

For a UNHCR Executive Committee Conclusion on Disability

There are 650 million persons with disabilities worldwide¹. This makes up 10% of the world's population, with an additional 25% directly impacted by the presence of a disability.

One third of the world's persons with disabilities are children and two-thirds have become disabled secondary to preventable diseases or accidents.

According to WHO method of calculation,
there are currently between 2.6 and 3.7 million persons with disabilities among the world's 37 million refugees and displaced persons due to conflict.

Stakeholders working in contexts of crisis and conflicts to provide assistance and protection to displaced populations have to cope with many difficulties: immediate and direct assistance has sometimes to be provided at the expense of longer term considerations for sustainability in order to save lives; working with local actors may not be easy in contexts of conflicts when they might be linked with one or the other party; restrictions on locations of camps for refugees or Internally Displaced Persons (IDP), lack of local infrastructures may not be ideal for enhancing accessibility.

However a number of **false ideas also** prevent persons with disabilities from accessing humanitarian relief:

- # Relief stakeholders think that there are not many persons with disabilities in affected populations as they are usually not visible. There is also a tendency to think that persons with disabilities have died during natural disasters or conflicts because they could not escape or find shelter.
- # Emergency stakeholders think that global relief measures cover basic needs for all and that response to the specific needs of persons with disabilities can be postponed to post-emergency period.
- # Many international and government organisations believe that as long as they do not discriminate and set barriers for participation intentionally, there is no barrier or discrimination for people to access services available to the mainstream population.
- # Disability issues are usually thought to require highly specialised expertise, costly infrastructures and complicated programs.

Consequences

⇒ In the end, global emergency actors do not take the necessary steps to make their assistance accessible and inclusive. At the same time, specific solutions proposed by organisations of persons with disabilities and/or by organisations specialised in disability are marginalised or postponed.

Persons with disabilities are not taken into account in an appropriate and timely way and thus deprived of the humanitarian aid to which they are entitled.

¹ WHO estimates

Definitions

- According to the United Nations Convention on the Rights of Persons with Disabilities “Persons with disabilities: include 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”².
- Persons with disabilities do not constitute a homogenous group. They come from all ages, ethnicities, gender, religions and economic classes. Impairments may be congenital or result from birth, accidents, physical or psychological traumas, violence and abuse, diseases, psychiatric disorders, poor access to healthcare, bad nutrition. Resulting disabilities can be transitory or permanent, but they tend to be magnified in situations of emergency and movements of population.

Specific protection and concerns of people with disabilities Identified gaps and issues

Persons with disabilities are often literally and programmatically “invisible” in the emergency response. They are excluded from or unable to access mainstream assistance programs as a result of attitudinal, physical, environmental and social barriers; they are often forgotten in the establishment of services specifically targeted for vulnerable groups; they are at risk of worsening their impairment or developing others due to lack of access to appropriate food, non food items, health services, etc which may even be the cause of death. These observations are all the more true in situations of displacement, where refugees or IDP with disabilities are facing increased vulnerability.

In addition to the misconceptions noted above, the inclusion of persons with disabilities into mainstream programs by humanitarian stakeholders remains extremely limited due to lack of awareness/knowledge of some needs that may be specifically linked with disabilities, lack of access to assessment processes at all phases, limited availability of specific services, lack of awareness and training on disability issues among service providers and lack of technical resources.

In situations where assistance is non sufficient for the overall population which is often the case at a start of a refugee/ IDP situation, priority is given to vulnerable groups but as persons with disabilities are not visible they are not included, putting them at survival risk.

Response to Bihar floods

While in many camps the situation (food, health, shelter, water and sanitation) might appear acceptable for the general population, it does not yet address the needs of those who are the most vulnerable, especially persons with disabilities.

No information on the number of persons with disabilities could be collected. No information template exists that captures information about the situation of persons with disabilities in the camps making them programmatically “invisible” in humanitarian assistance.

They have limited access to emergency health services, food distribution points, community kitchens, non-food item distribution and water and sanitation points. To date no provision of services to meet specific disability-related needs are either available or planned by the government authorities³.

Field studies show that in situations of emergencies, displacement, temporary settlement (urban or camps) and in the search for durable solutions, persons with disabilities face a number of difficulties that are a direct threat to their lives and the fulfilment of their basic rights.

² From: www.un.org/esa/socdev/enable

³ Source: HI assessment findings in flood affected districts, Bihar 2008

1 – General protection issues encountered in emergency and displacement situations

- Movement and access to documentation is made difficult for persons with disabilities who may face significant discrimination.
- In conflict situations, male persons with disabilities, especially with traumatic amputations, report being questioned at military road blocks as to the cause of their injury, and arrested on suspicion of being former combatants.
- Persons with injuries/disabilities are especially vulnerable to physical, sexual and emotional abuse and may require additional protection considerations. The lack of privacy associated by non-access to facilities (such as bath areas) increases the risk of abuse.
- The international protection system organised through the clusters does not systematically take into account persons with disabilities in its frame, as a result protection clusters often do not pay specific attention to them
- Isolated persons with disabilities (either left behind or in the camps) have difficulties to access tracing programs.

2 - Situations of flight in an emergency

- Persons with disabilities may face heightened risks during flight and have little or no option to escape, which poses serious concerns for their safety. Difficulties may be encountered due to:
 - Inaccessible escape routes, loss of assistive devices, or impairments that reduce mobility (which may include visual impairment and/or impaired physical mobility).
 - People may have a need for some kind of physical assistance, such as family or community members physically carrying or assisting them. However, in emergency situations, people often flee for their own lives, sometimes leaving behind those less able to flee. There are also examples of disruption of family structures in order not to leave persons with disabilities behind. Thus, the risk of disruption of family or social network structures is extremely high for persons with disabilities.
 - Social network disruptions, including the loss of main caretakers and more generally, the family support structure can impact on all levels of safety and security, including access to food and water, building of shelters and access to services/ facilities and general protection issues.

Sri Lanka

A woman having three children with cerebral palsy could not flee during the fighting because it was too difficult for her to carry her children. She had to dig a hole near her house and hide there with her children⁴.

3 – Lack of data, or poor accuracy of data regarding disability

- Even if data is available for the overall community, in many cases, the disaggregated data on the number of refugees or IDP with disabilities is simply not available from the governments, UNHCR or its implementing partners.
- Where data does exist, there is lack of consistency in the identification of persons with disabilities, classification of disability, collection methods, analysis, and/or training received by data collectors.

⁴ Source : HI case study, 2008

4 - Food aid and nutrition

Studies show that persons with disabilities do not have access to adequate food due to:

- Barriers to physically accessing food distribution points;
- Lack of appropriate action to counteract lengthy wait times at food distribution points that some persons with disabilities lack the strength for.
- No special food rations despite specific needs (i.e. supplementary feeding for children with difficulties to swallow, diabetic diet, etc)
- Use of schemes such as food-for-work which (unintentionally) discriminate against those who are unable to work, or may need support to work.
- Difficulties to carry home the food ration as no specific container or measures are in place to ensure they can bring their ration home

5 - Water and sanitation

- Difficulties in collecting water due to
 - Pumps and wells including those that have been built recently by NGOs, not accessible for persons with mobility difficulties,
 - Discrimination, verbal and physical abuse, and denial of access at water points, especially in urban settings
- Sanitation is also a particular issue, since most toilets/ bath areas built in camps are not designed for persons with disabilities to be able to use.

6 - Shelters

- In situations of displacement of population and destruction of property, the issue of shelter is often particularly acute for persons with disabilities who may not be able to construct shelter or wait at distribution points for shelter materials.
- Specific measures targeted towards persons with disabilities might also become a factor of abuse by the community or family.

7 - Access to health care

- Disruption in health and social services leading to lack of access to timely treatment, vaccination programmes, and maternal and child health care and may have a direct impact on some types of disabilities or on preventable conditions.
- Health services do not provide for specific disability-related needs of refugees, e.g. clinics are physically inaccessible, sign language interpretation is unavailable, medical information is not provided in alternate format of print for persons who are blind or have some learning disabilities, medical professionals often think persons with disabilities cannot speak for themselves and do not respectfully include them in discussion of their health needs, etc.
- Persons with disabilities are more vulnerable to HIV, in particular women and girls who face higher risks of violence and sexual abuse or because of exclusion from HIV education programmes, lack of access to testing and treatment centres; lack of accessible information, etc.
- In situations of displacement and temporary settlement, there is a lack of rehabilitation services for those in need, of access to assistive devices, and limited referral to rehabilitation facilities, appropriate communication, specific medical treatment (for epilepsy, diabetes, etc.) and information on measures to prevent certain disease.

8 – Livelihood

Tools necessary to engage in livelihood activities are often lost during displacement, making it difficult for many refugees, including persons with disabilities, to restart their activities. Persons with disabilities often face additional obstacles due to lack of opportunities for livelihood activities, lack of access to education or vocational training, discrimination for employment, or from consumers who will not use their services.

9 - Participation

- Persons with disabilities tend to be systematically excluded from evaluations, assessments, interviews, community committees, or leadership roles, thus reinforcing discrimination and undermining self-esteem.
- They are often not considered to be able to participate to camps relief activities where others get a chance to earn some consideration and income.

Haïti⁵

Persons with disabilities and their families encountered during the assessment stated lack of access to distribution (food, water and non-food items, damage or loss of assistive devices (prosthesis, white canes, crutches) and frustration (psychosocial trauma) at having lost everything (homes, belongings, livelihood tools/items) as their main areas of concern. With regard to livelihoods, some spoke specifically of the increased difficulty to regain livelihoods due to discrimination in society. In Gonaives specifically, they stated that it is difficult for them to access relief distributions or even to reach toilet or shower facilities due to the mud and water throughout, making accessibility even more difficult. Persons with disabilities and their families are currently living either in private homes (often many people in one home) or in temporary shelters.

Children with disabilities

Children with disabilities are often more vulnerable to exploitation, violence and abuse, and face additional obstacles such as exclusion, lack of confidence or communication barriers which makes it more difficult for them to seek support.

It is more difficult for them to have access to education for a number of reasons, including discrimination, verbal and physical abuse, physical access to school or to facilities within school, language and communication barriers, lack of schools for sensory impaired students, lack of assistive devices, fear, behaviour problems, cost ...etc.

Women with disabilities

Women with disabilities have even more difficulties than men to access relief and assistance in emergency situations. They are more likely to be exposed to sexual and gender based violence, domestic violence and abuse, physical abuse, trafficking, neglect, discrimination and stigmatization.

Sri Lanka

A woman with physical and intellectual disabilities has a 6 year old daughter who was born as a consequence of a rape incident. She relates that some 6 years ago, she was raped by a man whom she identified as one of her relatives. Since the incident, the woman is scared of remaining alone in the house – which happens often as her brother works and the children go to school. Moreover, she specifically mentioned that she is scared of military men (widely present in the area) and that she has 'fits' when they visit the house for any reason. When asked about her current well-being the woman's main concern is the lack of a birth certificate for her daughter. The family members do not want her to be provided with a birth certificate without the father's name that will 'publicize' the fact that she is an illegitimate child⁶.

⁵ Source: HI, assessment of persons with disabilities' situation after the hurricanes in Haïti, 2008

⁶ Source: HI protection case study, Sri Lanka, 2008

Priority measures

All stakeholders involved in providing assistance to refugees/displaced persons should immediately begin factoring full access to assistance and protection for persons with disabilities into the design, implementation and monitoring of their programmes. Inclusion will be achieved only if persons with disabilities are considered in their diversity and not as a homogenous group.

- Immediate steps should be taken to **raise awareness** of the main actors in the fields of protection, health, shelter, water and sanitation, to share field experience, disseminate practical tools and guidelines and provide technical support. In the process, organisations of persons with disabilities (DPOs) can support and provide their disability expertise in order to minimise barriers identified in programmes and activities assisted by international and government agencies. Discrimination, stigmatization and social exclusion are at the foundation of the difficulties faced by persons with disabilities. Programs must affect behaviour change on society and community members in order to achieve inclusion and sustainability.
- **Concrete measures** should be actively promoted, to achieve inclusion of persons with disabilities and their families at all stages of displacement, temporary settlement and durable solutions
 - Mechanisms should be put in place to ensure early identification of persons with disabilities and to determine their specific requirements.
 - They should not be separated from their caregivers or families or should be reunited.
 - Basic services and infrastructures such as shelters, food distribution points, water points, latrines and bathing areas, schools, health centres, camp offices and other community facilities must be made accessible, based on principles of universal design and appropriate information and communication for all persons with restricted mobility, sensorial impairments, learning, communication, intellectual or mental health disabilities.
 - Information and resource sharing, as well as referral systems, should be put into place between emergency relief actors, organisations specialising in disability issues and organisation representing persons with disabilities.
 - Work with those with knowledge and experience on disability, in particular organisations representing persons with disabilities (DPOs), and local organisation working on disability issues. Use existing networks (such as the International Disability and Development Consortium)
 - Specific healthcare and rehabilitation programs should be promoted as they are key to limiting after effects and long-term impairments and to improve the person's autonomy and quality of life.
 - All protection policies and measures should take into account specific needs of persons with disabilities, especially women and children.
- Persons with disabilities and their families should be **included** and **participate** in the initiatives and projects that concern their lives and their future. Their opinions, concerns and experiences have to be taken into account.
- **Cooperation and networking** between humanitarian aid agencies and organisations specialising in disability issues, both at the national and international level should be promoted as well as the active involvement and participation of persons with disabilities and their organisations.