

## **Disability Inclusion in Climate Change: Impacts and Intersections**

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### Abstract

The community of people with disabilities is uniquely affected by devastation brought on by climate change. This population is increasingly appearing on lists of "vulnerable" among many other groups in the social justice framework. Public policy in several countries, the Red Cross and United Nation's documents have begun to include the voices of persons with disabilities among the planning constituencies. Yet the needs of this constituency are poorly understood regarding which measures could realistically enable survival in environmentally compromised circumstance. This very diverse group comprises approximately 10 to 15% of the global population, and within all other sub-populations, this figure will likely increase with climate change impact. Discriminatory attitudes and policies tend to simplify this multiply intersectional population to "people with special needs." This simplification ignores the diverse, complex needs and circumstances of individuals with disabilities, for those with visual, hearing, and mobility impairments, and so on, as well as their various socio-economic cross-constituencies such as gender, ethnicity, age, etc. In this context, focus on climate change and disability is disturbingly rare. This article by U.S.-based authors explores key intersectional issues emphasizing their research in the U.S. related to disability and climate change impact, and recommending an educational, research and advocacy agenda for both the Climate Change and the Disability Rights movements.

### Introduction: Climate Change and Disability

Mention "climate change and disability" and most people are immediately puzzled— it's an issue that has often never occurred to them— but that surprise lasts only a sentence into further



explanation. Comprising a significant 10 to 15% <sup>1</sup> of the global population, people with disabilities are uniquely affected by climate change.<sup>2</sup> Climate change has many ground-level consequences, ranging from deeper droughts to stronger storms to sea level rise; these can result in food and water insecurity, storm-related injuries and mortality, damage to infrastructure, violent conflict, mass migration and more. This population includes a wide array of mobility, sensory (visual, hearing), developmental, intellectual and emotional impairments, as well as chronic health conditions and other disabilities. Many individuals may have multiple disabilities and may experience social or medical factors differently depending on their race, gender, culture, language (including sign language for Deaf people) nationality and other identities. The intersections between disabilities worldwide is impacted by climate change at a disproportionate level compared to those without disabilities.

This is demonstrated across climate change's multiple and inherently increasing impacts, from raised risk of storms to related escalation of violence. (IPCC) The clear evidence from past and current natural disasters and refugee situations shows that people with disabilities have a low survival rate, and in many situations are even neglected or left to die (Weigben, 2015.) Photo journalism showing the impact of Hurricane Katrina in the southeast United States in 2005 documented this with tragic photos of dead people in their wheelchairs as crowds of other displaced people streamed by. Stories of people trapped in flooded nursing homes revealed a lack of planning for people whom disaster preparedness leaders had failed to consider. A documentary, "The Right to Be Rescued," describes the experiences of people with disabilities

<sup>&</sup>lt;sup>1</sup> World Health Organization (2017) Many estimates are higher, for example, up to 19.8% of the U.S. (Brault, 2012.)

<sup>&</sup>lt;sup>2</sup> This number will undoubtedly increase worldwide with climate change impact. This population has been considered the "canaries in the mines" of climate change devastation, meaning the threat to survival facing all of humanity will first strike people with disabilities, and then other "vulnerable populations."

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affected by Hurricane Katrina (Rooted in Rights, 2015) intended to educate the public and policymakers about the need for planning for this population.

Stories also emerged of responders struggling to manage disabled persons' unique needs but with no training or resources to rescue or keep them alive. FEMA has begun to address this constituency's needs, including a series of educational webinars for agency leaders and policymakers, through FEMA's Office of Disability Integration and Coordination. Sadly, the majority of Community Emergency Response Team (CERT) training courses offer little or nothing to sensitize volunteers in regards to assisting persons with disabilities following a local disaster.<sup>3</sup> While CERT courses are for volunteers, there are not yet widely distributed, sufficient guidelines for formally trained responders as well.<sup>4</sup> This is in the United States, which is relatively advanced in its treatment of disability. Problems internationally may fare worse, with only beginning recognition of the problems. The category "people with special needs" is appearing on lists of "vulnerable populations" in climate change media in ways that can mask or trivialize the potential impact of climate disaster. Well-intentioned people grasp that this diverse population needs something "special," but it seems that simple mention on these lists can somehow allay concerns without actually addressing them. (Disaster Preparedness documents have begun using additional terms, such as people with access and functional needs, and individuals requiring additional assistance (IRAAs). Authors have not yet found these terms used in the climate change literature and media.)

Realistic consideration must include attention to specific, accurate approaches to assistance in extreme circumstances. The rough categories of disability include physical mobility impairment, vision/hearing impairment, cognitive disability, people with mental illness labels and chronic illness. Generalities about the broader population in this context are useless; the intersectional factors are essential. Examples are the effects of extreme heat on people with spinal cord injuries (who are unable to perspire); effective technologies for alerting people with hearing impairments

<sup>&</sup>lt;sup>3</sup> Authors have been trained and certified in CERT and in FAST (Functional Assessment Service Teams, described below) as part of our research on this topic.

<sup>&</sup>lt;sup>4</sup> FEMA is working to develop these for the U.S.

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on evacuation planning; approaches to feasible evacuation transportation for persons using respirators, who are unable to safely utilize standard evacuation methods (.e.g., buses.)

Attention must be directed to higher rates of disability in low-income populations; rural populations; incarcerated people; intersections with racism; ageism, sexism, and so forth. Each of these sub-populations are complexly impacted with respect to health and provision of assistance for survival. With greater vulnerability during storms, floods and extreme heat; susceptibility to invasive disease; the complex challenges of relocation and forced migration; climate disruptions are harder for these populations at all levels. Appropriate responses to "special needs" and "vulnerability" must address these accurately.

A United Nations document on Human Rights and Climate Change (2010) states that negative climate impact will "disproportionately affect individuals, groups and peoples in vulnerable situations including, women, children, older persons, indigenous peoples, minorities, migrants, rural people, persons with disabilities and the poor." Such language attempts to capture the range of groups likely the 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."

## Adaptation to Climate Change

Climate change is often framed in the media as "potential," as if keeping to certain limits would evade the devastation. We know impact is happening now all over the globe. "Adaptation to climate change" is the advance planning and infrastructure-building in anticipation of impact on all kinds of populations. Those peoples in process of forced migration due to climate change impact --now required to relocate entire communities, are the pioneers in this overwhelming experiment.

Both authors of this piece are individuals with disabilities, specifically mobility impaired. Saxton, Director of Research at the World Institute on Disability (WID) and a lecturer in Disability Studies at the University of California, Berkeley, was born with leg weakness and walks with leg submitted on the 28/2/1/ Accepted on the 26/6/17 Published under CC-BY 4.0 https://creativecommons.org/licenses/by/4.0/



braces. Ghenis is a Policy and Research Specialist at WID with a focus on Climate Change, and 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 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.

Our work group at the World Institute on Disability has connected with the United Nations, the International Organization on Migration, and local and national climate change action groups, to enlist them as meaningful allies. We have sought opportunities to conduct informal research (examples include gaining training and certification through CERT and FAST programs, described below, to enable our observations about how disability and people with disabilities are and are not addressed) We have participated in actions on climate change in general, and intend to explore broad impact. We have created a website <u>www.wid.org/ned</u>, given talks, and published articles and social media releases. We are enlisting disabled people and their allies as trainers and leaders in climate change and adaptation activism.

### **Disability is Multiply Intersectional**

People with disabilities are not defined solely by that characteristic. As is true of all people from any category, marginalized or not, human beings exist within a wide and fluid range of other roles, identities, and communities. "Intersectionality" addresses an analytic focus on the interplay of social characteristics of marginalized categories of individuals and groups. Stigmatized traits, such as disability, race, gender, and sexual orientation, interact or combine to further increase marginalization and disenfranchisement of the "other"—the "different one." Black feminist



sociologists, including Patricia Collins (2000) and Kimberle Crenshaw (1991) introduced this concept into the social analysis of biological and social categories of people targeted with social exclusion. Individuals may experience increasing oppression as a result of membership in multiple categories of marginalized constituencies. <sup>5</sup> This perspective appears to be playing out in climate change impact.

The assumption of raised likelihood of survival in disasters throughout history does not necessarily adhere to consistent and presumed patterns of relative privilege. An example is the phrase and code, "women and children first." This phrase is widely believed to have originated in a maritime incident, the sinking of the HMS Birkenhead, which went down off the coast of South Africa in 1852. (The Phrase Finder) The concept and practice was further reinforced in the sinking of the Titanic in 1912. In both these incidents, most of the men were killed and most of the women and children survived. Analogously, and perhaps causally related, Hollywood silver screen audiences appear to well tolerate the common representation (Faludi, 1999) of dozens, hundreds or thousands of men being violently killed before their eyes, from WWII movies to Star Wars. But this would no doubt be found shocking and unacceptable if the same degree of violence were targeted at similar numbers of either women or children. Another example comes from current media reporting of people killed in terrorist attacks: commentators will often state the total number of deaths, then additionally mention the numbers of women and children, as if their deaths are even more shocking, less anonymous than those of the civilian men. Perhaps the military notion of valor is enacted for men in the social construction of the violence in both war and disasters-that men may nobly die for their countries, but women and children are not expected to do so. Intersections are complex indeed. War and disaster may alter expected patterns of privilege and survival.

Intersectionality in its complexity is important to address with any marginalized constituency. Oppressive assumptions often tend to reduce individuals in the minds of those who stigmatize as if "those people" have lost their other human qualities,—gender, race, age, and so forth—

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foregrounding their unfamiliar or problematic uniqueness as the chief characteristics. The scholarly field of Disability Studies seeks to appreciate all aspects of the disabled individual's full range of constituency identities, roles and circumstances, and understand this interplay with respect to exclusion from community participation in mainstream life. (Meekosha & Shuttleworth, 2009; Saxton, 2016)

The rich and complex intersectionality of the population of people with disabilities is obscured by disability oppression. "People with disabilities" are very diverse with respect to types of disabilities, also including people with chronic illnesses. <sup>6</sup> Of course, these populations include people of all genders, races, class backgrounds and ethnicities, as well as all other social categories at the rate of 10 to 15%. Therefore, about 10% or more of the children of all ethnicities have disabilities, 10% or more of all women have disabilities and so forth. Disability is even more prevalent in poorer communities; the rates of disability of low-income persons, older persons and migrants will increase above 10 to 15% because these populations become disabled and chronically ill at higher rates due to poorer access to healthcare and health-supporting resources such as quality nutrition and adequate assistance and services in the home and community.

Since this intersectional diversity is not obvious to many in the public, even among well-intended people, attitudes about disability tend to reduce people with disabilities to "other," as if their visible impairments essentially defined them. To persons unfamiliar with wheelchair users, these individuals may unawarely be assumed to be incompetent or unable to speak for themselves. This is revealed, for example, in the high likelihood that a waitperson in a restaurant will ask the companion of a wheelchair user, what "she would like to order," instead of directly addressing that individual about her own order. People with disabilities can thus be objectified in ways that obscure these individuals' humanness and competence.

<sup>&</sup>lt;sup>6</sup> by definitions set by the World Health Organization, as well as the *Americans with Disabilities Act*, and many other statutes and organizations. Submitted on the 28/2/17 Accepted on the 26/6/17

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As a result, "differences" can be magnified, but also important distinctions can be hidden. For example, *children with disabilities* may be regarded primarily as "disabled" rather than primarily as "children." The recommended "People-First" language (Snow, 2015) e.g., *child with a disability* versus *disabled child*, does little to mitigate the rigid notion that *disabled children* are to be perceived as very different from *children* (Fitzmaurice, 2009) In fact, children with disabilities are very much *children*! They are children who may or may not have "special needs," but will always, indeed, have children's needs. Conversely with older age, for example, "disability" can hide in the category "old." Older people are not *disabled* by grey hair or wrinkles, but can be stereotyped as incompetent or burdensome. And, indeed, many older people experience age-related impairments which result in significant limitation in mobility, seeing, hearing and so forth, and experience higher rates of chronic illness. Yet, they may simply be regarded as "old" and may themselves resist joining the constituency of "people with disabilities" even though their impairments would be considered *disabling* in younger persons.

While it is imperative that we understand the diversity that characterizes the larger grouping of people with disabilities, it is important to note the particular position that their disability places them in in this context. The emerging agenda of *diversity* has alerted institutions, organizations, and services to challenge their own limiting practices, which may prioritize some and exclude other populations and communities. However, it still seems that disability is not a prioritized group in these efforts. Many, including Lennard Davis (2011), assert that the disability community has yet to make it to the list of the "diversity imperative" in current discourse about marginalized constituencies.

### **Multiple Intersectional Characteristics**

Consideration of additional intersectional human characteristics brings the multiplying complexity to light. The intersectional category of disability most explored in the scholarly and community literature is *women and disability*. "Double discrimination" within social institutions, including



health care services, deeply affects women and girls with disabilities; this has been well documented for over four decades (Deegan & Brookes, 1985). "Triple discrimination" can refer to a focus on disability, gender, and race and/or ethnicity. The resulting extensive literature attests to a well-developed, thriving international community of women with disabilities (Kern, 1979; Saxton, 2016)

The Syrian Refugee crisis is assumed to be caused by war and the current and historic political circumstances, though this is controversial. Gleick's article on Syria (2015) offers convincing evidence that the political factors leading to the situation in Syria have been significantly shaped by climate change impact resulting in drought and hunger. At any rate, this situation gives a grim prospective view of the impact of displacement on women and girls with disabilities and for these populations worldwide with the coming climate change impact and force migration. Data on this population's survival rates in migratory circumstances are extremely difficult to obtain (Skinner, 2014). This is echoed in several existing publications on refugees. The Women's Refugee Commission (WRC) asserted, that women with disabilities "remain one of the most vulnerable and socially excluded groups in any displaced community and have difficulty accessing humanitarian assistance due to a variety of societal and communication barriers." A *Refugees Fact Sheet* states, "Women, children and older persons with disabilities are particularly vulnerable to discrimination, exploitation and violence, including gender-based violence, and they may have difficulty accessing support and services that could reduce their risk and vulnerability."

### **Disability Has a History**

Discrimination against people with disabilities 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; disabled beings from infancy through old age were ostracized, marginalized, vilified, or killed (Winzor,1997.)



Rosemarie 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 19th 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. 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 targeted people with disabilities, as well as immigrants, people of color, and other "undesirables," through public campaigns that included both institutionalization and systematic sterilization, affecting over 70,000 people in the U.S. (Kevles, 1985). This history still haunts us in the form of discriminatory attitudes, as well as persistent exclusionary policies and programs.

People with disabilities 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 a smaller circle of community resources. (Gill, 1996). The deeper message clearly comes across: your needs 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".

Two models contrast in describing the "problem of disability." The *Medical Model*, also referred to as the *Deficit Model*, (Pffeifer, 2002) operates on the assumption that an individual's bodily limitations, their impairments," <sup>7</sup> are the locus and cause of their difficulties in achieving social,

 <sup>&</sup>lt;sup>7</sup> Impairment is the term employed by Disability Studies to describe the physically-based components of a disabling condition as opposed to societal factors that may impose limits (Linton, 1999.).
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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** 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 disabilities, which are deeply rooted in ancient history (Winzer,1997) and reinforced by current cultural practices, and which 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.

• *Programmatic barriers,* which prevent or reduce full participation in services and programs (U.S. Department of Health and Human Services, 2010).

These barriers occur when systems, facilities and services are created and operated without the needs of people with disabilities 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 <sup>8</sup> Accessible transportation, includes busses with lifts, and level entrances to trains in stations with elevators and ramps. These facilitate not only physical mobility and participation in the community, they transcend low socio-

<sup>&</sup>lt;sup>8</sup> 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 disabilities, 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.)



economic status associated with disability (Longmore & Umansky 2001) supporting disabled people to attend school, work and socialize just like everyone else.

The disability community has emerged as a powerful, world-wide movement of civil and human rights, enacted, over the past six to seven decades through public education and laws, such as the *Americans with Disabilities Act* (ADA) and the *United Nations Convention of the Rights of People with Disabilities* (CRPD). Creation of disability *inclusion*, via specific measures of *access and accommodations* remove these barriers to participation in the mainstream community (lezzoni, O'Day, 2006) and include ramps, assistive devices, technologies and services that enable people with disabilities to participate fully.

This movement is led by people with disabilities, and supported by our allies: families, service providers, advocates and policy-makers. Our slogan, "Nothing About Us Without Us!" asserts our insistence in full participation in all activities that affect us, and declare great pride in challenging the Medical Model of disability with the advent of a Social Model's successes.

Based on the evidence from environmental devastation from disasters and refugee situations, of great concern to the authors of this piece, is that climate change impact will potentially undermine the requirements of the Social Model of Disability, disrupting our progress with inclusion and equality. The Social Model forms the basis of the modern disability movement's claim to full inclusion (Longmore, 2001). However *a well-maintained and stable infrastructure* of inclusive architecture, accessible transportation, and a dependable network of programs and financial benefits and logistical resources are essential for this inclusion. Under the extreme duress of environmental devastation, these resources are greatly disrupted, as we have seen in disasters and refugee situations. The barriers, the exclusion, and *vulnerability to exclusion* return. The disability advocacy and services communities have just begun to address disaster preparedness, but the longer-range implications, including ongoing duration and increasing severity of climate change (as opposed to shorter range, "temporary" impact of disasters) has as yet, barely been raised. The infrastructural underpinnings of the Social Model cannot be taken for granted on our vulnerable planet. 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. Through our research, publications and educational events we hope to engage and alert the disability community to the urgent need to enlist our members as climate change activists along with all other goals for this community. Indeed waiting for the other goals for inclusion to be achieved before addressing climate change impact is particularly self-defeating for this community.

# "Vulnerability"

Conventional thinking presumes that some categories of people are "dependent" and others "independent," the dependent category including babies, children, people with disabilities and seniors. Disability awareness trainers enjoy challenging this notion, pointing out that walking people who didn't bring their own chairs to the workshop are dependent upon the facilities for this helpful resource; that sighted people require electric lighting, and so forth. Everyone is highly "dependent" upon the 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, etc, etc, are all brought to us through an interwoven network of mutual dependencies. Yet often, people assume such resources to be normal, taken for granted, and therefore "just there." In this sense chairs and electric lighting are almost universally available, but it requires "*special*" resources to provide wheelchairs, white-tipped canes and guide dogs; these are then produced, purchased and distributed through special methods related to disability. The above labeling of "special" supports creates a veneer of dependency unlike that of the "normal population," even though the support resources are simply different rather than addition per se. <sup>9</sup>

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

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<sup>&</sup>lt;sup>9</sup> 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.

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personal support for activities of daily living (ADLs) leading in the extreme to vilifying the disabled people with these needs (Longmore & Umansky, 2001)

What is "vulnerability?" The population(s) of people with disabilities do indeed have unique, untypical needs in relation to extreme environmental conditions, especially where *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 climate 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 (Glieck 2014). Dozens of other climate-related consequences lead to direct and overlapping effects on existing systems and populations. Each of these many consequences must be addressed regarding *specific* climate change impact on *specific* individuals and categories of people with disabilities.

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. Because natural disasters are arguably the most immediate and widely-discussed analogy to climate change impact, this may be a starting point when analyzing the connection between climate change and disability – and when addressing it with relevant agencies, organizations and the general public.

Following Katrina, a report (U.S. House of Representatives, 2006) chastised Louisiana for having failed to develop a "registry of special needs persons" which could alert responders to seek out these individuals, especially if communications systems fail. However, no other U.S. state has



developed anything like this. For example, Berkeley, California, 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. The community of people with disabilities in the U.S. has not asked for such a registry to address the problem of their vulnerability. This notion of such registries or even identifying signs in windows (e.g., "disabled person here") is thought to give false hope of promise of rescue. <sup>10</sup> Furthermore, disabled persons cannot be assumed to *stay home* any more than other people. Few cities in the U.S. could begin to avail funds to create such lists, never mind plan or prepare to reserve or store various kinds of supplies or resources for persons so identified." 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 needed to link disabled people with community networks that realistically connect people.

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 fire fighters 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 text book, reference to the phrase "special needs" was employed once, in the section on escape planning (p. 1-20) along with the sentence, "Consider the needs of children and individuals with disabilities." Then, p. 1-38, under "Additional Training for CERTs," several bulleted points indicated possibilities for training on

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<sup>&</sup>lt;sup>10</sup> As explained by the instructor in CERT class, 2.15. 17. 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.

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issues such as Advanced First Aid, Animals in Disasters, and Shelter Management. "Special Needs Concerns" was in this list. However, people with disabilities, 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 weren't aware of this, though they readily agreed that it was important (and that this might be taught elsewhere.) Authors were later able to obtain access to these Advanced Training documents, though it is unclear how widely distributed they are. The training films did not mention persons with disabilities, though people newly injured from the disaster was a major focus.

Rescue of people with disabilities is, in fact, often indirectly or even explicitly not prioritized in disaster response. An example comes from the evacuation of 200,000 residents downstream from the Oroville, CA Dam disaster in February, 2017, where the dam's spillway became damaged due to unexpected water volume from persistent storms, in concert with long-ignored warnings from environmental engineers, of increased weakening of dam supports. A resident, interviewed on National Public Radio, stated with dismay that "we had to leave a disabled family member behind," after they had tried to summon an ambulance for this individual, 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, etc. The instructor verbally reinforced the standard directive given to responders. The order of priority of who 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; third priority, is, as the CERT trainer stated, "people easiest to rescue," The logic here appears to be that this category of "easiest" people, within the triage mentality, are those most likely to survive and then to further to 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 Submitted on the 28/2/17

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disabilities 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, versus 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 to remove from compromised 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: "who should survive to enable the greatest number of survivors?" This raises more questions, including: under extreme duress of stressful situations, whether natural disaster or climate change impact will triage decision-making regress to stereotypes? This triage logic may be influenced or at best complicated by disability discriminatory notions that people with disabilities are less worthy, non-contributory, and a burdensome barrier to the survival of the larger number of more worthy, and more potentially resourceful *able-bodied persons*. Decisions about rescue, allocation of resource and distribution of scarce supplies will likely get made based on regressive notions of who is *valued, and valuable*, not necessarily on who is human and deserves to live and survive as much as anyone else.

There are many programs working to address disability in a constructive manner during disaster readiness and response that can become relevant to climate change impact, for example the United Nations International Strategy for Disaster Risk and Reduction (UN DRR) and the Functional Assessment Service Teams (FAST) trainings, a Red Cross program which addresses disability concerns during emergency situations. This includes effective communication and interaction; ensuring accessibility and medical support in disaster shelters; organizing personal assistant care; and other areas of focus. While FAST is not flawless, and not yet widely disseminated and thus not yet implemented, it is a valuable model program that can be used as a framework for inclusive disaster response.

### **Disabled People in Forced Migration**



Another significant impact upon people with disabilities as a consequence of climate change is that of forced migration (Pisani & Grech, 2015.) The causes for climate change-induced forced migration include, but are not limited to: sea level rise inundating coastlines and coastal populations; extreme weather events displacing individuals who may not return; resource shortages (i.e. diminished water supplies or collapsing fisheries) which drive populations elsewhere; and potential violent conflicts instigated by climate factors leading to many refugees. The International Organization on Migration (IOM) has projected that there will be at least 100 million "climate migrants" by midcentury, with a potential for several hundred million more. (IOM) This is one of the most severe global consequences of climate change and will present massive human and geopolitical costs, especially as climate migrants put pressures on international borders and increase related tensions. However, unlike extreme weather events, this projected climate-related migration, still an abstraction, and likely gradual, is rarely addressed in the public sphere. Ultimately, refugees and climate migrants with disabilities may encounter any of the following difficulties:

• "Social cohesion," the network of stable relationships in one's family and community, are especially significant to people with disabilities, whose lives depend upon such connections. A huge challenge facing displaced persons with disabilities 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 are typically provided through a range of close relationships, which can be greatly disrupted in refugee and migration situations.

• Reliable availability of medicines such as insulin, and durable medical equipment or clean or sterile products (catheters, ostomy products, and so forth) may become non-existent in migratory dwellings.

• Government benefits such as supplemental income, healthcare or funding for personal care support are generally tied to location and residency. People with disabilities will likely lose these vital benefits during migration.



• People with disabilities may not be able to navigate migration in general due to a lack of accessible transit or the requirement to migrate "on foot" through assorted terrain.

• Individuals with disabilities, including those who become disabled from the current crisis, due to a lack of medical care and personal supports, may be abandoned during migration if deemed too much burden.

• People with disabilities may be denied entrance into host countries simply because they are disabled, viewed as "dependent" and a burden on social systems and the able-bodied population. It also stems from host countries prioritizing labor potential in immigration criteria, with the assumption that people with disabilities are unable to work.

• In some cases, individuals will simply be left behind as others relocate, left to experience extreme negative effects of environmental change along with the potential collapse of needed services and supports.

• Broader impact at an abstract yet predictable level would include strains on government budgets, imposed austerity and cuts to disability services (among many other cuts to services.)

## **UNCRPD** as a Framework

A testimony to the success of the disability rights movement and a cornerstone document is the *UN Convention on the Rights of Persons with Disabilities (*UNCRPD), officially adopted in 2006, currently with 160 Signatory countries. The UNCRPD recognizes the disproportionate marginalization of people with disabilities and provides a number of obligations for Signatories to (plan for and eventually) ensure human rights and equality.



It is hoped that a widely-recognized and ratified Convention can elicit engagement and eventual compliance for disability-inclusive, adaptive climate justice. The Convention contains specific statute Articles--internationally-agreed-upon obligations, which can be considered related to climate change when framed in the correct context.

The "General principles," the UNCRPD are: (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (b) Nondiscrimination; (c) Full and effective participation and inclusion in society; (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (e) Equality of opportunity; (f) Accessibility; (g) Equality between men and women; (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities."

Many of the "General Obligations," which imply expected actions or outcomes, can be applied to "disability inclusive climate adaptation". These include the obligations to adopt legislative, administrative and other measures; abolish existing discriminatory or harmful laws; take into account protection and promotion of human rights of people with disabilities; eliminate discrimination by individuals, organizations, private enterprise or governments; promote research and development of Universal design and accessible technology; provide accessible information; and promote training of professionals and staff in these policies. These are powerful statements on their own, each of which can be used to advocate for inclusive climate efforts given the correct framing, and support the Convention's many other Articles directly and indirectly. Several stand out for use in efforts toward climate justice, including:

Article 9: "Accessibility." Article 9 may be used to advocate for accessibility of disaster response, physical areas (i.e. climate resilience infrastructure), planning efforts, public engagement, and more.



Article 11: "Situations of risk and humanitarian emergencies." This article, which is a single but powerful sentence highlighting "measures to ensure the protection and safety of persons with disabilities" in risk and emergencies, is related to and can be applied to all these situations.

Article 18: "Liberty of movement and nationality." Climate change is projected to lead to significant migration within and between countries due to factors such as coastal flooding from sea level rise, desertification and water scarcity, dislocation from extreme weather, and refugees from climate-related conflict. Many estimates stand upward of 100 million individuals by midcentury. People with disabilities will face many physical economic, social and political barriers to this migration. Article 18 can be used to advocate for fair treatment and supports throughout this migration.

Article 20: "Personal mobility." may maintain focus on the importance of mobility aids and related supports as Climate change will stress economies, healthcare systems and the provision of medical equipment.

Article 21: "Freedom of expression and opinion, and access to information." People with disabilities will undoubtedly need to advocate for their rights as climate change progresses, which will require venues to do so as well as accommodations where needed. People with disabilities also do not often access information about climate change due to isolation, a lack of engagement by climate advocates and other stakeholders, and a shortage of accessible materials. Article 21 especially highlights need for accessible materials and stakeholders must develop these materials to fully reach those with disabilities. The UNCRPD can be used as a tool to advocate for climate justice, especially with signatories who have already stated a commitment to disability rights.

## Recommendations

Reflecting these concerns, we offer recommendations to initiate priorities for research and action.

 Policy and pragmatic planning must include substantial input from people with disabilities in keeping with the community's tenet, "nothing about us without us." From policy-makers to first Submitted on the 28/2/17 Accepted on the 26/6/17 Published under CC-BY 4.0 https://creativecommons.org/licenses/by/4.0/



responders, allies to people with disabilities must understand that this community best knows it's own needs and solutions to difficulties in all areas of life.

- Education, training and coordination for all appropriate agencies related to climate change impact must address the needs of people with disabilities. This includes government agencies, climate change organizations, disability rights organizations, and all related services agencies; Extensive searches could reveal emerging models among cities and states.
- Educational curricula and informational guidance for the disability community about climate change impact must be made accessible and in appropriate formats for the various sub-communities mentioned.
- Agencies which address the needs of all other intersecting vulnerable populations must also address their constituents with disabilities;
- Existing emergency infrastructure, including evacuation transportation and shelters, must be assessed for current and potential accessibility for people with disabilities.
- Research is needed to explore the health effects and survival implications of climate change impact upon the particular constituencies of persons with disabilities and recommendations for interventions and needed resources.

The UNCRPD promotes and enables people with disabilities and their rights to be included in the conversation and planning about climate change. We must hold them to this.

## Conclusions

Climate change will affect the lives and well-being of hundreds of millions of people with disabilities in the coming years and decades. The many consequences of climate change Submitted on the 28/2/17 Accepted on the 26/6/17 Published under CC-BY 4.0 https://creativecommons.org/licenses/by/4.0/



including extreme weather events, economic upheaval and large-scale migration will uniquely impact this population. As yet, stakeholders have only begun to address the needs of people with disabilities in this regard, be it in research, policy or concrete actions. The disability community has made impressive advances in many arenas regarding the goal of full social and political inclusion in recent decades The UN Convention on the Rights of Persons with Disabilities has greatly encouraged and emboldened people with disabilities around the world to view ourselves as deserving of human rights protection. Climate change presents even higher stakes; bringing on this new challenge is daunting.

Many governments, including those that are Signatories of this UN document are taking climate change impact seriously. This will be a complex undertaking due to climate impacts and personal, social and economic characteristics of this community. Responses will require large-scale initiatives, focused actions and strong collaborations between stakeholders across the climate and disability spectrum. It is fortunate that those currently addressing climate change and disability, respectively, are well-engaged with a social justice framework. Both groups must understand the scope and complexities between climate change and disability. The key is thus to educate and activate these stakeholders to develop strategies to safeguard people with disabilities as climate change unfolds.



## References

Baynton, Douglas. (2001) "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. Accessed November 12, 2015. http://www.uua.org/documents/ bayntondouglas/justification\_inequality.pdf.

Brault, Mathew W. (2012) (2010) Americans with Disabilities. *United States Census Bureau* <u>https://www.census.gov/newsroom/cspan/disability/20120726\_cspan\_disability\_slides.pdf</u>

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

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

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

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

Deegan, M. J. & Brooks, N. (1985). *Women and Disability: The Double Handicap*.New Brunswick: Transaction Books.

Faludi, Susan. (1999) Stiffed: The Betrayal of the American Male. (p 291) New York: William Morrow & Co.

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



FEMA Fact Sheet. 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(I):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.

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

Iezoni, L. & O'Day, B. (2006). *More than Ramps: A Guide to Improving Health Care Quality and Access for People with Disabilities.* Oxford, England: Oxford University Press.

India Climate Dialog. (2017) Women Bear the Brunt of Climate Change. http://indiaclimatedialogue.net/2017/01/04/women-bear-brunt-climate-forced-migration/

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

Institute for Human Centered Design. http://www.humancentereddesign.org/universal-design

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

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



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

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

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.

New Earth Disability, www.wid.org/ned

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

Phrase Finder. "Women and children first" <u>http://www.phrases.org.uk/meanings/women-and-</u> 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*. <u>https://www.disabilityisnatural.com/people-first-language.html</u> (Retrieved 2.22.17).

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



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

Titchkosky, Tanya. (2011) *The Question of Access: Disability, Space, Meaning*. Toronto: University of Toronto Press.

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. 109<sup>th</sup> Congress, 2<sup>nd</sup>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 Disabilities. http://www.hhs.gov/ocr/civilrights/clearance/exauxaids.html. (Retrieved April 12, 2016).

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

World Health Organization. (2017) World Report on Disability http://www.who.int/disabilities/world\_report/2011/report/en/

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

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

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



United Nations (2010) International Strategy for Disaster Risk and Reduction and Climate Change in the

Pacific. http://www.unisdr.org/files/26725\_26725drrandccainthepacificaninstitu.pdf

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