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Policies in the Context of Humanitarian Emergencies Involving Persons with Disabilities

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Résumé de l'article

Cet article présente une revue non-systématique discutant de la représentation
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d'urgence humanitaire. Cette revue a trouvé des différences dans la
représentation entre les organisations qui ont une approche spécialisée sur la
question du handicap et celles qui n'en ont pas. Ces dernières tendent à ne pas
mentionner les PLF comme constituant un groupe cible de leur intervention et
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Ceci peut également être influencé par le contexte de création des diverses
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contexte ou le modèle de charité et le modèle médical constituait les modèles
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Les solutions proposées pour contrer ce problème consistent à impliquer les
PLF et les organisations non-gouvernementales (ONG) faisant la défense des
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étapes de l'analyse, de la planification, du développement des règles,
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Policies in the Context of Humanitarian Emergencies Involving Persons with Disabilities

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Article

Abstract

This paper presents a non-systematic review discussing the representation of people with disabilities (PWDs) in humanitarian emergency policies. This review found a difference between disability-focused organizations and organizations not focused on disability. Those not focusing on disability tend not to directly mention PWDs as being a target group for their action. They also present PWDs in a more passive or victimizing role.

This may be influenced by differences in organisational culture, as well as by contextual differences in the creation of the non-governmental organizations (NGO's). NGO's that have existed for a long time were most commonly created in a charitable or a medical model, whereas more recently created organizations tend to be based on a rights oriented model.

Solutions proposed to counteract this problem include involving PWDs and disability advocacy NGOs in all steps of the analysis, planning, policy development, implementation, response and relief, rehabilitation and reconstruction. PWDs should be involved in disaster activities which would in turn allow for a better inclusion of persons with disability in policies and in relief efforts.

Key words : non-governmental organisations (NGO), handicap, people with disabilities, humanitarian emergencies, policies, non-systematic review

Résumé

Cet article présente une revue non-systématique discutant de la représentation des personnes vivant avec une limitation fonctionelle (PLF) dans les politiques d'urgence humanitaire. Cette revue a trouvé des différences dans la représentation entre les organisations qui ont une approche spécialisée sur la question du handicap et celles qui n'en ont pas. Ces dernières tendent à ne pas mentionner les PLF comme constituant un groupe cible de leur intervention et lorsqu'elles le font à les dépendre dans un rôle plus passif ou de victime.

Ceci peut être influencé par les différences de culture organisationnelles entre les diverses organisations. Ceci peut également être influencé par le contexte de création des diverses organisations. Les organisations plus anciennes ont été créées dans un contexte ou le modèle de charité et le modèle médical constituait les modèles dominants. Les organisations plus récentes se sont développées dans un environnement ou l'approche basée sur les droits est de plus en plus dominante.

Les solutions proposées pour contrer ce problème consistent à impliquer les PLF et les organisations non-gouvernementales (ONG) faisant la défense des droits des personnes vivant avec une limitation fonctionnelle dans toute les étapes de l'analyse, de la planification, du développement des règles, politiques, de la réponse et de la provision de services humanitaire, de la réadaptation et de la reconstruction.

Mots-clés : organisation non-gouvernementale (ONG), handicap, personnes vivant avec une limitation fonctionnelle, urgence humanitaire, politiques, revue non-systématique

Introduction

n 2007, the International Federation of Red Cross and Red Crescent Societies (IFRC) stated that, over the last ten years, "the number of people affected by disasters globally increased by one-third" (IFRC, 2007, 1). The last decade has seen a constant increase in the number of reported disasters, which represents an average of 250 million people affected annually. The greater part of these events occurs in countries of medium human development. The United Nations Development Programme (UNPD) estimates that 80% of the 650 millions of people with disabilities worldwide live in such countries, many of them facing the challenges of poverty and social exclusion. When they cause humanitarian crises, natural disasters and armed conflicts may significantly worsen their already harsh living conditions.

High, medium and low human development states, as well as international agencies, have been developing humanitarian policies and programs over the years, aiming at providing assistance to people involved in disasters and armed conflicts. Experience has shown that not all general policies are effective when it comes to meeting the needs of minorities such as people with disabilities. The difficulty resides in the broad approach that many humanitarian policies take in designing humanitarian policies insofar as the general population is considered on the forefront, whereas the vulnerable population is not given specific consideration. The expected result of this approach is a negative impact on particularly vulnerable segments of population that can be under-represented and under-served.

The intent of this article is to discuss the representation of persons with disabilities (PWDs) in policies, specifically in the context of humanitarian emergencies related to natural disasters and armed conflicts. This non-systematic review will draw from examples of best practices in place in order to better advocate for policies that would improve the assistance, protection and inclusion of persons with disabilities in situations of humanitarian emergencies. This paper does not pretend to be a comprehensive review on the topic, but focuses on a few existing policies for persons with disabilities in the context of humanitarian emergencies, and discuss the potential impact of the existence, or lack thereof, of these policies for the population requiring specific provisions.

Humanitarian Approach to Policy Analysis

It is of interest to retrieve some aspects of the reviewed policies and address step by step. The approach used is not based on standardized literature review methods, but rather on a non-standard selection of documents in accordance with the research question previously mentioned.

First, the description of persons with disabilities that each policy presents is likely to influence the policy orientation and level of inclusion of PWDs in the context of humanitarian emergencies.

Second, it is of interest to determine the humanitarian policies in place in each organization. This includes looking for specific provisions or inclusive measures in the context of disability. We certainly want to retrieve positive experiences and representations that can be used to list examples of good practices. Although it may not be an exhaustive list, it can nonetheless inspire other individuals and organizations to further develop them.

Wherever possible, specific requirements that can assist to plainly fill up the rights to security of persons with disabilities in humanitarian emergencies situations are identified.

The utility of using this approach is that it shows examples of different representations of PWDs by various organizations, which can lead to comparison between these representations. It is then possible to suggest areas to further explore. Practice may also be improved by identifying good practices and specific requirements.

In brief, the approach involves policy and best practices review:

- Description of the population;
- Identification of specific needs and requirements.

Description of the population

This involves reporting the ways in which the population affected by disasters is described, more specifically persons with disabilities.

In disaster management activities, it is important to think about disability in a broader perspective. Traditional definitions of disability are narrow and inappropriate. The term 'disability' does not only apply to people whose disabilities are noticeable, such as wheelchair users and people who are blind or deaf. The term also applies to people with heart diseases, emotional or psychiatric conditions, arthritis, significant allergies, asthma, multiple chemical sensitivities, respiratory conditions, and some visual, hearing, and cognitive disabilities (NCD, 2005). For the purpose of this paper, the definition from Section 1 of the Convention on the Rights of Persons with Disabilities will be used: *"Persons with disabilities are those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others"* (United Nations, enable). It is highly important to consider environmental factors when discussing disability. It can be assumed that, whenever these factors are not taken into account prior to an emergency, it will result in inadequacy of the environment, which will most likely increase PWDs' dependence following a disaster. If services were able to satisfy the needs of all categories of individuals, it would also limit the impact on PWDs in cases of difficulties in the normal operation of specialized healthcare systems, which could be difficult to access in times of crisis. One can also assume that another advantage of universal accessibility is to decrease the costs of operations, both during the acute disaster phase and response phase, and even more so during the recovery phase. If we think of the reconstruction phase

as a time during which more people than ever live with a disability in the country, why would not buildings and services be reconstructed under the scope of universal access? This has the potential of maximizing societal recovery as a whole and allowing access to productivity for all available capacities in the country. It really would mainstream disability issues at a time when people usually desire and are open to positive change.

Identification of specific needs and provisions:

This is the process of retrieving examples of areas requiring special interventions and practice recommendations encountered.

According to some anecdotal reports, there is a clear need for improvement in specific emergency preparedness and humanitarian relief policies for PWDs. We can retrieve a wealth of such omissions in the report *Saving Lives: Including People with Disabilities in Emergency Planning*. Such examples include, but are not limited to the fact that "people with disabilities have little input into countries disaster planning" (White et al., 2004). Another example of failure in emergency response identified by the California State Independent Living Council in 2004 is that the lack of captioning during the California wildfires of 2003 led many individuals unable to understand the level of danger they were exposed to, and the areas that were affected. Also, it was impossible for many people with a hearing impairment to hear broadcasts of emergency warnings for evacuation.

Another survey conducted by the California Specialized Training Institute and carried out with the collaboration of 1,200 Californian agencies concluded that "fewer than half had plans to assist people with disabilities".

These few examples not only highlight the need to include persons with disabilities in emergency preparedness, but they also consider the possible implications of not having planned in advance for the specific needs of PWDs. The presence of persons with disabilities and experts on that issue to the discussion

tables within every major emergency response organizations would help to alleviate this issue. Ideally, there should be PWDs involved in any emergency planning and response procedures, be it in specialized organizations or in every governmental or non-governmental settings.

Failures in responding to emergency requirements for PWDs that are observed often seem to happen where there is a lack of universal accessibility, therefore making exit routes and services inaccessible to persons with disabilities. The NCD report mentioned that some PWDs were physically unable to access temporary housing resources or were denied access based on misconceptions about their disability and referred to acute care hospitals. It is essential to accommodate special needs, and even more critical to set up inclusive services accessible to all.

Relationships between population description and identification of specific needs and provisions in humanitarian policy analysis

There is a logical relationship between the definition that an organization has of the population affected (in this case, PWDs) and the identification it makes of its specific needs and requirements. This also leads to acknowledge or deny certain roles for this segment of the population. In simple terms, someone can either be seen as a hopeless victim deserving pity or conversely, as an individual with specific capabilities and resources, and which is a subject of rights, and as such deserves to be supported in a time of struggle. What changes is not the individual himself, but our way to see things when dealing with a person living with a disability.

The impact of considering such an individual as a helpless victim is not only a form of disregard for the dignity and rights of that person, but also the inefficient treatment of his/her needs. Hence, there is an urgent need for organizations to take into consideration the specific requirements of persons with disabilities and incorporate these into main programs to render these most accessible. This would help organizations to provide better response to humanitarian emergencies, without leaving any sub-segment of the population behind.

Review of specific or inclusive policies encountered

Policies were selected following an informal research made for the production of a status report on resources listing existing documents pertaining to humanitarian emergencies and disability. Four policies were selected so as to represent a broad range of organizations, governmental and non-governmental, as well as disability-focused and non-disability focused organizations. Since this is an exploratory review, the process would benefit from a more extensive and formalized focus in a subsequent analysis.

The number of policies presented here is not sufficient in itself to represent the wide array of policies in various countries. However, it would be highly educative to analyze the differences between such policies related to the field of humanitarian emergencies in a subsequent study, as did Degener and Quinn in 2002 for national legislations, and to compare those to the existing international human rights treaties, particularly in the context of the Convention on the Rights of Persons with Disabilities. It is to be expected that a review of various national legislations would lead to the selection of the best practices from each country. It would also help to advocate for the ratification of international human rights treaties so as to advance rights protection of PWDs worldwide.

Case studies: National Council on Disabilities, International Disability and Development Consortium, International Federation of the Red Cross and Red Crescent, Handicap International

National Council on Disabilities (NCD), *Saving Lives: Including People with Disabilities in Emergency Planning*

This report includes a thorough analysis of the situation in the United States in terms of emergency preparedness, disaster relief and homeland security programs. It mainly draws from

past experiences, often with dire consequences. For example, the events that occurred on 9/11 when elevators were out of order and during which the vast majority of persons with mobility impairments did not survive. On one hand, this was in part due to the fact that the emergency response planned in their case was only to gather them in specific areas to wait for further assistance that never came in time. On the other hand, there was also the example of the Associated Blind (a NGO for the blind or low vision individuals) who organized evacuation drills and procedures, and whose staff all made it out safely from the ninth floor.

The NCD, while providing good comments about the general disaster preparedness, advocates the need for improvement in such planning. Those needs include:

- Ensuring that persons with disabilities are included into planning.

- Identifying persons with disabilities who would require specific assistance in the event of natural disasters so as to be reachable when necessary, for example in the event of a prolonged power failure.

- Ensuring that emergency preparedness material is available in various formats (large prints, Braille, audio, captioned websites and videos, etc.)

- Ensuring access to emergency warnings, including captions on broadcast systems. Conversely, persons with visual impairments might be unable to access the content of flashing news broadcasted on TV without the accompanying vocal messages.

- Organizing a number of mitigation activities, which involve installing hurricane shutters, strengthening roofs, clearing dry fire-prone plants from around buildings, bolting bookshelves to walls, placing fuses higher on walls of flood-prone areas, etc.

In the field of disaster recovery, the use of accessible information and program access is promoted. It is also important to ensure that facilities are physically accessible. Bowencamp (1994) and Lathrop (1994) even found that

some shelters denied access to some PWDs during the 1994 wildfires in California.

The report also identifies the need for accommodation in terms of food and water distribution, since there is not only a need for ensuring information accessibility, but also accommodation for those with physical impairments, including increased access to mobility and lower waiting times for those with limited capacity to wait in line for hours.

Also highlighted in this report is the need to prepare for a disaster, not only for PWDs, but for all professionals and volunteers involved in humanitarian relief activities. They must be trained specifically to assist PWDs and include them in the preparedness and relief activities, so as to consider all of their needs, but also their strengths and capabilities.

International Disability and Development Consortium (IDDC): Disability and Conflict. IDDC Seminar Report, May 29-June 4, 2000.

The IDDC consists of 14 international non-governmental organizations involved in disability and development issues. IDDC identified Disability and Conflict as a key issue because "in conflict situation disability increases and disabled people become even more vulnerable. Conflict situations are increasing, yet the needs and rights of disabled people are either ignored or dealt with very inappropriately".

Participants to the consortium were coming from a broad range of backgrounds, including situations of civil war, occupation, displacement, and mined areas. They experienced both short-term and long-term conflicts. Despite the identification of a range of actors, most discussions focused on the role of Disabled People Organizations (DPOs).

They drew examples of good practices, among which were included:

- Acting as an effective pressure group on the government.

- Working with families and communities to raise awareness and promote the rights of disabled children (Mozambique).

- Taking the lead in peace-making activities.

- Creating large and effective networks.

- Influencing policy and providing effective Community-Based Rehabilitation (Palestine).

- Program led by parents during the acute phase of the conflict thanks to a pre-established strong network of these parents before the war (former Yugoslavia).

The participants also distinguished three stages of conflict: pre-conflict, acute conflict and post-conflict stages. Examples of such good practices for the pre-conflict stage were that "concrete plans for evacuation, inclusive planning for basic needs provision and strong decentralized CBR were good strategies in pre-conflict situations".

The key messages summarized at the end of the paper that need to be shared were:

- Promoting DPO role in peace-making.

- Planning relating to conflict should be inclusive:
  - in NGO country plans;
  - in NGOs and DPOs internal workshops and publications.

- Key messages need to be extracted from the workshop report according to the needs of each country and their respective settings.

International Federation of Red Cross and Red Crescent Societies (IFRC)

The Red Cross and Red Crescent Societies are two of the oldest and largest existing humanitarian organizations. How does their position influence their approach in the area of emergency and disability situations? There was no specific document addressing this issue. However, it is possible to retrieve a number of times from their website and policy papers.

They have a policy against discrimination, as stated in their principles and values (IFRC, 2003). This is a broader policy statement, which is the starting point of the Resolution 3 (2005), who provides for a further exploration on that issue, and also guiding notes for National Societies.

These notes form a very detailed checklist allowing these Societies to monitor observance of the Federation principles. References to diversity include the following items: culture, language, ethnic origin, religion, age, sex, and minority groups. This checklist system is very operational for all items of diversity. It is important to note that there is no mention made here of persons with disabilities.

The importance of providing health services to the most vulnerable populations is reinforced and repeated in the new health policy (2005). The importance of providing these services to everyone without any regard to race, religion, colour, nationality, sex or origin is also highlighted.

Who are these vulnerable populations? It is specified in one of the pages encountered on the website, titled *About Disasters: What is Vulnerability?*, in which a large number of groups are listed, with 'disabled persons' being at the end of this list.

In a regional paper on the Inter-American Conference (2003), the health disparity experienced by PWDs enjoys a much more prominent place, where it is stated that: "This situation particularly affects women, children, elderly people, disabled persons as well as geographically isolated populations".

The other mention of persons with disabilities encountered in the literature was through a very specific program focusing on the protection of persons living with albinism in the Great Lakes region.

To summarize the IFRC findings, the IFRC based its work on core values that are at the core of humanitarianism, dedicating its attention to various segments of the population. It also included PWDs, even though this is a very discrete part of the international policies in place. One can thus wonder whether it could

involve the risk of neglecting the provision of an inclusive approach to PWDs despite the specialized and well-renowned operational capacities of the IFRC in situation of humanitarian emergencies. This is only an assumption, as it would be essential to observe how the inclusion of PWDs is dealt with in all spheres of the organization's work.

Then simple initiatives could be implemented, along with ensuring a better visibility of this population in general policies to promote a more specific approach for and with PWDs, just like the Inter-American group did.

Handicap International (HI)

It is very educational to see how Handicap International (HI) deals with the specific approach taken towards people with disabilities in situations of humanitarian emergencies. It should be noted that HI defines itself neither as an emergency relief nor a development organization, and chooses to promote the fact that the development process should be planned immediately during the emergency phase, but also that the emergency phase should be considered during the development process (Scherrer, 2006).

HI defines this approach by the fact that their mandate is not based on a specific field of action, but rather on a specific population: people with disabilities. As disabilities generally are of a long-term nature, so is the importance for HI to enroll this action in its long-term activities.

The actions of HI in emergency situations usually focus on the most vulnerable groups in each specific situation, with the intent to remove barriers in the provision of assistance in order to get the same extent as the other groups of the population. Thus, it is not only a matter of providing rehabilitation services, but ensuring accessibility to services provided by other service providers. HI also clearly states that their focus is not solely on specific needs, but also on strengths and capabilities to work with local Disabled People Organizations. This allows for increased efficiency, cultural proficiency and sustainability.

There is a wealth of examples of successful inclusion of persons with disabilities both in development and emergencies settings through HI. This seems to reinforce the importance of including PWDs in the primary policies and approach, therefore allowing for successful interventions that cater to their specific needs and capacities. The fact that PWDs are HI's primary target population is even more obvious in their approach and may explain to a large extent their success in this field. However, it should be possible to draw from these good practices in order to influence other mainstream organizations in relation to disability policies.

Comparison between policies

The first difference observed in the population description is between disability-focused and more generic organizations. This review is not intended to be representative of the humanitarian field at large, as the number of disability-related NGOs represented is proportionally higher. In the field, there are a greater number of organizations that are not disability-related. In the actual review, the IFRC description of the group requiring assistance barely mentions PWDs, and when such mention is made, it is in a more victimizing way than other organizations describe it. This leads to a lack of an appropriate response to cater for specific requirements, despite the huge experience of the IFRC in responding to humanitarian emergencies. Simple changes in the description of the population and its inclusion into main guidelines would probably improve the situation. This leads us to the change paradigm that existed between the creation of the IFRC and the other organizations. The Red Cross has existed long before any other organizations, established at a time when the medical model was the leading model, and when charity stood as the humanitarian motto.

Nowadays, as illustrated by the NCD, IDDC and HI experiences, there is a growing use of the human rights model which places persons with disabilities right at the center of the approach, taking into account their capabilities and promoting empowerment and full inclusion

so as to benefit the society at large. This shift of paradigm from the medical model to a human rights model explains the discrepancies in the description of this population and in the identification of their specific requirements.

Effectively, if one seeks to assist on a more charitable model, it will tend to take control of the situation rather than involving persons affected by the situation and allowing space to maximize use of their capacities. Using the same train of thought, it will generally aim at fulfilling their physical needs, but can often neglect the needs of human rights such as freedom of speech and decision-making skills.

The major impact observed in the identification of specific needs and requirements is that the organizations focusing on disability automatically involve PWDs, experts on the issue and disability advocacy NGOs in all steps of planning and analysis, which helps to be more sensitive and inclusive both throughout the process and at the end of it. This is the likely way to follow in the future.

Discussion

This review is not designed to be fully extensive. It would rather ideally use a systematic review of the literature and policies on the subject. This article offers an overview of the issue discussed, without pretending to include every existing policies and literature. However, it may serve as a basis for further review on the subject.

A number of institutions with an already good working knowledge of the specific needs of PWDs were reviewed in the present paper. In a further review, it would be interesting to select a more diverse background of NGOs policies.

Conclusion

Based on this non-systematic review, it is already possible to observe that there is a further need to plan, design and implement policies specifically for persons with disabilities in the context of humanitarian emergencies.

However, the evidence shown made it clear that there are also promising strategies to tackle the difficulties that may arise from emergency situations. These strategies should rely on inclusive policies, suitable for everyone and able to provide access to specific resources when needed. These strategies also have to involve PWDs in every step so as to maximize the use of existing abilities. Accessibility to information resources is a key point, which stresses the fact that such accessibility needs to be made available rapidly and to a larger portion of the population, as well as provided in various formats.

There is a need to draw examples from best practices already in place, often stemming from NGOs and DPOs with a greater experience in the disability area, as well as to establish similar policies in all of major humanitarian assistance organizations and governments. Much work, research and advocacy is left to do, but the current circumstances are encouraging considering the fact that there are already good examples to draw and use as models to create best practice guidelines.

The conclusion of a workshop led by Shanta Memorial Rehabilitation Center (2008) can resume a number of the key points outlined in the above policies through the adoption of a twin-track approach:

- Disaster management for persons with disabilities: Mainstreaming in policy development, planning, implementation, response and relief, rehabilitation and reconstruction.

- Disaster management with persons with disabilities: Capacity building of persons with disabilities on disaster safety practices and involving persons with disabilities in various disaster activities.

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