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Using a Human Rights-Based Approach to Disability in Disaster Management Initiatives

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1. Introduction

1.1 Prevalence and incidence of disability

Worldwide, 15% of the global population, an estimated 1 billion people are living with a disability (World Health Organization (WHO), 2011). While the prevalence of disability is higher in high-income countries, due to increased survival and longevity, the incidence of disability is higher in low and middle-income countries. Therefore, the majority of the world's people with disabilities live in low and middle-income countries (WHO, 2011).

1.2 Defining disability

In congruence with the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), within this chapter disability will refer to "long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder people's full and effective participation in society on an equal basis with others" (CRPD, 2006). This broad definition appeals to a social model of disability that emerged in the 1980s as an alternative to earlier charity-based and medical models that conceptualized disability as an individual problem. The social model, and the World Health Organization's bio-psychosocial model of disability (demonstrated in Figure 1) reflect how people are disabled through stigmatizing social interactions, environmental barriers and other social phenomena.

The bio-psychosocial model of disability demonstrates how it is a combination of physical, environmental and personal factors that can affect participation. This means that people with different impairments (sensory, physical, intellectual, cognitive, etc.) will experience varying degrees of disability based on their social and environmental contexts. Therefore, what is considered a disability can vary across different geographic and cultural contexts. For example, in East Africa people with albinism face extreme cultural prejudices and due to this social alienation their organizations belong to the disability movement in countries such as Tanzania. Whereas in Canada people with albinism may not consider themselves disabled unless they acquire a visual impairment.
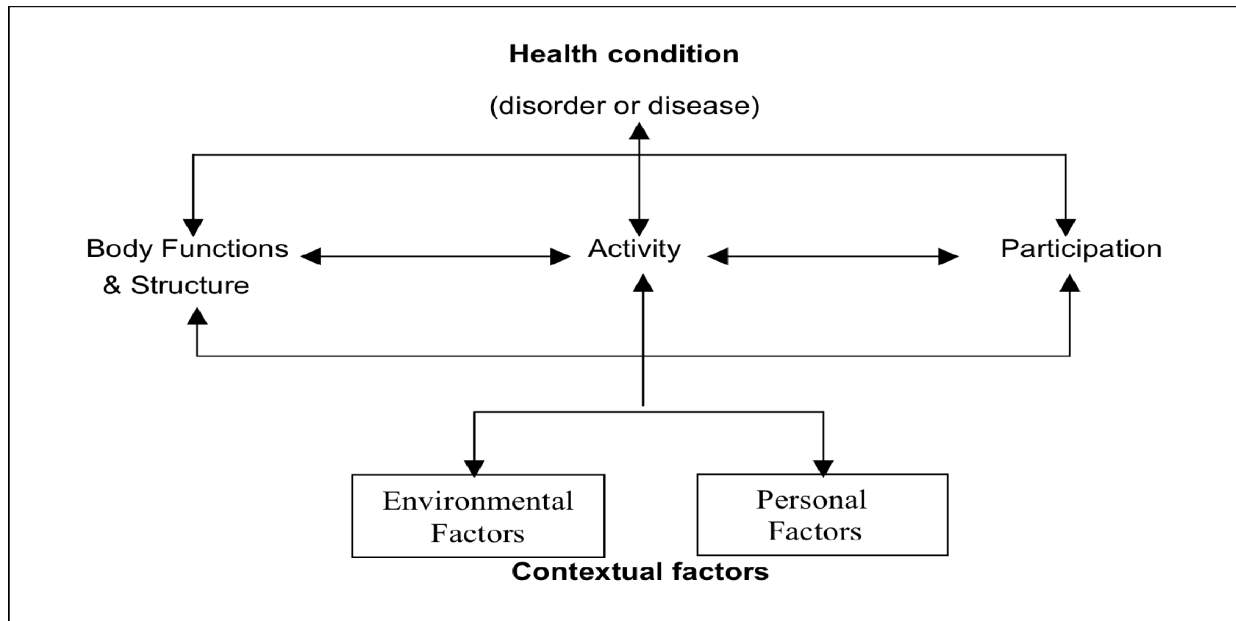
Fig. 1. The bio-psychosocial model of disability (WHO, 2001)

1.3 Disability in the context of natural disasters

Disability issues need to be considered in all natural disasters, not only because of the global prevalence of disability but also because of the effects of natural disasters on individuals, families and communities.

1.3.1 Different groups of people with disabilities arise in disaster situations

People with newly acquired injuries and impairments. If a person's injuries are not treated properly they can develop into impairments, such as bone fractures that are not followed up. Disasters (particularly earthquakes) also often result in many people acquiring permanent impairments, such as amputations and spinal cord injuries, as seen in Haiti where approximately 200 000 people are expected to live with disabilities as a result of their injuries from the earthquake in 2010 (United Nations Enable, n.d). This group of people are often the first to be targeted and treated post-disaster.

People with pre-existing disabilities. During natural disasters persons with disabilities not only suffer the same impact of the disaster as the general population but also are less able to cope with the deterioration of their environment as a result of socio-economic conditions, empowerment and access to resources (United Nations Enable, n.d). Additionally, persons with disabilities suffer particularly high rates of mortality and morbidity in disasters partially as a result of being less able to flee or find protection, or from being left behind or abandoned during evacuation. These instances result due to a lack of prevention and planning, and inaccessible services and transportation (United Nations Enable, n.d). Persons with disabilities also experience greater loss of autonomy following disasters. For example, people with mobility impairments who are able to flee may subsequently become more dependent because mobility aids were left behind.

People with pre-existing impairments. People with certain impairments may have not found their condition to be particularly disabling prior to a disaster; but, if infrastructure is destroyed or mobility or communication aids lost (or destroyed) during the disaster, then a previously relatively benign impairment may become severely disabling. Similarly, people with chronic diseases (such as diabetes, epilepsy and HIV) conditions can deteriorate if their access to medication is interrupted.

> "Persons with disabilities are doubly vulnerable to disasters, both on account of impairments and poverty; yet they are often ignored or excluded at all levels of disaster preparedness, mitigation and intervention." (International Federation of Red Cross and Red Crescent Societies [IFRC], 2007)

1.4 Considering human rights in addressing disability in disaster management initiatives

1.4.1 Human rights approach to disability

Where persons with disabilities have been poorly supported in the past, during times of disaster existing unequal power distributions, discrimination and inequality are exacerbated (SPHERE, 2011) putting persons with disabilities at greater risk of being denied their basic rights. Failure to recognize the rights of persons with disabilities and the barriers they face in gaining access to disaster management initiatives can result in further marginalization and denial of vital assistance. For example, persons with disabilities tend to be invisible to emergency registration systems. They are frequently left unregistered, which means that they fail to receive their basic entitlements to food, water and clothing. Furthermore, the assumption cannot be made that provisions made to the public will reach persons with disabilities, or that people will automatically have equitable access to whatever is made available. There are many reasons why people fail to receive their entitlements including: they may be hidden by their families; they may not know about services because they cannot attend community meetings due to physical inaccessibility; they cannot hear radio announcements; or they may not be able to access services due to poor terrain or lack of mobility aids. Despite that many of the services that persons with disabilities need in emergencies are no different from other peoples' needs, it is important to recognize that persons with disabilities may have some specific needs. For example, it can be harder for people with physical impairments to keep warm due to lack of movement and poor circulation, so they may have an increased need for warmer clothing or blankets.

The human rights approach to disability reflects a paradigm shift in attitudes and approaches to persons with disabilities, in the direction of the social model of disability described above. It is a shift in focus from a person's limitations arising from impairments, to the barriers within society that prevent the person from having access to basic social services and from enjoying her or his rights. The human rights approach to disability moves from the treatment of persons with disabilities as objects of charity, medical treatment and social protection, towards viewing persons with disabilities as people with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as well as being active members of society. This moving away from

equating inclusion as a charitable act, drives the approach to be inspired by the promotion of human rights that benefits the entire population of a country and provides a clear statement of a government's commitment to all its citizens and to the principles of good governance. In the context of disaster management, looking from this perspective has the benefit of not only improving access to quality services, but also increasing participation in decision making and creating public awareness and demand.

> Disability is a human rights issue because:
> - People with disabilities experience inequalities – for example, when they are denied equal access to health care, employment, education, or political participation because of their disability.
> - People with disabilities are subject to violations of dignity – for example, when they are subjected to violence, abuse, prejudice, or disrespect because of their disability.
> - Some people with disability are denied autonomy – for example, when they are subjected to involuntary sterilization, or when they are confined in institutions against their will, or when they are regarded as legally incompetent because of their disability.
>
> (WHO World Report on Disability, 2011, pp. 9)

1.4.2 Recognition of persons with disabilities rights in disaster management initiatives

While disability equality issues have historically been marginalized they are increasingly referenced in disaster evaluation and practice development (SPHERE, 2011). Following the 2004 tsunami in Asia, major relief organizations and international non-governmental organizations (NGOs) commissioned disability audits in their post-tsunami evaluations resulting in recognition of the rights of persons with disabilities in natural disasters by the international community. Disability specific working groups have since been incorporated into the United Nations cluster coordination system and disability issues were included in the 2011 edition of the SPHERE guidelines. The SPHERE guidelines set out what people affected by disasters have a right to expect from humanitarian assistance. They are based on the principles and provisions of international humanitarian, human rights and refugee law and point out that disability is an important crosscutting issue that needs to be addressed by all those involved. They include minimum standards for non-discrimination and specific reference to strategies for persons with disabilities in each chapter (SPHERE, 2011).

1.4.3 The Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities is a human rights instrument with an explicit social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and describes how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where the protection of their rights must be reinforced. By the end of 2011, 108 countries have ratified the CRPD, but the inclusion of persons with disabilities during natural disaster management

initiatives remains highly inadequate. This is demonstrated by the fact that the response to the specific rights of persons with disabilities is often postponed or disregarded as most agencies fail to adequately plan for or include persons with disabilities in their disaster preparedness or response plans. The lack of inclusion causes severe inequities in access to services for people who had a disability prior to the disaster and also those who acquire a disability as a result of the disaster.

In order for the rights of persons with disabilities to be meet in disaster management initiatives, it is necessary to propose direct and practical solutions. These solutions must include persons with disabilities, their families and communities as well as Disabled Persons' Organisations at every stage. Human rights-based approaches are often considered to be approaches that only lawyers are capable of as they may appear to be too obscure for people without human rights training to actually engage with; however, the CRPD offers a framework for addressing the rights of persons with disabilities that can be broken down into practical tips for putting a rights-based approach into action. Therefore, the aim of this chapter is to introduce a human rights-based approach for meeting the needs of persons with disabilities in disaster management initiatives and to present practical strategies for operationalizing this approach. Following this introduction, part 2 of this chapter introduces a human rights-based approach to disability. Part 3 uses the cases of the January 2010 earthquake in Haiti and Hurricane Katrina in the United States in 2005 to illustrate how the dimensions of a human rights-based approach play out in real-world situations. Finally, in part 4, practical strategies for addressing the rights of persons with disabilities in disaster management initiatives are presented.

2. Using a human rights-based approach to promote the inclusion of persons with disabilities in disaster management initiatives

A human rights based approach includes explicitly including human rights into programs. Using a rights-based approach focuses on the way initiatives are undertaken and also the outcomes (Klasing, Moses & Satterthwaite, 2011). "A rights-based approach is set apart from others in that it draws on the existing legal framework of human rights, which codifies relationships between rights-holders—those individuals and groups with valid claims and legal entitlements— and duty-bearers, those with correlative obligations to those claims or legal entitlements" (Klasing, Moses & Satterthwaite, 2011, pp. 11). The overall role of a rights based approach is to strengthen the opportunities for rights-holders to claim their rights and the capacity of duty-bearers to respond to such claims and fulfill rights.

There are nine core international human rights treaties (see Figure 2), which can guide the way disaster management initiatives are undertaken. These human rights instruments all reinforce the rights of persons with disabilities, because the principle of non-discrimination is a fundamental part of all international human rights instruments, thus guaranteeing their relevance to persons with disabilities.

Despite the inclusion of persons with disabilities in all of the treaties and the fact that the CRPD contains neither new human rights nor new disability rights, the CRPD was chosen as the focus of this chapter as it is the only disability specific convention and as such shapes the existing set of general human rights to the specific situation of people with disabilities and also because it provides disability specific references.

1. International Convention on the Elimination of All Forms of Racial Discrimination (in force January 4, 1969)
2. International Covenant on Civil and Political Rights (in force March 23, 1976)
3. International Covenant on Economic, Social and Cultural Rights (in force January 3, 1976)
4. Convention on the Elimination of All Forms of Discrimination against Women (in force September 3, 1981)
5. Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (in force June 26, 1987)
6. Convention on the Rights of the Child (in force September 2, 1990)
7. International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (in force July 1, 2003)
8. Convention on the Rights of Persons with Disabilities (in force May 3, 2008)
9. International Convention for the Protection of All Persons from Enforced Disappearance (in force December 23, 2010)

Fig. 2. The nine core international human rights treaties

The Convention on the Rights of Persons with Disabilities is a universal, legally binding standard that was adopted in 2006 and entered into force in international law in 2008. The purpose of the Convention on the Rights of Persons with Disabilities is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (CRPD, 2006). Member States that have signed the Convention agree to promote, protect and ensure the full and equal enjoyment of the human rights of persons with disabilities and prompt respect for their inherent dignity. The Convention provides a moral compass for state actors, as the primary guarantors of rights; however, in some circumstance including the weakening of a state following a natural disaster, non-state actors (e.g., NGOs) may respond and take on some of the state's obligations. Non-state actors may take on these obligations in efforts to ensure the provision of services and to prevent further suffering caused by the disaster (Klasing, Moses & Satterthwaite, 2011). The Convention also explicitly underpins disability work for United Nations organizations (e.g., World Health Organization, UNICEF) and many international organizations (e.g., CBM International, Handicap International [HI]). The Convention covers a number of key areas such as accessibility, personal mobility, health, education, employment, habilitation and rehabilitation, participation in political life, and equality and non-discrimination. Specifically to natural disasters, Article 11 of the CRPD embeds, into international law, the need for measures for the "protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters".

There are eight guiding principles that underlie the CRPD (see Figure 3). These are articulated in the text of the Convention in order to guide the interpretation and implementation of the rights enshrined by the Convention. The principles offer a rationale and clarity to why and how the CRPD should and can be used. They provide a guide for stakeholders to consciously include the rights of persons with disabilities in disaster

management initiatives and as such are identified and discussed below and also underlie the strategies identified in section 4.0 of this chapter.

> 1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
> 2. Non-discrimination
> 3. Full and effective participation and inclusion in society
> 4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
> 5. Equality of opportunity
> 6. Accessibility
> 7. Equality between men and women
> 8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Fig. 3. Guiding principles that underlie the CRPD (CRPD, 2006)

2.1 Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

The first principle recognizes the rights and agency of persons with disabilities. It emphasizes that rather than simply seeing people with disabilities as passive victims of assistance, people have the right and thus need to be involved. When applied to natural disasters, this principle emphasizes the involvement of persons with disabilities and disabled peoples organizations in disaster management initiatives. When persons with disabilities are included in leadership roles not only are disaster management initiatives improved in the short-term, but their involvement also helps to avoid rights violations in future occurring disasters.

2.2 Non-discrimination

Non-discrimination means treating people fairly without prejudice. The principle of non-discrimination is fundamental to all human rights instruments and includes acts of both direct and indirect discrimination. Persons with disabilities must not be denied access to emergency evacuation, shelter, food aid, non-food items, health care and other services integral to the disaster response. It is also important to take steps to ensure equity within groups of persons with disabilities: that persons with disabilities are not discriminated against on the basis of race, gender, religion, impairment, or other classifications. Too often persons with disabilities are portrayed as a homogenous group, which obscures the diversity between people with disabilities. This phenomenon has been noticed within other marginalized groups, as is evident in the quote from Amartya Sen, below.

The most common example of ways in which discrimination can occur in disability-focused interventions is that, in trying to reach persons with disabilities, project implementers may fail to recognize the gendered dimensions of service uptake and although men with disabilities may receive the services they need, women with disabilities due to gendered dimensions of resource distribution may not receive the necessary services (see Guiding Principle 2.7).

> "A small peasant and a landless laborer may both be poor, but their fortunes are not tied together. In understanding the proneness to starvation of either we have to view them not as members of the huge army of the 'poor', but as members of particular classes, belonging to particular occupational groups, having different endowments, being governed by rather different entitlement relations. The category of the poor is not merely inadequate for evaluative exercises and a nuisance for causal analysis, it can also have distorting effects on policy matters" (Sen, 1981, pp.3).

2.3 Full and effective participation and inclusion in society

Full and effective participation and inclusion in society is recognized in the Convention as a general principle (Article 3), a general obligation (Article 4) and a right (Articles 29 and 30). Participation is important to correctly identify specific needs as decisions made about persons with disabilities are better informed and more likely to produce positive outcomes if they are involved in the process. Participation and inclusion also empowers individuals, as persons with disabilities with no voice are vulnerable to abuse, violence and exploitation, since they have no means of challenging this oppression. Through participation the needs and concerns of persons with disabilities become clearer, and persons with disabilities have the opportunity to raise issues and hold decision makers accountable. Through inclusion, persons with disabilities become more visible and persons without disabilities have the opportunity to learn and change from the experience of persons with disabilities – and vice-versa.

2.4 Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

Disability is an intrinsic part of life and impairments do not always need to or should be "fixed" or rehabilitated. Programs must meet people where they are, through designing programs to accommodate varying abilities, rather than expecting people (and their bodies) to conform to a certain norm. Often this norm is attainable to few people beyond young, non-disabled men. Programs that address the rights of persons with disabilities will benefit a range of people beyond those labeled as disabled, such as pregnant women, young children and the elderly.

2.5 Equality of opportunity

Even though people with certain disabilities may not be able to conduct certain tasks as a result of their physical or intellectual impairments, they should still be afforded with every opportunity to participate in society. Accommodations should be made to ensure that they have opportunities to go to school or attend informal educational opportunities, to participate in daily social life and practice the religion of their choice.

2.6 Accessibility

Accessibility appears both as a general principle (Article 3) as well as a stand-alone article (Article 9). Accessibility is essential to enable persons with disabilities to live independently and participate fully in life – it is therefore an outcome as well as a means to the realization of rights. Within the CRPD accessibility includes not only the accessibility of the physical

environment but also accessibility to transport, communication and information in urban and rural areas.

2.7 Equality between men and women

"Women living in post-disaster situations are at daily risk of physical, emotional, economic and social harm in ways that have no direct parallels for their male counterparts" (Davis & Bookey, 2011, pp. 2). While disability correlates with disadvantage, not all people with disabilities are equally disadvantaged. Women with disabilities experience the combined disadvantages associated with gender as well as disability (WHO, 2011). Evidence suggests that women are more likely than men to become disabled during their lives due to access to fewer resources, receiving less medical attention when ill and getting less preventative care and immunizations. Data compiled in the World Report on Disability demonstrates the larger of burden of disability amongst women as compared to men in both low and high-income countries, although the difference is even greater in low-income countries (WHO, 2011).

2.8 Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Children with disabilities are especially vulnerable following natural disasters. They are often the first to be abandoned by families and the last to receive relief and support (UNICEF, 2007). Several factors that increase the vulnerability of children following natural disasters include the collapse of social infrastructure, inequitable access to social services, absence of law and order, and loss of autonomy resulting in dependence on others due to disruption of communities and families.

3. Using a human rights-based approach to examine disaster management initiatives: The cases of Haiti and the United States

3.1 Haiti earthquake of 2010

On January 12, 2010 at 4:45 pm (local time) an earthquake measuring 7 on the Richter scale hit Haiti. The epicenter of the most violent earthquake in 200 years in Haiti was located 14 kilometers from the capital city of Port-au-Prince. This disaster drew attention to the rights of persons with disabilities in disaster response efforts, especially due to the number of new amputations and injuries. Before the earthquake, it was estimated that between 500 000 to 800 000 Haitians were living with a disability (PAHO, 2010). It is estimated that as a result of the earthquake there were 300 000 new injuries, with approximately 1500 people with amputations, hundreds of thousands with fractures and close to 200 people with spinal cord injuries (O'Connell et al., 2010). In addition to physical injuries, post quake, there was a high incidence of post-traumatic stress disorder, psychosis and hysterical paralysis (Phillips, 2011). The earthquake caused the destruction and damage of over 300 00 homes, the majority of government and ministerial buildings and a large number of hospitals and health centers (Government of the Republic of Haiti, 2010).

In 2009, Haiti signed and ratified the CRPD. Other initiatives supporting the rights of persons with disabilities that were in place prior to the earthquake included the Secretariat of State for the Integration of Persons with Disabilities in Haiti (SEIPH) under the Ministry

Fig. 4. The earthquake in Haiti caused significant damage to buildings in Port-au-Prince (UN, 2010)

of Social Affairs and Labor, which advocated for the rights of persons with disabilities and inclusive programming. Nonetheless, the pre-existing challenges of implementing rights-based approaches in Haiti (Klasing, Moses, & Satterthwaite, 2011) and the further weakening of the state following the earthquake and its resultant of loss of personnel and infrastructure created a situation where the government alone was not equipped to address all of the rights for persons with disabilities in Haiti. Despite the numerous challenges, there are also many examples of success of how the rights of persons with disabilities were met following the 2010 earthquake in a place where resources were limited and in which logistical and security constraints placed severe limitations on what could be achieved. Opportunities also arose out of the disaster, as the devastation of infrastructure in Haiti created an opportunity through the reconstruction process for the rights of persons with disabilities to be met. Not only did reconstruction offer an opportunity for the building of accessible communities but also an opportunity to facilitate social and economic integration.

3.2 Hurricane Katrina 2005

Hurricane Katrina of the 2005 Atlantic hurricane season was one of the five deadliest hurricanes in the history of the United States (Knabb, Rhome & Brown, 2006). Destruction from the hurricane occurred all over the Gulf Coast, but the most significant number of deaths occurred in Louisiana, as eighty percent of the city was submerged (United States Congress, 2006). When the hurricane arrived in Louisiana, over 350,000 families were living

with a member with a disability (US Census Bureau, 2000). While there are no concrete estimates of how many people with disabilities died as a result of Hurricane Katrina, 71 percent of the 1,330 victims were older than 60, suggesting people living with disabilities suffered disproportionately (White House, 2006). Furthermore, as indicated in the report that assessed the impact of Hurricane Katrina on persons with disabilities by White et. al (2007), "every person interviewed lost their residence and household belongings, while over half lost items that significantly affected their independence for weeks or even months after the storm. These included such things as vehicles, durable medical equipment, or accessible housing. Many also lost the family or social networks that sustained them" (p. 12). Despite the United States having the Americans with Disabilities Act (ADA), which requires emergency preparedness and response programs to be accessible to people with disabilities and the fact that most of the states had emergency shelters and designated transportation providers allocated throughout, the losses occurred because the services were not significantly coordinated to maximize evacuation of residents with disabilities (White et al, 2007) and many local emergency management offices did not have appropriate plans in place to account for the needs of person with disabilities.

Fig. 5. The potential needs of people using mobility devices in times of disasters were not significantly considered (USA TechGuide, 2011).

Examining the disaster management initiatives of the 2010 Haiti earthquake and the 2005 Hurricane Katrina through the lens of a human rights-based approach, using the principles of the CRPD as a guide, reveals lessons that can be applied to future disaster management initiatives.

3.3 Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

3.3.1 Disabled persons organizations possess knowledge and expertise that is vital to the inclusion of persons with disabilities in disaster response. Following both disasters, there existed not only a lack of coordination between disaster response organizations and disabled persons organizations but also a lack of involvement of persons living with disabilities. The participation of persons with disabilities and disabled persons organizations is not only crucial but is also an obligation as cited in Article 4 of the CRPD, "decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, … through their representative organizations" (CRPD, 2006).

3.4 Non-discrimination

3.4.1 The needs of people with different disabilities should have been more widely considered. For example, many people will experience emotional and behavioral reactions following a natural disaster and disasters can also exacerbate pre-exiting vulnerabilities (Eustache et al., 2010). Despite the high incidence of post-traumatic stress disorder, psychosis and hysterical paralysis following the earthquake in Haiti, fewer services existed for people with psychological health conditions than those for people with physical impairments as government mental health services in Haiti were limited to two mental hospitals located in the West Department and the Ministry of Health and Population did not have any mental health units at general hospitals (PAHO, 2010). Furthermore, the specific needs of people with cognitive conditions and who were dependent on their caregivers but were separated from their caregivers as in the case in the United States or their caregivers were injured or killed as was commonly seen in Haiti were not widely addressed.

3.4.2 In regards to access to services, Haiti had few rehabilitation professionals of its own prior to the earthquake with disability and rehabilitation knowledge to address rights of persons with disabilities. Rehabilitation professionals are regarded as [one of the types of] professionals who are well equipped to help persons with disabilities and access to rehabilitation is considered a right according to Article 26 of the CRPD. The lack of rehabilitation providers was due to many factors including the absence of any rehabilitation professional training programs in higher education institutions and the lack of a nation-wide system for rehabilitative care. Of the Haitian rehabilitation providers that were working in country, training in disaster response was limited. From international rehabilitation actors, over 27 organizations provided specialized services for people with disabilities following the earthquake during the period from January through November 2010. Assistive device distribution to persons with disabilities included over 1 800 artificial limbs, 2 000 braces, 4 500 wheelchairs and nearly 10 000 walking aids. Over 23 000 people received physical therapy and nearly 37 000 received counseling (Eitel, 2011).

3.4.3 The evacuation plans for Hurricane Katrina often required a person being able to walk, drive, see or hear, and therefore many plans were not appropriate for people living with disabilities. For example, most evacuation buses did not have wheelchair lifts. Furthermore, when evacuated, persons with disabilities were often evacuated without their medicine, medical equipment, wheelchairs or guide animals. Most people in the United States received emergency information about the storm from the television; therefore, effective communication may not have been available to people with sensory disabilities. "Without closed captioning or sign language interpretations of the televised emergency information, people with hearing disabilities often remained unaware of the scope or nature of the emergency. Moreover, effective communication was troublesome for people with visual impairments because television broadcasts typically did not provide audio descriptions of visual displays of critical information, such as maps or lists of affected areas" (Emergency Management, 2006, p. 4-5).

3.4.4 Persons with disabilities were not entirely included in mainstream rescue and evacuation services, relief access, safe location/ adequate shelter, water, and sanitation services in either Haiti or following Hurricane Katarina due to the inconsistent awareness of the rights of persons with disabilities among mainstream relief groups and the thought that including persons with disabilities may require highly specialized expertise, costly facilities or complex programs.

3.5 Full and effective participation and inclusion in society

3.5.1 Persons with disabilities and representatives of Disabled Peoples Organizations were not consistently invited to attend disaster planning meetings, camp coordination meetings and cluster coordination meetings in Haiti. Not including persons with disabilities or representatives of Disabled Peoples Organizations resulted in the absence of recognition of the broad spectrum of rights persons with disabilities. Where persons with disabilities were involved, including in the "Inclusion Working Group", that was situated under the health cluster, there remained a divide between them and the organizations providing services, as non-governmental organizations had a separate "Injury, Rehabilitation and Disability Working Group" which rarely included a person with a disability. It was not until over one year post-disaster (May 2011) that these two groups merged through the recognition that collaboration was essential to both the appropriateness and the sustainability of services.

3.5.2 A National Plan for People Living with Disabilities in Haiti led by SEIPH, was developed and guided by the CRPD principles, which considered the needs of the range of stakeholders and the rights of persons with disabilities. The Plan was created through consulting various Disabled Peoples Organizations in order to identify specific needs. Consensus was gained from Disabled Peoples Organizations by having representatives attend planning workshops and final validation was also gained through having representatives review the Plan's final objectives and actions.

3.5.3 Despite having plans in place for persons with disabilities prior to the Hurricane in the United States, the plans failed because service organizations did not sufficiently involve persons with disabilities in the planning processes. One example of a plan failure is when during the Katrina evacuation, many people with disabilities could not evacuate because to

do so would require them to abandon support services and personnel. The need for some people to receive support from personnel in order to evacuate had not been sufficiently considered by all disaster response organizations.

3.6 Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

3.6.1 As a range of international organizations largely provided the disaster response services in Haiti there appeared to be an unrealistic sense of the local resources available. This was seen when people were fitted with medical equipment that could not be maintained with existing technology or human resources in Haiti, resulting in a poorer fit on the individual and more equipment breakdowns.

3.6.2 Following Hurricane Katrina, many shelters refused to admit persons with disabilities or inappropriately referred them to special needs shelters. "American Red Cross implemented a policy to refuse shelter access for people with obvious disabilities. Sometimes, people with disabilities were referred to special needs shelters. Families were sometimes split up when Red Cross officials refused to allow family members with disabilities to access the general shelters. In other instances, people with disabilities were admitted to the general shelters but segregated from the general population by physical barriers" (Emergency Management, 2006, p. 12).

3.7 Equality of opportunity

3.7.1 One example of creating equality in opportunities in post-disaster responses is interim employment initiatives. One such cash-for-work project in Haiti included a segment devoted and made explicitly to securing positions for people with amputations, inherently improving the inclusivity of the entire program towards persons with disabilities. However, there were too few of such opportunities created for persons with disabilities as in Haiti the majority of cash for work opportunities emphasized physical labor and thus were in line with the strengths of persons without disabilities than those with – thereby creating an inequality of opportunity.

3.7.2 After meeting the essential short-term needs of evacuees in the United States, such as housing and food, government turned toward employment concerns. Government worked to provide employment opportunities for persons with disabilities affected by the hurricane. In 2005, President Bush signed into law the "Assistance for Individuals with Disabilities Affected by Hurricanes Katrina and Rita Act of 2005," providing $25.9 million in vocational rehabilitation funds for hurricane survivors (U.S. Department of Education, 2005).

3.8 Accessibility

3.8.1 The physical accessibility of services in Haiti was a barrier as persons with disabilities were particularly affected by changes in terrain and the amount of rubble resulting from the earthquake. For example, people who used wheelchairs could not roll over the mounds of rubble. To address the barrier of accessing services, several international organizations have partnered with local organizations in order to deliver services to persons with disabilities in their homes through a community based rehabilitation model.

3.8.2 Following Hurricane Katrina, many evacuation sites were not equipped for people with disabilities. According to the National Organization on Disability (2009), "Over 80 percent of the shelters did not have access to TTY; 60 percent of the shelters did not have captioning TV capabilities. Less than 30 percent had access to sign language interpreters (pp. 14)." These lack of services resulted in people who were deaf not being able to use phones to contact family members or arrange for housing and people with visual impairments not being able to access information only handed out in flyers. Recognizing that the rights of persons with disabilities were not being met, non-profit organizations, such as Centers for Independent Living (CILs), provided persons with disabilities in shelters with the resources that the shelters lacked, such as teletypewriters, wheelchairs, walkers and oxygen.

3.8.3 In Article 2 of the CRPD, universal design "means the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design". Building with a universal design benefits everyone; however, universal designs (e.g., ramps, handrails) were not followed in the construction of the majority of the formal displaced persons camps throughout Haiti due in part because the camps were planned with people who were not familiar with universal design. With over 1.3 million people living in camps (IOM, 2010), camp design features such as large ditches running through the camps without bridges being built across, made the camp not accessible not only to persons with physical disabilities but also made it difficult for older adults and small children to walk around (see Figure 6). Accessible toilet facilities were also not widely available in most camps. Making a toilet accessible includes building a toilet with a ramp, wide door, and handrails outside and inside the toilet stall. This design could have increased the accessibility and safety of toilets not only for people with mobility impairments but also for the elderly, pregnant women and parents needing to accompany their children to the toilet. The barriers to accessibility were even greater in the informal camps (e.g., Camp Canaan), where no planning occurred at all as people moved in and the camp grew larger.

3.8.4 Following the Hurricane, the most common forms of short-term housing for disaster survivors were apartments and trailers; however, persons with disabilities were not being supplied with accessible trailers and often had difficulties securing accessible apartments. When trailers were deemed to be accessible because they had ramps at the entrances; they often did not meet the needs of persons with mobility impairments due to their lack of space to turn a wheelchair and inaccessibility of bathrooms and kitchens.

3.8.5 It is estimated that more than 500 000 people left areas affected by the earthquake in Haiti to either return to rural homes or live with extended family or hosts (IOM, 2010). Despite the majority of people living in rural areas the geographical accessibility of services, both disability specific and not, were limited to the capital city of Port-au-Prince, creating a barrier for all Haitians living in rural areas. However, this barrier created by the geographic concentration of services was more severe for persons with disabilities, as a person with a physical disability would have had more difficulty hiking down the hillside, jumping on a camion and being able to pay the fare.

3.8.6 Information was not widely distributed in multiple formats about disaster response services available. Haiti is a country where oral communication strategies are culturally entrenched, so when communication strategies for individuals with hearing impairments were not used (e.g., visual communication), messages, warnings and other forms of communication did not reach them.

Fig. 6. Large ditch to be crossed when using the footpath within the camp (Camp Corail, Croix-des-Mission, Haiti)

3.9 Equality between men and women

3.9.1 In a culture that prioritizes men, following the earthquake in Haiti, men were seen as the priority for the receipt of food and non-food items and assistance; therefore, steps should have been taken to ensure that aid destined for women with disabilities actually reached them.

3.9.2 In both Haiti and the United States the relative lack of status, power, and resources put many women with disabilities at risk of being sexually assaulted in shelters and camps. In many cases, after an assault occurred there was no one for the victim to report the incident. In a number of instances in the United States when an assault was reported to a police officer, an official statement was not taken because of other life-threatening priorities (Thornton & Voigt, 2007).

3.10 Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

3.10.1 It is estimated that up to 80% of schools within Port-au-Prince, Haiti were damaged or destroyed as a result of the disaster (CBM, 2011). Education initiatives set up post-disaster did not consistently take an inclusive education approach and therefore some of the schools constructed after the earthquake by agencies such as UNICEF were built with physical accessibility in mind, but so far efforts have been piecemeal (see Figure 7).

Fig. 7. New classroom buildings with ramps (Camp Corail, Croix-des-Mission, Haiti).

3.10.2 Over 200,000 school age children became homeless because of Hurricanes Katrina and some estimates indicate that 12 percent of the displaced students had disabilities (Council of Parent Attorneys and Advocates, 2005). Some student-evacuees with disabilities were unable to register for school because they had not secured housing in the evacuation area and therefore could not provide documentation. This issue was addressed when the McKinney-Vento Homeless Assistance Act came into effect and allowed students to attend school despite the lack of formal documentation. Despite the Act coming into effect some schools still denied students their rights to necessary educational services because many student-evacuees with disabilities did not bring documentation about the nature of their disability when they fled from the hurricane (Council of Parent Attorneys and Advocates, 2005).

4. How to begin: A four-point plan for how disaster management initiatives can take a rights-based approach to disability

The review of the 2010 Haitian earthquake and the 2005 Hurricane in the United States demonstrates how persons with disabilities were not included in disaster response, despite the fact that there is a human rights imperative do so. Reviews of the inclusion of disability into the responses of other disasters have demonstrated similar findings (IFRC, 2007). The proposed explanations for this repeated discrimination in the face of international conventions and laws include the perspective that a) disability is a specialized field and b) that accommodating for disability implies increased expense and time (IFRC, 2007; Handicap International, 2010).

Seeing as a sizeable proportion of the population is disabled (WHO & World Bank, 2011), disability should be seen as an issue of importance to all actors along the continuum (preparedness, prevention, response and rehabilitation) of disaster management initiatives. Disability occurs in every continent, amongst people of every nationality, race and religion. The consideration of disability rights by all disaster management initiatives, as opposed to the focused contributions of a precious "specialized" few, will improve the probability that persons with disabilities rights are met. Furthermore, with good planning and foresight these considerations need not be expensive or onerous. The building of accessible physical structures serves as an example of this principle: building to ensure accessibility is of a similar cost as compared to building an inaccessible environment. Furthermore, to do so is far more effective and efficient than trying to adapt and retrofit built environments once local expectations or legislation require such accessibility. Through this example we can see how foresight in a disaster management initiative can lead to an overall cost savings while yielding a result that meets human rights.

The strategies presented here are intended to be the starting point of a good planning process to allow "mainstream" (i.e., non-disability focused) disaster management initiatives to meet their obligation to address the rights of persons with disabilities. These strategies are applicable along the continuum of disaster management initiatives and practical but allow for flexibility of application. Individual initiatives are free to determine the precise way in which they will address disability as part of their disaster intervention (HI, 2005), but it is

now well established that the longstanding tactic doing nothing (Wisner, 2002) is no longer acceptable.

In order to respect the human rights principles surrounding the inclusion of persons with disabilities, every disaster management initiative should include:

- making a commitment to persons with disabilities, review this commitment regularly and incorporate it into the idea of success;
- involving persons with disabilities in positions of leadership and decision-making processes;
- training staff on issues that persons with disabilities face; and
- building as much as possible using universal design principles.

4.1 Make a commitment to persons with disabilities, review this commitment regularly and incorporate it into the idea of success

Effectively including persons with disabilities as part of a disaster response begins with a conscious decision. When this decision is made it can become second nature to incorporate the rights of persons with disabilities and identify the gaps as they arise. Current practice in all fields of disaster response includes a review of activities to ensure that they have successfully met their objectives and a review of these objectives to ensure that they are appropriate for the situation. The intertwining of disability into this framework can have a significant impact upon how the objectives are framed and subsequently how activities are oriented.

For example, let us imagine an intervention that is designed to accommodate 90% of a given population that is affected by a disaster, which could be a realistic and reasonable target in a challenging situation. If the implementation and evaluation of this intervention do not account for disability there is a high probability that the intervention could effectively be considered successful by remaining completely inaccessible to the 10% of the population that is disabled. In this case, the design of the intervention would be ignorant towards meeting the rights of persons with disabilities and the evaluation would likely remain uncritical towards this ignorance, especially in light of the success of the intervention according to its own objectives. By contrast, let us consider an intervention where the objective was to reach 90% of a given population including 90% of persons with disabilities. This intervention would need to incorporate specific considerations to allow it to be accessible to persons with disabilities from the outset. If during the evaluation phase it was found that 95% of persons without disabilities but only 50% of persons with disabilities were able to access the service there would likely be a critical analysis of the barriers that persons with disabilities faced that would stimulate reflections, learning and improvements for subsequent interventions.

The preceding example is intentionally simplistic in order to clearly represent the influence that a conscious incorporation of disability can have on programming. The same principle applies to the more complex planning and implementation that are used in the many aspects of disaster response; the key is that the decision must be made to include disability. Furthermore, it is really only with the acceptance of this first step that the additional strategies proposed here can be utilized to their full effectiveness.

4.2 Involve persons with disabilities in positions of leadership and decision-making processes

People are the true experts of their situation and therefore are in the ideal position to give recommendations about how to best include disability into a disaster response (HI, 2005). Those involved in disaster management should therefore seek out persons with disabilities and include them in the leadership and decision-making process (IFRC, 2007). Beyond the principle of "full and effective participation and inclusion" being an underlying principle of the CRPD (CRPD, 2006), there is empirical evidence to support that including persons with disabilities the leadership of disaster management activities reduces their vulnerability and improves the effectiveness of the initiatives (United Nations Enable, n.d.). It must be noted that the inclusion of persons with disabilities in disaster management leadership is best done at as early a stage as is possible; and far easier in the disaster prevention or preparedness stages than it is in the disaster response stage when there is less available time and communications are hampered (IFRC, 2007).

To facilitate the operationalization of this principle, the National Organization on Disability in the USA has identified types of disability organizations (see Figure 8) and recommended strategies that disaster management initiatives can use to approach them (National Organization on Disability, 2009). Although the organizations and the strategies are contextually oriented to the situation in the USA, they provide a framework and methodical structure that could be adapted and emulated according to the structures available in other jurisdictions.

The category "advocacy organizations" merits special mention. This type of organization generally consists of persons with disabilities who have organized themselves into disabled persons' organizations. Collaboration with disabled persons' organizations allows the benefits of improving the probability that the persons with disabilities involved with the disaster management activities will arrive with more leadership experience and systematically including persons with disabilities who are members of that association through the organization's representatives. Nonetheless, it must be known that the inclusion of representatives from a disabled persons' organization does not constitute the perspectives of all persons with disabilities: just as persons with disabilities constitute a heterogeneous group, so are disabled persons' organizations diverse in nature. A given disabled persons' organization could be focused on a given community (i.e., city or town) or embedded within an institution (e.g., a university or a union). Furthermore, a disabled persons' organization could link members with a single type of disability or characteristic (i.e., a given gender or age category) or be more broadly focused upon people from all walks of life with all types of disabilities. It is thus important to remember this variety when reaching out to disabled persons' organizations (and persons with disabilities more generally) in order to recognize the strengths and potential gaps in perspective.

A final point to consider when incorporating persons with disabilities into the leadership of disaster management activities is that of true participation: as members of a generally disadvantaged and often neglected group, persons with disabilities are often on the weak side of an imbalanced power dynamic. Disaster management activities must therefore be aware of the possibility of this dynamic to limit participation and seek ways to encourage true and equitable participation.

Government Organizations

Usually, the best place to start in selecting and involving disability representatives is the disability agency or task force within the Governor's office, the Mayor's office, or the state or county government. Typically, officials in these organizations can assist in identifying a cross-section of disability representatives within a locality. Other government entities that may be helpful include:

- Department of Health and/or Mental Health
- Department of Aging
- Department of Veterans Affairs
- The local Americans with Disabilities Act (ADA) Coordinator

Institutional Participants

Examples of institutional partners are:

- Representatives from the home-based care industry, such as the local Visiting Nurse Service and the Home Health Aides Association
- Residential healthcare facilities, such as nursing homes, skilled care homes, and assisted living facilities
- Hospital associations
- The local end stage renal disease (ESRD) network (a.k.a. local dialysis network)
- The ambulette and private accessible transportation industry

Advocacy Groups

It is important to include representatives from advocacy groups in the disability community, such as:

- The local Independent Living Center
- Local groups serving specific and general disability populations (e.g., people who are blind, deaf, or have limited mobility or cognitive disabilities)
- Individuals with disabilities who, though not affiliated with a group, are known to emergency professionals and who are willing to participate in the planning efforts

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Fig. 8. Examples of organizations to approach in order to incorporate the perspective of persons with disabilities in disaster management activities (National Organization Disability, 2009, pp. 25-26).

4.3 Train staff on issues that persons with disabilities face

Inclusion efforts will not be successful if they lack broad support in an organization, especially at the level of the front-line staff. Literature on this subject cites specific situations where the accessibility of a disaster response towards persons with disabilities was directly influenced by the awareness of frontline staff. Clear examples from the 2007 World Disaster Report (IFRC, 2007) include instances of persons with disabilities being turned away from shelters where the staff thought that they would not be able to meet their needs, interpreted the presentation of their disabilities as intoxication or sent them to hospitals on the mistaken belief that they were sick or injured. The examples above demonstrate situations where the decisions and subsequent actions of staff created a barrier to a service for persons with disabilities. Training that increases awareness of the issues that persons with disabilities face in disasters can prevent the occurrence of such instances and can therefore improve the accessibility of services (IFRC, 2007).

Beyond the mitigation of unnecessary barriers to access, a staff that is more sensitive to issues of disability can provide an important positive contribution that can make services more accommodating for persons with disabilities (HI, 2005). Possibilities include frontline workers becoming more helpful towards persons with disabilities and their contribution to adaptations and creative solutions. Furthermore, frontline workers are in a key position to identify existing barriers and challenges and feed this information into a perspective of the disaster response. The improved sensitivity towards disability as stimulated by training can thus have an enormous impact upon how an organization addresses disability.

Handicap International (HI, 2005) recommends various training options that range from sensitization through the visits of persons with disabilities to the inclusion of disability specialists on an organization's staff. The ultimate choice in staff training will depend upon a given disaster management initiative's specific situation, which can be determined through the goals that it has related to disability and the input of the persons with disabilities as part of its leadership.

4.4 Build as much as possible using universal design principles

The benefits of universal design to persons with disabilities in disaster management are tremendous: in the event of an emergency it can be far more feasible for a person with a disability to evacuate from such an area, creating a direct and immediate effect upon the probability of survival. After the occurrence of a disaster the physical environment of emergency shelters or camps, of sanitation and hygiene facilities and of health care installations will all impact the well-being of persons with disabilities. The reconstruction phase of a disaster is an opportunity to design the built environment in order to allow the participation of persons with disabilities in society. Finally, holding disaster management planning sessions and meetings in locations that are physically inaccessible creates a barrier to participation in these activities by persons with disabilities that can in turn weaken the entire disaster management initiative's ability to incorporate a disability perspective.

Ramps are generally the best option to facilitate passage between areas of different elevations. Although ramps are not only of benefit to wheelchair users, it is their needs that often drive the design. Ramps should therefore be sufficiently wide to allow the passage of a wheelchair, have a handrail on each side and be of a grade that permits a wheelchair user to push him or herself up the ramp and have a landing that is large enough for a wheelchair user to turn around.

Sites should have at least one or a reasonable percentage of accessible **toilets or latrines.** That is to say that they have an approach that allows a person in a wheelchair to reach the entrance and an entrance that is wide enough to allow the passage of a wheelchair. Once inside the toilet area there must be sufficient space to allow a wheelchair to turn and handrails to allow someone to move from the wheelchair to the toileting surface. The toilet should include or be sufficiently close to an accessible facility for washing and hygiene activities.

Fig. 9. Examples of universal design features (HI, 2005; Smith, 1996)

To demonstrate examples of the practical aspects of universal design Figure 9 presents some features that are common to allow for improved accessibility, especially among people with

mobility impairments. Those seeking an introductory text on universal design principles should consult "The Universal Design File" made available by the Center for Universal Design in the USA (Story et al., 1998). Nonetheless, the effective and extensive application of universal design requires more discussion of the technical aspects than what is possible here. Where possible it is advisable for the leaders of disaster management initiatives to only contract to designers who are well versed in universal design or at least willing to learn. In situations where this is not possible those responsible for designing facilities should use the resources above as a starting point. Regardless of the designers' experience or interest in universal design, responsiveness to the feedback and perspectives of the persons with disabilities using the facilities remains a critical aspect of this strategy.

5. Conclusion

Due to the exclusion of persons with disabilities in disaster management initiatives, their rights are often unmet resulting in unnecessarily high rates of mortality and morbidity, deterioration of health conditions and loss of autonomy. The exclusion of persons with disabilities from disaster management initiatives can be reversed through using a rights-based approach to disaster management initiatives that are based on the guiding principles of the CRPD. The strategies presented above are intended to be complementary and interrelated: accessible physical environments and communications are precursors to allow the inclusion of persons with disabilities in planning and review activities. In turn, the inclusion of persons with disabilities in these activities will serve as a constant reminder of the necessity of accessible physical environments and communications. These processes must not be limited to merely the domain of disability specialists but rather embraced and incorporated into the modus operandi of all disaster management initiatives, and to do so is now necessary according to international convention. When inclusion is practiced effectively the rights of persons with disabilities are given equal weight to other considerations. Inclusion thus transforms the philosophy towards meeting the rights of persons with disabilities from one of peripheral concern to one of unconscious operating.

6. Acknowledgements

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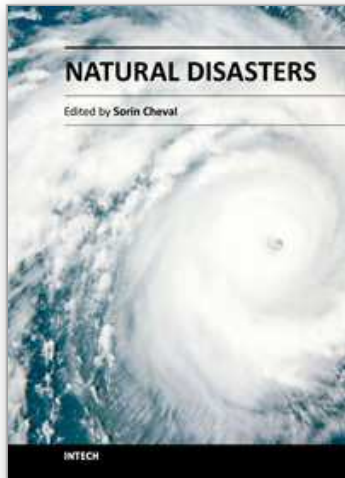
Natural Disasters

Edited by Dr. Sorin Cheval

The crossroads between a more and more populated human communities and their changing environment pose different challenges than ever before. Therefore, any attempt to identify and deliver possible solutions is more than welcome. The book Natural Disasters addresses the needs of various users, interested in a better understanding of hazards and their more efficient management. It is a scientific enterprise tackling a variety of natural hazards potentially deriving into disasters, i.e. tropical storms, avalanches, coastal floods. The case studies presented cover different geographical areas, and they comprise mechanisms for being transferred to other spots and circumstances. Hopefully, the book will be beneficial to those who invest their efforts in building communities resilient to natural disasters.

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