

A Culture of Neglect: Climate Discourse and Disabled People

Introduction

The scientific validity of climate change claims, how to intervene (if at all) in environmental, economic, political and social consequences of climate change, and the adaptation and mitigation needed with any given climate change scenario, are contested areas of public, policy and academic discourses. For marginalised populations, the climate discourses around adaptation, mitigation, vulnerability and resilience are of particular importance. This paper considers the silence around disabled people in these discourses.

Marci Roth of the Spinal Cord Injury Association testified before Congress in regards to the Katrina disaster:

[On August 29] Susan Daniels called me to enlist my help because her sister in-law, a quadriplegic woman in New Orleans, had been unsuccessfully trying to evacuate to the Superdome for two days. [...] It was clear that this woman, Benilda Caixetta, was not being evacuated. I stayed on the phone with Benilda, for the most part of the day. [...] She kept telling me she'd been calling for a ride to the Superdome since Saturday; but, despite promises, no one came. *The very same paratransit system that people can't rely on in good weather is what was being relied on in the evacuation.* [...] I was on the phone with Benilda when she told me, with panic in her voice "the water is rushing in." And then her phone went dead. We learned five days later that she had been found in her apartment dead, floating next to her wheelchair. [...] *Benilda did not have to drown.* (National Council on Disability, emphasis added)

According to the Intergovernmental Panel on Climate Change (IPCC), adaptation is the "Adjustment in natural or *human systems* in response to actual or expected climatic stimuli or their effects, which moderates harm or exploits beneficial opportunities" (IPCC, *Climate Change 2007*). Adaptations can be anticipatory or reactive, and depending on their degree of spontaneity they can be autonomous or planned (IPCC, *Fourth Assessment Report*). Adaptations can be private or public (IPCC, *Fourth Assessment Report*), technological, behavioural, managerial and structural (National Research Council of Canada). Adaptation, in the context of human dimensions of global change, usually refers to a process, action or outcome in a system (household, community, group, sector, region, country) in order for that system to better cope with, manage or adjust to some changing condition, stress, hazard, risk or opportunity (Smit and Wandel). Adaptation can encompass national or regional strategies as well as practical steps taken at the community level or by individuals. According to Smit et al, a framework for systematically defining adaptations is based on three questions: (i) adaptation to what; (ii) who or what

adapts; and (iii) how does adaptation occur? These are essential questions that have to be looked at from many angles including cultural and anthropological lenses as well as lenses of marginalised and highly vulnerable populations.

Mitigation (to reduce or prevent changes in the climate system), vulnerability (the degree to which a system is susceptible to, and unable to cope with, the adverse effects of climate change), and resilience (the amount of change a system can undergo without changing state), are other important concepts within the climate change discourse. Non-climate stresses can increase vulnerability to climate change by reducing resilience and can also reduce adaptive capacity because of resource deployment to competing needs. Extending this to the context of disabled people, ableism (sentiment to expect certain abilities within humans) (Wolbring, “Is there an end to out-able?”) and disablism (the unwillingness to accommodate different needs) (Miller, Parker and Gillinson) are two concepts that will thus play themselves out in climate discourses.

The “Summary for Policymakers” of the IPCC 2007 report, *Climate Change 2007: Impacts, Adaptation and Vulnerability*, states: “Poor communities can be especially vulnerable, in particular those concentrated in high-risk areas. They tend to have more limited adaptive capacities, and are more dependent on climate-sensitive resources such as local water and food supplies.” From this quote one can conclude that disabled people are particularly impacted, as the majority of disabled people live in poverty (Elwan). For instance, CARE International, a humanitarian organisation fighting global poverty, the UN Office for the Coordination of Humanitarian Affairs, and Maplecroft, a company that specialises in the calculation, analysis and visualisation of global risks, conclude: “The degree of vulnerability is determined by underlying natural, human, social, physical and financial factors and is a major reason why poor people—especially those in marginalised social groups like women, children, the elderly and people with disabilities—are most affected by disasters” (CARE International).

The purpose of this paper is to expose the reader to (a) how disabled people are situated in the culture of the climate, adaptation, mitigation and resilience discourse; (b) how one would answer the three questions, (i) adaptation to what, (ii) who or what adapts, and (iii) how does adaptation occur (Smit et al), using a disabled people lens; and (c) what that reality of the involvement of disabled people within the climate change discourse might herald for other groups in the future. The paper contends that there is a pressing need for the climate discourse to be more inclusive and to develop a new social contract to modify existing dynamics of ableism and disablism so as to avoid the uneven distribution of evident burdens already linked to climate change.

A Culture of Neglect: The Situation of Disabled People

As climates changes, environmental events that are classified as natural disasters are expected to be more frequent. In the face of recent disaster responses, how effective have these efforts been as they relate to the needs and challenges faced by disabled people? Almost immediately after Hurricane Katrina devastated the Gulf Coast, the National Council on Disability (NCD) in the United States estimated that 155,000 people with disabilities lived in the three cities hardest hit by the hurricane (about 25 per cent of the cities’ populations). The NCD urged emergency managers and government officials to recognise that the need for basic necessities by hurricane survivors with disabilities was “compounded by chronic health conditions and functional impairments ... [which include] people who are blind, people who are deaf, people who use wheelchairs, canes, walkers, crutches, people with service animals,

and people with mental health needs.” The NCD estimated that a disproportionate number of fatalities were people with disabilities. They cited one statistic from the American Association of Retired Persons (AARP): “73 per cent of Hurricane Katrina-related deaths in New Orleans area were among persons age 60 and over, although they comprised only 15 per cent of the population in New Orleans.” As the NCD stated, “most of those individuals had medical conditions and functional or sensory disabilities that made them more vulnerable. Many more people with disabilities under the age of 60 died or were otherwise impacted by the hurricanes.” As these numbers are very likely linked to the impaired status of the elderly, it seems reasonable to assume similar numbers for non-elderly disabled people.

Hurricane Katrina is but one example of how disabled people are neglected in a disaster (Hemingway and Priestley; Fjord and Manderson). Disabled people were also disproportionately impacted in other disasters, such as the 1995 Great Hanshin Earthquake in Japan (Nakamura) or the 2003 heatwave in France, where 63 per cent of heat-related deaths occurred in institutions, with a quarter of these in nursing homes (Holstein et al.). A review of 18 US heatwave response plans revealed that although people with mental or chronic illnesses and the homeless constitute a significant proportion of the victims in recent heatwaves, only one plan emphasised outreach to disabled persons, and only two addressed the shelter and water needs of the homeless (Ebi and Meehl; Bernhard and McGeehin).

Presence of Disabled People in Climate Discourse

Although climate change will disproportionately impact disabled people, despite the less than stellar record of disaster adaptation and mitigation efforts towards disabled people, and despite the fact that other social groups (such as women, children, ‘the poor’, indigenous people, farmers and displaced people) are mentioned in climate-related reports such as the IPCC reports and the Human Development Report 2007/2008, the same reports do not mention disabled people. Even worse, the majority of the material generated by, and physically set up for, discourses on climate, is inaccessible for many disabled people (Australian Human Rights Commission).

For instance, the IPCC report, *Climate Change 2007: Impacts, Adaptation and Vulnerability*, contains *Box 8.2: Gender and natural disasters*, makes the following points: (a) “men and women are affected differently in all phases of a disaster, from exposure to risk and risk perception; to preparedness behaviour, warning communication and response; physical, psychological, social and economic impacts; emergency response; and ultimately to recovery and reconstruction”; (b) “natural disasters have been shown to result in increased domestic violence against, and post-traumatic stress disorders in, women”; and (c) “women make an important contribution to disaster reduction, often informally through participating in disaster management and acting as agents of social change. Their resilience and their networks are critical in household and community recovery.”

The content of Box 8.2 acknowledges the existence of different perspectives and contributions to the climate discourse, and that it is beneficial to explore these differences. It seems reasonable to assume that differences in perspectives, contributions and impact may well also exist between people with and without disabilities, and that it may be likewise beneficial to explore these differences. Disabled people are differently affected in all phases of a disaster, from exposure to risk and risk perception; to preparedness behaviour, warning communication and response; physical, psychological, social and economic impacts; emergency response; and ultimately to recovery and reconstruction. Disabled people could also make an important contribution to disaster reduction, often informally through participating

in disaster management and acting as agents of social change. Their resilience and their networks are critical in household and community recovery, important as distributors of relief efforts and in reconstruction design.

The Bonn Declaration from the 2007 international conference, *Disasters are always Inclusive: Persons with Disabilities in Humanitarian Emergency Situations*, highlighted many problems disabled people are facing and gives recommendations for inclusive disaster preparedness planning, for inclusive response in acute emergency situations and immediate rehabilitation measures, and for inclusive post-disaster reconstruction and development measures. Many workshops were initiated by disabled people groups, such as Rehabilitation International. However, the disabled people disaster adaptation and mitigation discourse is not mainstreamed. Advocacy by people with disability for accessible transport and universal or “life-cycle” housing (among other things) shows how they can contribute significantly to more effective social systems and public facilities. These benefit everyone and help to shift public expectations towards accessible and flexible amenities and services—for example, emergency response and evacuation procedures are much easier for all if such facilities are universally accessible. Most suggestions by disabled people for a more integrative, accessible physical environment and societal attitude benefit everyone, and gain special importance with the ever-increasing proportion of elderly people in society.

The *IPCC Fourth Assessment Report* is intended to be a balanced assessment of current knowledge on climate change mitigation. However, none of the 2007 IPCC reports mention disabled people. Does that mean that disabled people are not impacted by, or impact, climate change? Does no knowledge of adaptation, mitigation and adaptation capacity from a disabled people lens exist, or does the knowledge not reach the IPCC, or does the IPCC judge this knowledge as irrelevant? This culture of neglect and unbalanced assessment of knowledge evident in the IPCC reports was recognised before for rise of a ‘global’ climate discourse. For instance, a 2001 Canadian government document asked that research agendas be developed with the involvement of, among others, disabled people (Health Canada). The 2009 *Nairobi Declaration* on Africa’s response to climate change (paragraph 36) also asks for the involvement of disabled people (African Ministerial Conference on the Environment). However, so far nothing has trickled up to the international bodies, like the IPCC, or leading conferences such as the United Nations Climate Change Conference Copenhagen 2009.

Where Will It End?

In his essay, “We do not need climate change apartheid in adaptation”, in the *Human Development Report 2007/2008*, Archbishop Desmond Tutu suggests that we are drifting into a situation of global *adaptation apartheid*—that adaptation becomes a euphemism for social injustice on a global scale (United Nations Development Programme). He uses the term “adaptation apartheid” to highlight the inequality of support for adaptation capacity between high and low income countries: “Inequality in capacity to adapt to climate change is emerging as a potential driver of wider disparities in wealth, security and opportunities for human development”. I submit that “adaptation apartheid” also exists in regard to disabled people, with the invisibility of disabled people in the climate discourse being just one facet.

The unwillingness to accommodate, to help the “other,” is nothing new for disabled people. The ableism that favours species-typical bodily functioning (Wolbring, “Is there an end to out-able?”; Wolbring, “Why MBIC?”) and disablism (Miller, Parker, and Gillinson)—the lack of accommodation enthusiasm for the needs of people with ‘below’ species-typical body abilities and the unwillingness to adapt to the

needs of “others”—is a form of “adaptation apartheid,” of accommodation apartheid, of adaptation disablism that has been battled by disabled people for a long time. In a 2009 online survey of 2000 British people, 38 per cent believed that most people in British society see disabled people as a “drain on resources” (Scope). A majority of human geneticist concluded in a survey in 1999 that disabled people will never be given the support they need (Nippert and Wolff). Adaptation disablism is visible in the literature and studies around other disasters. The 1988 British Medical Association discussion document, *Selection of casualties for treatment after nuclear attack*, stated “casualties whose injuries were likely to lead to a permanent disability would receive lower priority than those expected to fully recover” (Sunday Morning Herald). Famine is seen to lead to increased infanticide, increased competitiveness and decreased collaboration (Participants of the Nuclear Winter: The Anthropology of Human Survival Session).

Ableism and disablism notions experienced by disabled people can now be extended to include those challenges expected to arise from the need to adapt to climate change. It is reasonable to expect that ableism will prevail, expecting people to cope with certain forms of climate change, and that disablism will be extended, with the ones less affected being unwilling to accommodate the ones more affected beyond a certain point. This ableism/disablism will not only play itself out between high and low income countries, as Desmond Tutu described, but also within high income countries, as not every need will be accommodated. The disaster experience of disabled people is just one example. And there might be climate change consequences that one can only mitigate through high tech bodily adaptations that will not be available to many of the ones who are so far accommodated in high income countries. Desmond Tutu submits that adaptation apartheid might work for the fortunate ones in the short term, but will be destructive for them in the long term (United Nations Development Programme).

Disability studies scholar Erik Leipoldt proposed that the disability perspective of interdependence is a practical guide from the margins for making new choices that may lead to a just and sustainable world—a concept that reduces the distance between each other and our environment (Leipoldt). This perspective rejects ableism and disablism as it plays itself out today, including adaptation apartheid. Planned adaptation involves four basic steps: information development and awareness-raising; planning and design; implementation; and monitoring and evaluation (Smit et al). Disabled people have important knowledge to contribute to these four basic steps that goes far beyond their community. Their understanding and acceptance of, for example, the concept of interdependence, is just one major contribution. Including the concept of interdependence within the set of tools that inform the four basic steps of adaptation and other facets of climate discourse has the potential to lead to a decrease of adaptation apartheid, and to increase the utility of the climate discourse for the global community as a whole.

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