publication, "Evacuating Populations with Special Needs," available at <https://ops.fhwa.dot.gov/publications/fhwahop09022/fhwahop09022.pdf>

- Emergency managers should educate the public on the importance of personal emergency and evacuation preparedness—and do so in a way that motivates personal action. This can include public service announcements, community events, designated websites, social media accounts, webinars and more. Managers must support people with paralysis and other disabilities through focused materials (print, video, digital, etc.) and community engagement.
- Emergency managers—in partnership with social service agencies, NGOs, and other community groups—should support people with paralysis in developing and implementing personal emergency and evacuation plans. This can include providing donated or reduced-cost “go bags,” generators, and other emergency supplies; visiting homes to clear evacuation pathways and secure furniture (especially in “earthquake country”); distributing disaster preparedness worksheets; and more.
- Public education should not make promises that cannot be kept. For example, disaster managers should acknowledge the capabilities and limitations of transportation infrastructure to support evacuation of wheelchair users without personal vehicles. If the transportation system may be overwhelmed—and agencies cannot evacuate all people with paralysis, say in advance of a hurricane—then managers should advise people with paralysis to prioritize transportation (e.g., with friends or family) in their emergency plans and support those who may have to shelter-in-place (by distributing generators, nonperishable food, or other supplies).

Recommendations for Disability and Related Services Agencies

A wide array of government entities and NGOs provide resources and services to people with paralysis. Government agencies include departments of social services, departments of health, accessible transportation providers (e.g., for paratransit), departments of rehabilitation, and personal attendant care agencies (e.g., In-Home Supportive Services). Nonprofits include those that address disability in general, such as Centers for Independent Living and accessible recreation groups, as well as organizations supporting individuals with specific disability categories (e.g., United Cerebral Palsy, United Spinal Association, and the Multiple Sclerosis Foundation). For-profit organizations include technology developers, healthcare providers, medical equipment providers, specialized transportation companies, and more (some of these products and services are also provided by nonprofit organizations). The following are recommendations for disability- and paralysis-focused agencies and organizations; some address specific categories as noted below.

Full inclusion of people with paralysis for disaster readiness must be addressed in consideration of attitudinal, architectural and programmatic barriers. Organize outreach, community engagement, etc. considering such topics as the intersection of the Medical Model and Social Model of disability, disproportionate levels of poverty and unemployment, accessibility of emergency transportation and shelter, and other relevant factors mentioned in this paper.

- Disability organizations and other service agencies which serve the paralysis community must advocate for their local, state and federal agencies to achieve the recommendations described in this document and referenced materials. Advocates may pursue one or multiple strategies

ranging from petitions to meetings with legislators to media engagement. Some organizations have utilized lawsuits for inclusive, accessible disaster readiness and response.³⁷

- Agencies serving individuals with paralysis may establish dedicated emergency management initiatives to assist with preparation, evacuation, sheltering, recovery and other relevant efforts. A good example is the California Department of Social Services (CDSS) Disaster Services Bureau: this Bureau supports shelter managers and manages Functional Assessment Service Team (FAST) training and deployment, all while staying in close contact with the Governor’s Office of Emergency Services and assorted disability-related organizations.³⁸
- Agencies can take responsibility to educate their clients, families, and other allies about disaster readiness, in a variety of ways. For example, newsletters, blogs, mailings, workshops and events of all kinds can include disaster readiness information in articles or tips. Informative fliers and brochures (such as included in our package) can be displayed at events and lobby areas. Media and information can be diverse, fun and creative—with a mix of community profiles, individual stories, personal preparedness worksheets, and more.
- Nonprofits can include these issues in their fund-raising efforts as a sideline or central focus for workshops and educational materials, such as fliers and videos. Direct service providers can seek funding for hands-on disaster readiness assistants to help with such tasks as assembling Go Bags and securing furniture. Managers should be creative when applying for grants and other funding: there are limited opportunities specifically for disaster readiness and paralysis, but many sources can address disaster readiness when framed appropriately. Organizations should always address the costs and benefits of funding options (for example, the nature of non-renewable grants juxtaposed against goals of long-term community initiatives).
- Government agencies can include initiatives and related line items in annual budget proposals and/or apply for grants and other relevant funding opportunities. State, regional, and city agencies may find funding opportunities from federal and/or state-level grants.
- Events can focus on, or include, creating “go-kits” (with, for example, a week’s supply of medications, emergency food rations, such as power bars, cash, batteries, etc. of course, tailored to the individual’s specific needs such as bowel and bladder routine items, skin/wound care supplies, and a spare wheelchair charger).
- Organizations should contact state and local governmental resources to research and post local options for temporary sheltering for people with paralysis. If government representatives do not respond with adequate information about fully accessible shelters, organizations can pursue activism or legal actions to guarantee inclusive disaster response.
- Offer a ready to “copy and paste” email for consumers to register as a person with paralysis with relevant agencies and first responders at the city and county levels. This can be distributed through newsletters and by staff to clients, community members and partner organizations.³⁹

³⁷ For example, the Disability Rights Advocates (DRA) utilizes the courts to hold cities accountable for addressing the needs of people with disabilities in emergency plans. Favorable outcomes can also support future efforts at inclusive emergency planning by setting court precedent and demonstrating effective legal strategies.

³⁸ More information available at <http://www.cdss.ca.gov/inforesources/Disaster-Services-Bureau>

³⁹ Emails advertising sign-ups for government announcements, registries, etc., can note both the benefits and limitations of enlisting as a person with paralysis, especially constraints around evacuation assistance.

- Centers for Independent Living, Senior Centers and other disability-related services agencies can store, then distribute equipment, such as wheelchairs, portable equipment, medical necessities, etc. Plans for drills for communications, client registries, personal assistance staff and so forth can be made in advance, and practiced in advance so the process will go more smoothly in the moment of need.
- Some communities have created Community Resilience Centers, for example, in Berkeley, CA,⁴⁰ (as well as “Apartment Resiliency Centers”) which provide and distribute emergency tools and medical provisions in advance in anticipation of potential disasters. Individual local neighborhood leaders take responsibility for storing, and then distributing these materials in the event of a disaster.
- Disability organizations, advocates and relevant government agencies/staff may join coalitions of stakeholders interested in disability-inclusive disaster readiness, response and recovery. Existing groups include the Partnership for Inclusive Disaster Strategies (which provides regular newsletters, conference calls and more) and the California Disability and Disaster Coalition. Stakeholders may also establish coalitions for their geographic area or disability constituency, if an appropriate group does not already exist.

Planning for Individuals and Families

Planning by individuals and families for disasters is essential for the well-being of people with paralysis. Raising the priority for this is essential. As much as we’d like to think that local emergency services such as fire departments and ambulances will rescue vulnerable people, experience has shown that this is unlikely, given the overwhelming demand for services for the general population during and after disasters. Here are suggestions for planning:

- Individuals and families should develop comprehensive plans as early as possible. Plans should include general considerations (communication, transportation, emergency supplies, etc.) and paralysis-specific concerns (medication, personal care, accessible shelter and so forth).
- Individuals and families should understand the natural and industrial hazards associated with their area. For example, the Southeastern U.S. has risks from hurricanes, thunderstorms and flooding; the upper-Midwest experiences flooding, blizzards, and summer heat waves; and the West Coast may experience forest fires, earthquakes, and tsunamis. Each type of disaster has a unique timeframe (for advance warning, if any, and expected recovery) and risk profile. It is important to understand one’s local hazards and prepare accordingly.
- Individuals and families need to discuss and plan for options for communications and connections during a disaster. Useful communication options are walkie-talkies, two-way radios, or even wireless doorbells in some cases.
- Connecting with a network of friends and resource providers must be central to the planning process because one’s circles of support people are the most important resources in a disaster.

⁴⁰ More information on Berkeley’s initiative is available at <https://www.cityofberkeley.info/CommunityResilienceCenter/>

Disaster planners recommend a list of at least five emergency contacts, and ideally more, and notifying those contacts that you may need assistance in a crisis. This is especially important for individuals who may need hands-on help in an emergency (for example, transferring from bed to a wheelchair or asking someone to drive a vehicle during evacuation). Individuals with paralysis may ask their contacts to check on them in a disaster (for example, by calling their phone or visiting their home) and revisit emergency plans every several months.

- People with paralysis must consider and take concrete actions for the following:
 - Who will you contact or who will check in with you about your immediate safety or longer term sheltering in the event of home displacement or disruption? Will it be neighbors? Close-by friends? Consider a few layers of people as back-up to those who may be distracted with their own difficulties.
 - What plans do you have if ordinary communications, such as phone or computers, aren't working? If you purchase communications equipment—such as two-way radios—be sure to check their battery levels regularly.
 - Consider purchasing or storing equipment, such as back-up batteries, chargers, or an old wheelchair, with charger, left in an accessible location in the event of need for abandonment of current wheelchair. If you live or work on the upper floors of a building, consider your potential means of immediate evacuation. An example is an *evacuation sling* for descending stairs without a wheelchair, which is valuable for people with paralysis in the event of elevator dysfunction or power outage.
 - For individuals without a personal vehicle, ask yourself: What options are available for transportation to safety, if local transit services are disrupted (which is possible or likely in a disaster)? For example, can you transfer to a friend's car using a sliding board? If evacuation is impossible or improbable, do you have enough supplies to shelter-in-place, ideally for one week or more?
 - What are options for shelter after a disaster (both short- and long-term), and how can you reach them? If possible, connect with friends or family that live far enough away that they will not be affected by any disaster that hits your city, and ask about a spare bed that could be used in a crisis. Depending on the emergency, you may need to stay in a local shelter for several days or more—so identify your local emergency shelters and ask in advance which are fully accessible.
 - For those who have the means to do so, build up an emergency fund for transportation, lodging, purchasing replacement supplies and equipment, and other expenses related to disaster response and recovery. Individuals who are constrained by asset limits tied to government benefits can explore options such as Special Needs Trusts and ABLE Accounts, which enable qualifying individuals to save money without jeopardizing their benefits.

If, when developing emergency plans, individuals find that their local disaster managers (at the city, county, or state level) do not address the needs of people with paralysis or other disabilities, they can work to improve local emergency plans. This may simply involve alerting paralysis and disability advocacy organizations, who can take coordinated action.

Conclusions

In recent decades, the Disability Community has made impressive advances in many arenas towards the goal of full social and political inclusion. The U.N. Convention on the Rights of Persons with Disabilities (UNCRPD) has greatly encouraged and emboldened people with paralysis around the world to view themselves as deserving of human rights protection. Disaster preparedness presents even higher stakes; bringing on this new challenge is daunting. This will be a complex undertaking due to the personal, social and economic characteristics of this community. Responses will require large-scale initiatives, focused actions, and strong collaborations between stakeholders across the disability spectrum. We can succeed in this challenge with connection, commitment, and perseverance.

Authors

The authors of this piece are both members of the paralysis community. Marsha Saxton, Director of Research at the World Institute on Disability, WID, and lecturer at the University of California, Berkeley, was born with leg weakness and walks with leg braces. Alex Ghemis, Policy and Research Specialist at WID, has a spinal cord injury and uses a wheelchair, as well as personal attendant care. Both can easily imagine scenarios of inability to jump into a boat in a flood, or run from a fire, anticipate being in a refugee camp or shelter unable to obtain the most basic resources to meet needs for well-being, even survival. Beyond concern for our own personal safety, we identify with a close community of disability rights comrades, our friends, *our people*, a wonderfully resilient group of creative and diverse humans with bodies and minds who work and thrive worldwide, in communities, nonprofits, services agencies, legal centers, schools, and universities. *Our people* are advocates, organizers, activists, researchers, and leaders, as well as students, clients, and recipients of services. Our closest allies include parents, relatives, and friends and healthcare and service providers and the informed public. We invite you to join us.

References

Baynton, Douglas. "Disability & Justification of Inequality in American History." *The New Disability History: American Perspectives*. Edited by Paul K. Longmore & Lauri Umansky. New York: New York University Press, 2001. Accessed November 12, 2015. http://www.uua.org/documents/bayntondouglas/justification_inequality.pdf.

Brault, Mathew W. (2012) (2010) Americans with Paralysis. *United States Census Bureau* https://www.census.gov/newsroom/cspan/disability/20120726_cspan_disability_slides.pdf

Community Emergency Response Teams (CERT). <https://www.fema.gov/community-emergency-response-teams>

Collins, Patricia H. "Gender, Black Feminism, and Black Political Economy." *Annals of the American Academy of Political and Social Science* 568 (2000): 41–51.

Crenshaw, Kimberlé W. "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color." *Stanford Law Review* 43, no. 6. (1991): 1241-99.

Davis, Lennard. "Why Is Disability Missing From the Discourse on Diversity?" *Chronicle of Higher Education* Accessed November 11, 2015 <http://chronicle.com/article/Why-Is-Disability-Missing-From/129088/>

Deegan, Mary J. and Brooks, Nancy A. (1985). *Women and Disability: The Double Handicap*. New Brunswick: Transaction Books.

Functional Assessment Service Team (FAST)

<http://www.acphd.org/media/357999/functional%20assessment%20service%20team.pdf>—Retrieved 2.12.16.

Federal Emergency Management Agency, FEMA Office of Disability Integration and Coordination. <https://www.fema.gov/office-disability-integration-and-coordination>; <https://www.fema.gov/media-library-data/1465938725925->

FEMA Fact Sheet. [ef9b417a39940def69c8e86b24cc5ab7/ODIC_FactSheet_2016.pdf](http://www.fema.gov/media-library-data/1465938725925-ef9b417a39940def69c8e86b24cc5ab7/ODIC_FactSheet_2016.pdf)

Fjord, Lakshmi. (2015) "Disasters, race, and Disability: [Un] Seen through the Political Lands on Katrina," *The Journal of Race and Policy* 3(1):65 University of California, Berkeley

Fitzmaurice, Susan. (2009) "The Names for a Child with a Disability," in *Sticks & Stones: Disabled People's Stories of Abuse, Defiance and Resilience*, Berkeley, CA: World Institute on Disability. (p. 79)

Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997.

Gleick, Peter H. (2015) Water, Drought, Disaster Change, and Conflict in Syria. *Pacific Institute*, Oakland, California <http://journals.ametsoc.org/doi/abs/10.1175/WCAS-D-13-00059.1> (retrieved 2.10.17)

lezzoni, Lisa I. & O'Day, Bonnie L. (2006). *More than Ramps: A Guide to Improving Health Care Quality and Access for People with Paralysis*. Oxford, England: Oxford University Press.

India Disaster Dialog. (2017) Women Bear the Brunt of Disaster Change.

<http://indiadisasterdialogue.net/2017/01/04/women-bear-brunt-disaster-forced-migration/>

Intergovernmental Panel on Disaster Change. Fifth Assessment Report IPCC AR5: (AR5) <https://www.ipcc.ch/report/ar5/wg2/> (Retrieved 2.10.17)

International Organization for Migration. <http://www.iom.int/>

Kevles, Daniel J. *In the Name of Eugenics: Genetics and the Uses of Human Heredity*. New York: Knopf, 1985.

Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York: New York University Press, 1998.

Longmore, Paul K., and Lauri Umansky, eds. *The New Disability History: American Perspectives*. New York: New York University Press, 2001.

Meekosha, Helen, and Russell Shuttleworth. (2009) "What's So 'Critical' about Critical Disability Studies?" *Australian Journal of Human Rights* 15, no. 1(2009): 47–75.

Oliver, Mike. (2013) "The Social Model of Disability: Thirty Years On." *Disability & Society*, Vol. 28, No 7.

Pfeiffer, David. "The Philosophical Foundations of Disability Studies." *Disability Studies Quarterly* 22, no. 2 (Spring 2002).

Phrase Finder. "Women and children first" <http://www.phrases.org.uk/meanings/women-and-children-first.html>

Pisani, Maria, & Shaun Grech. (2015) Disability and Forced Migration: Critical Intersectionalities. *Disability and the Global South*. Vol. 2, No. 1, 521-441

Rooted in Rights. (2015) "The Right to Be Rescued" Documentary. Rooted in Rights. <https://www.youtube.com/watch?v=vSGxW1uh8Pw>

Snow, Kathi. People First Language. *Disability is Natural Books and Media*. <https://www.disabilityisnatural.com/people-first-language.html> (Retrieved 2.22.17)

Author, Marsha. "Access to Care: The Heart of Equity in Healthcare." *Eliminating Inequities for Women with Paralysis: An Agenda for Health and Wellness*. Edited by Shari Miles-Cohen. Washington D.C.: American Psychological Association, 2016.

Women's Refugee Commission. (2014) "Refugees with Paralysis –Fact Sheet" <https://www.womensrefugeecommission.org/paralysis/paralysis-fact-sheet> (Retrieved 2.10.17)

Skinner, Marcus. (2014) The Impact of Displacements on Disabled, Injured and Older Syrian Refugees. *Forced Migration Review*. <http://www.fmreview.org/syria/skinner.html> (retrieved 2.15.17)

Titchkosky, Tanya. *The Question of Access: Disability, Space, Meaning*. Toronto: University of Toronto Press, 2011. Institute for Human Centered Design. <http://www.humancentereddesign.org/universal-design>

U.S. House of Representatives. (2006) A Failure of Initiative: Final Report of the Select Bipartisan Committee to Investigate the Preparation for and Response to Hurricane Katrina. 109th Congress, 2nd Session, Report 000-000. February 2006, <http://www.gpoaccess.gov/congress/index> (retrieved Feb. 2.22.2017)

U.S. Department of Health and Human Services (2012) Auxiliary Aids and Services for Persons with Paralysis. <http://www.hhs.gov/ocr/civilrights/clearance/exauxaids.html>. (Retrieved April 12, 2016)

National Council on Disability (2019) "Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters." <https://www.prnewswire.com/news-releases/federal-report-highlights-trend-of-involuntary-institutionalization-during-and-after-disasters-300856426.html>

Weibgen, Adrien A. (2015) "The Right To Be Rescued: Disability Justice in an Age of Disaster" *The Yale Law Review*. Vol 124, No. 7 <http://www.yalelawjournal.org/note/the-right-to-be-rescued>, (Retrieved 2.22.17)

Winzer, Margaret A. "Disability and Society before the Eighteenth Century: Dread and Despair." *The Disability Studies Reader*. New York: Routledge, 1997.

World Institute on Disability. <https://wid.org/programs/disaster-change-disaster-prep/>

United Nations (2010) International Strategy for Disaster Risk and Reduction and Disaster Change in the Pacific. http://www.unisdr.org/files/26725_26725drrandccainthepacificaninstitu.pdf

United Nations Convention on the Human Rights of People with Paralysis UNCRPD
<http://www.un.org/paralysis/documents/convention/convoptprot-e.pdf>