

Disaster Management and Disability: promoting a research agenda:

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Introduction

The Draft Convention of the Rights of Persons with Disabilities passed by the United Nations Ad Hoc Committee on Disability on 25th August 2006 under Article 11 proposes that "State parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights necessary measures to ensure protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters". The Convention has been signed by more than 100 nations-

The article in the Convention is the result of a number of campaigns across the globe by disabled people and groups. With a rough estimate of 10% or more of the population being disabled, this group it is inevitable would feel the need to demand attention in regards to disaster management and response. Due to these campaigns disabled people are coming to be included along with other 'vulnerable groups' i.e. children, older people, women and ethnic minorities, but as their specific vulnerabilities influences peoples' ability to cope and survive in a disaster and those most at risk need to be identified and action taken so that they are not discriminated. This can be done through research both normative and empirical. .

The paper discusses the creation of a research agenda built around the subject especially prioritize those with policy implication. The paper looks at the limited research carried out and the findings of this and then categories a further research need:

First, why do we bring this issue to a global health meeting⁹ Because:

Disabled persons suffer disproportionately during disasters. Disasters not only create impairment, they also further discrimination against already disabled people, compromising the determinants of their health and creating conditions for the worsening of their overall health and well-being. They perpetuate a cycle of poverty and isolation that is heightened during disasters. Understanding these issues is problematic as there is inadequate documentation of the structural, social, financial and cultural barriers to improving the health and well-being of people with disabilities, in general, and during disasters in particular.

The other issue is that more people become impaired during disasters. How can we prevent or minimize these impairments? We know that the main pathologies related to disasters are respiratory infections, over-infected wounds — leading sometimes to amputations, spinal injury, brain injury, tetanus cases and above all psychological trauma. This means that disasters directly cause an increase in impairment in all forms increases, and in mortality Situations of disasters also indirectly may lead to increases in impairment and ill-health, as the health and well-being of disabled people already living in the disaster zones is often neglected and un-addressed.

Health of already disabled people and response towards them during disasters

Studies following the recent disasters i.e. Tsunami, Katrina and Kashmir earthquake suggest that the disability needs were not taken into account and there was no preparedness for the same. The **mortality** of the physically disabled during the Tsunami was very high A report from Andaman Islands suggests that none of the 700 people with post polio paralysis in an island had not survived as they were not able run to reach the hill tops. Similarly reports from Indonesia & Thailand suggest high mortality among the physically disabled. Lack of access to shelters for the disabled and the absence of any plan for disaster response in the community is the root cause (fn.).

Epidemics such as typhoid, malaria and gastrointestinal diseases are known to break. Clean drinking water can become unavailable for weeks or months together. Many thus die or are left severely physically and mentally challenged and are mostly left behind to die.

Worsening of disability Disabled people are rehabilitated following any disaster. Their special needs are not available leading to worsening of their status i.e. bedsores, urinary and respiratory infection etc. Inadequate support system and care can lead to severe problems and death

Trauma: Disasters can lead to severe injuries to spine, head and limbs. Inadequate recognition and appropriate care can lead to irreversible disabilities. Usually there are no emergency trauma care services or blood banks available locally to deal with their different disabilities. Though early identification and care can limit the extent of disability arising from injuries following disasters and adequate manpower training, planned response, i.e. triage, referral and prompt medical care can significantly reduce or prevent disabilities to occur very little seems to have been done even during the Tsunami, Katrina and other Disasters.

There is rarely any care for those who are mentally traumatized. During most disasters psychological trauma affects a large number of people disabling them for life when psychological counseling is not provided.

Women find it access RCH services those pregnant with disabled children due to the disaster find it more so

Recent research has shown that immediate mortality of the disabled during a disaster can be altered with sufficient planning, accessible shelters and preparedness of emergency personnel. The disaster responses for the disabled who survive and for those that can become disabled due to injury are of great concern. Inclusion of the disabled in planning for this response, adequate funding, involvement of DPO in disaster response and change in attitude are urgently necessary to address these issues The first norm is to create awareness, the second to allocate specific finances and third services and thus create an environment of inclusion that worse (SMRC).

Disabled persons health in particular, remains inadequate and disabled persons suffer disproportionately as a result.

Research program should include research on

1. health of already disabled people and response towards them during disasters.
2. Specific important issues such as time frame for arrival of professionals to help out - i.e. when should psychiatrists get involved - before, during, after. How many - what ratio needed per person.
3. Effectiveness of execution of relief efforts, relief coordination/codification

Social & familial conditions

Disasters leave behind large number of disabled, widows and orphans, and older groups left alone to cope with life. Most Disasters end in child labour which include the very vulnerable disabled groups. Girls usually disabled are forced into marriages with older men (as old as 85 years) or to anti social elements by the relatives with a view to grab their property (SMRC).

Sexual abuse of girl children, especially disabled and those who have been orphaned are known to increase. Disasters themselves lead to increase a person's vulnerability and studies have shown an increase in levels of domestic and sexual violence following disaster.

A major issue that came up during the tsunami was the high mortality and widowhood among women (fn). Children also suffered as large numbers become orphans and impaired, leading to their neglect in the context of health care and education.

The above have to be paid due attention. There are few laws and conventions to meet these challenges. The United Nations 2005 Guidelines on Victims provide for compensation. But, compensation is not

going to bring back the limb of a person impaired by a landmine or psychological trauma resulting from disaster or an unending conflict Nor will it reduce disability resulting from the social discrimination and exclusion of people living with impairments that is structurally embedded in most societies.

Many of the official channels related to disaster management are dominated by non-affected or suppressive and patriarchal groups. As so often happens in everyday life, disabled stay behind the scenes during disaster, or are even hidden by families making it difficult to acknowledge either their concerns or their contributions. When taken to an extreme, this tradition can put disabled at increased vulnerability to risk and danger.

The disabled do have specific issues that make them more vulnerable, and this fact is not clearly understood or accepted. Until recently, researchers felt that natural disasters did not discriminate among their victims but study of post disaster stress shows that disabled are usually marginalized, abused and invariably abandoned.

Social inequality stems from a set of three basic problems [1]. First and foremost is maintaining a social hierarchy. Placement on a hierarchy determines one's access to all types of resources, for example: power and decision-making; health; education; income; employment; and even the media. Dominant groups use different means to maintain their position on the hierarchy: non-disabled routinely pathologizes disabled people; the perspective of non-disabled people defines what are seen to be societal issues, and where funding and resources should go. In disasters, this means that few donor hands are ever directed to disabled peoples organizations (DPOs) or to address the needs of disabled people, contravening their equality rights.

The second problem is failing to recognize differences. Social policies and programs routinely fail to recognise the differing contexts of disabled people lives, and their differing needs. Situations of disasters vividly expose the gross violation of the human rights of disabled people that result: Communications and evacuation plans and relief and reconstruction efforts give little thought to these differences, putting in place warning systems, emergency shelters, latrines, emergency kitchens that are inaccessible to disabled people and in other ways fail to meet their basic needs

The third problem is using double standards. Societal practices that treat one group of people differently from another — include some people and exclude others are overt double standards. Being involved in decision-making that affects you as a person is a basic human right. For disabled people, this basic right is violated routinely. Disabled people are excluded from governance structures — in local communities, in national governments and in the international community. They are also denied access to other resources such as medical care, income, employment and education. Rarely do the media give voice to their human rights concerns.

In this context we therefore should.

1. Promote the inclusion and active involvement of disabled persons in the governance of general health and emergency/conflict response.
2. Create a system whereby collaboration between key stakeholders (DPOs, Governments, UN, donors, NGOs etc) actively considers disability issues during disasters to assure the health, safety and other human rights of disabled people.
3. Provide a set of policy guidelines or principles to stakeholders in the region (Governments, NGOs, etc.) to follow during disasters Standards should include measures to:???
4. Ensure that disability organizations are actively involved with disaster relief organizations and governments in the overall governance of response coordination offices during disasters.

Use research to effect social change and constructing new inclusive, equality-seeking structures

1. Look at intersections of social hierarchies and marginalization, exclusion (employment, income, savings, etc.) - gender, poor, homeless, etc. and other cultural practices that undermine identity/

- inclusion/Tights - through research with focus on health.
2. Some research on community coping mechanism when the indigenous ways of coping with any type of disaster, as people have indigenous coping capacity,
 3. Medical interventions versus social interventions re. Disabled persons - when are they needed,
 4. How to define which is appropriate and when?

Review of legislation on existing international standards

Our knowledge on existing legislation is non-existent. Some information includes:

Realizing the need of the disabled community the Humanitarian Charter and Minimum Standards in Disaster response (The Sphere Project 2004 edition) has included Disabled people and their special needs in their latest edition. The scope though still remains medical in character and not social. There is therefore a need to change the standards.

At the international level lobbying of the EU has produced a written response for inclusion of the disabled in disaster response but in practice it still means delegation to a specialist agency It is only disability specialist INGOs such as Handicap International which are involved in wide range of relief & accessible reconstruction. And most importantly collaborating with local DPOs in capacity building and support. In general inclusion of disabled people seems to be limited to surveys, receiving relief, aid and equipment and does not involve inclusion in planning, decision making and management.

What has been done, what gaps there are for instance in sphere project and national legislation are not known. The research agenda must include a documentation of existing standards at all levels.

Research for establishing Standards

Funding for health research in the context of disability is a basic problem, especially in donor agendas in low- and middle-income countries (LMIC). During Disasters as funding goes to large CBOs the DPOs are left out of the Donor circle or only little is allowed to trickle down to them. DPOs therefore suffer from the double constraints of limited financial resources to fund necessary research and action themselves, and the low priority given to disability problems in LMICs by the global research community acerbates the existing situation. Given the influence of major international health research funders on resource allocation decisions it is time that attention is given to this existing gap.

Research on current situation, weakness of existing laws, policies, programs, services, responses.

Review of legislation on existing international standards.

1. What has been done, what gaps there are for instance in sphere project and national legislation.
2. Use research to effect social change and constructing new inclusive, equality-seeking structures.
3. Recognition of difference but see that this difference is taken care off there is no discrimination and disaster as a new situation is going to create possibility of constructing new structure that are not hierarchy.

International Standards must be adopted as they would:

- Ensure that warning systems are disability-friendly, that is, meet universal design principles.
- Ensure that universal design principles are met in facilities housing services for disaster relief to ensure that they are disability-friendly accessible for the many more people becoming impaired during disasters and for disabled people already living in disaster-affected countries
- Create a 'level playing field' by providing funding for the active participation of members of the disability community in governance, including for attendance at meetings and policy-making initiatives at all levels, to ensure that their right to participate is not violated.

INGOs, DPOS, Disability and Inclusion

There is a change in perception of donor agencies and disability is now included in the disaster response by few but in a very limited way. Inclusion has not been perused in terms of agenda setting and decision making. It is striking that agencies now use the language of social model and inclusion, but have misunderstandings and do to really apply it in practice. Disabled persons are still lumped under 'vulnerable groups' rather than be perceived as rights-holders.

Many INGOs receiving funds from donor agencies have initiated policies / commitments to include disabled persons, but usually this meant referring them to specialist organizations, or including them as the vulnerable group for receiving relief. (IDDC Research Report June 2005), Written policies in many instances do not translate to into practice on the ground. E.g. latrines in Sri Lanka or shelters in India without ramps although there are published manuals for access. These inclusive guide lines and manuals are rarely known about by the grass root worker and therefore rarely used.

Issues specific to funding

Ensure that services and funding are in place to provide care. Donors need to acknowledge the importance of a disability-inclusive response. To achieve this, advocacy initiatives should be undertaken to highlight the pressing need to address the increasing level of risk and vulnerability, and the vicious cycle of poverty caused by recurrent disasters in risk prone zones. However, care must be taken that this does not result in good words like "inclusive" but little in the way of real action. Monitoring of a disability inclusive response will be required. Agreement needs to be reached about appropriate disability specific protocols that will ensure comprehensive support is afforded people with disabilities. (For example Spheres appears to be more of a medical model rather than a rights or social approach)

The policy environment at national, regional and international levels must be influenced to include people with disabilities at all level of dialogues. Unless Disability finds a place in policy dialogue, it will remain challenging to secure sufficient funding.

Accountability in the use of resources dedicated to disasters will require constant review and reporting to highlight situations like hurricanes Katrina and Rita where funding did not reach most in poverty situations.

This paper sets forth research ideas that are important to create the above environment:

Donors and Disabled during Disasters

At an International Meeting on "Good Humanitarian Donor ship", in Stockholm, June 2003. donor countries agreed to the Stockholm principles:

- Humanity: Central is saving human lives and alleviating suffering wherever it is found.
- Impartiality: Actions must be implemented solely on the basis of need, without discrimination between populations or within an affected population.
- Neutrality: Humanitarian action must not favor any side in an armed conflict or other dispute where such action is carried out.
- Independence: All actors' humanitarian objectives must be autonomous from their political, economic, military, or other objectives in the affected areas.

Reviewing the available data of existing policies, practices in providing funding and the disaster responses illustrates that very little has been done as yet.

As per data available in the Financial Tracking System: Global Humanitarian Database, of the total donations for disasters coming into India US \$ 2,860,714 in 2006 and US \$ 97,468,423 from countries varying from Sweden, Canada, USA, European Commission (ECHO) Denmark, Germany, Finland and Luxembourg no

mention of disability was made (<http://www.reliefweb.int/nv/dbc/nsf/doc!02?OpenForm>). No mention of disability was made.

After the Tsunami some of the larger funding agencies for instance IDRC (Canada) at Davos overlooked disability (outcome of the IDRC Davos 2006 http://www.davos2006.ch/Declaration/rjJRC_Davos_Declaration_20060908.pdf)

NOVIB-OXFAM in India a large donor it was communicated that no finances were earmarked for disabled and a field review only would tell even if any disabled were included in their programmes. The other organization involved with relief work e.g., CONCERN provided the same answer. The only donor found to have made special provision for disability was Dan Church Aid of Denmark working in India.

It can be argued that the present status of decision making for disaster response in relation to inclusion of disability was made by those with influence, finances and power. There is little evidence of horizontal networking and including the DPOs and poor communities in needs assessment & decision making. These are donor driven, so that is not influenced by the need of the local agencies during disaster response. Although there was huge amount of funds available for the Tsunami, this was a missed opportunity for putting into practice the inclusion practices in reconstruction

Funding agencies have to recognize that these additional facilities will cost more but their utilization will benefit many more than the classically disabled. Evacuation services, plan for prioritizing referring severe head injuries to specialist centers, developing a community plan to intervene (with a pre-exercised protocol) for disaster response to reduce deaths, optimizing care to avoid new disabilities and care to prevent worsening of disabilities help all people esp , old age people and women esp. pregnant who can benefit from many of the relief benefits, accessible buildings etc.

Research on Funding issues:

Research needed on identification of resources needed for disabled costing re. inclusion

- i. Funding available for disabled as part of disaster funding
- ii. Research around educational pedagogy, best practices - and inclusion principals and budgetary needs.
- iii. Track finances to review the amounts allocated and spent on the disability sector.

Another important gap in research is related to:

Statistics.

- i. Need better data, registration - planning budgeting on basis of Census registration Community mapping to know where people are when disasters strike.
- ii. Rapid Assessment of needs during each disaster as all disasters has different impact,
- iii. Gender disaggregated disability database

Research challenges

The challenges before us will be related specifically to measures of integrating uniform engagement of the various groups in the planning segment of disasters, with an understanding of disability as a social and human rights issue (World Bank 2006); to get governments and civil society activists to plan the research agendas together, and to take into account cross-current issues such as gender environment, psychosocial issues, disability diversity concerns, human and material resources, and training and networking; and finally, to look at individual needs while also mainstreaming in practical terms and maintaining a theoretical perspective. The research strategies should therefore be multiple and based on knowledge of the disabled themselves.

Conclusion: principles to guide the research

It is clear that there is tremendous scope for carrying out research related to the disabled so that their inclusion during **disasters becomes easier**

To conclude there are no guidelines to have an effective process of identifying the needs of the disabled in a disaster response, ability of the decision makers to understand the complexities of delivering an inclusive response and taking appropriate steps to allocate funds which can be used after consultation with DPOs in a community. All this requires proactive planning, training and sensitizing bureaucracy that inclusive policies are feasible and be beneficial

Research around what it already happening around disasters and the needs to integrate disability in it.