

# INCLUDING PEOPLE WITH DISABILITIES IN EMERGENCY RELIEF EFFORTS

The World Health Organization (WHO) estimates that around 15 per cent of the world's population, or one billion people, have some form of disability. According to United Nations Development Programme (UNDP), 80 per cent live in poor countries, where communities are already more vulnerable to disasters and crises such as the current Ebola epidemic, with people with disabilities often disproportionately affected. More must be done to ensure the needs and rights of people with disabilities are fully recognised in disaster risk reduction and emergency responses. Accelerating progress will require inclusive humanitarian programming and the use of technological solutions to be effectively promoted and incentivised, and people with disabilities and their organisations to be involved from the outset in the design and implementation of policies and programmes.

## Recognising the needs and rights of people with disabilities

The Indian Ocean tsunami of December 2004, Hurricane Katrina in 2005 and the Haiti earthquake in 2010, were all milestones in recognising the importance of including the needs and rights of people with disabilities in emergency relief efforts. A review of disability inclusion in the 2004 tsunami outlined a number of recommendations to increase the inclusion of people with disabilities in humanitarian responses. In spite of good intentions, the lessons of the tsunami had been forgotten by the time Hurricane Katrina arrived a year later. Disabled people in communities, camps and residential facilities were forgotten and abandoned during all of these emergencies. The international outcry that followed contributed to the passage of Article 11 of the Convention on the Rights of Persons with Disabilities (UNCRPD), which mandates that emergency relief efforts take the specific needs of disabled people into account.

Despite the UNCRPD, evaluations of the humanitarian response to the conflict in Syria, and anecdotal evidence concerning the current Ebola outbreak in West Africa, highlight that the needs and rights of people with disabilities affected by these emergencies continue to be overlooked and disregarded. In Syria, people with new disabilities – often conflict-related – are generally unable to access longer-term rehabilitation. As a result, they face difficulties accessing basic requirements such as food, water and livelihoods. In Ebola-affected countries, for example, people with disabilities who cannot mobilise (or are not allowed to move, due to quarantine) are left entirely dependent on medical staff and visitors for all requirements, including information. Such visitors are rare in an Ebola epidemic, as is accessible information in sign language and Braille.

## Disability and emergencies

According to the UNCRPD, disability is best understood as the interaction between an individual's impairment and their environment. It is clear that armed conflict, humanitarian emergencies and the occurrence of natural disasters can create a radical disjuncture between people and their environment, creating new needs, as well as human rights abuses, security and protection issues. All humanitarian action should be based on needs and rights. It is important to remember that people with disabilities live and work in communities, have families, and have the same needs as other members of society, including access to humanitarian aid.



*Worldwide, one billion people have some form of disability. More must be done to ensure their needs and rights are fully recognised in emergency responses.*



However, as there are never enough resources to meet all needs in emergencies, priority is given to those in most urgent need, which should often include people with disabilities as a result of their marginalisation.

Comprehensive assessments, which include disaggregated data (both quantitative and qualitative and by age, sex and disability), are required to develop an effective and impartial response. However, the response should not be conditional on collecting data first, given that there is often ignorance of disability issues pre-disaster. In addition to being a significant cause of disability, conflicts and disasters disproportionately affect people with pre-existing disabilities. They may be left behind or excluded from emergency responses due to a lack of accessible information, transport, food, shelter and other support. Emergency situations destroy the social networks that support people with disabilities, thus marginalising them even further. A person using a wheelchair or on crutches may be visible in a crowd, but someone with hearing or learning difficulties may go unnoticed. This invisibility can be deadly in an emergency. War and emergencies can be a significant source of mental health problems, yet, in many countries, understanding and access to treatment and support may be very limited. Many mental health conditions can be regulated by medication, the absence of which can be distressing at least, and downright dangerous at worst.

### The role of technology and developing more inclusive responses

Technology offers some promising ways to address the challenge, and the forthcoming 2014 International Day of Persons with Disabilities (3 December) has a specific focus on the role of technology in disaster risk reduction and emergency response. It is important to remember that people with disabilities have diverse needs, and a one-size fits all approach to disability inclusion in humanitarian responses will not meet the various physical, communication and social needs and rights of people with different disabilities.

Technological advances have been hugely beneficial for disaster response and have helped overcome barriers faced by people with disabilities. The International Federation of Red Cross and Red Crescent Societies (IFRC) World Disaster Report (2013), which focused on technology and humanitarian actions, noted significant impacts on everything from the use of information communication technology to improved logistics, Geographic Information Systems (GIS) mapping and data collection. However, the report also highlights the risks of technology, including a lack of accountability and the inequities of access to technology for those who are the most vulnerable to disasters, which includes people with disabilities.

To mitigate these risks the following issues must be addressed:

- 1. Technology can only be effective if consideration of all users and beneficiaries is made from the beginning.** One way technology may be used is in the collection of spatial distribution data before, during and after a humanitarian emergency. New technology may help overcome communication barriers and improve disaster awareness, but in and by itself does not solve social stigma that leads families and communities to hide or abandon relatives. Merely gathering the data is also not enough: the data needs to be interpreted and analysed to ensure a better understanding of where the barriers, gaps and bottlenecks are to ensuring equitable humanitarian aid. It is crucial to avoid equating technological progress with social progress and to recognise the impact of lived experiences and community support systems on inclusive disaster response.
- 2. Without requirements and motivations to include adults and children with disabilities in humanitarian programmes, they will continue to be excluded.** Where inclusion has been done, it is often done in an *ad hoc* manner, with little recourse for either beneficiaries or practitioners if it is done badly, or not done at all. Technology already supports the dissemination and sharing of good practices, guidelines, checklists and other information through web-based platforms and other fora, but these still need to be translated into offline action.
- 3. People with disabilities and their organisations need to be included in each phase of humanitarian programming – from planning through to implementation and evaluation.** Again, technology can be used to support each of these phases – for example, the use of mobile phone technology to provide updates on aid deliveries, and the use of laptops to support delivery of education. Yet without consideration of how accessible and equitable these technologies are, they risk becoming yet another mechanism of exclusion.

## Determining disability and special needs in emergencies

Definitions of disability are culturally and socially constructed, and the extent to which people are disabled by society can be affected by factors such as availability of resources, social protection mechanisms, and health and rehabilitation programmes. The general lack of data around disability contributes to the invisibility of people with disabilities, and to ineffective or inappropriate emergency responses.

For example, during the Indian Ocean tsunami in 2004, the lack of data and knowledge about people with disabilities resulted in a standardised post-disaster response. This meant that an unknown number of people with disabilities were all treated as one homogeneous group, even though the communication and information needs of deaf people, for example, are clearly different from people with physical disabilities or intellectual impairments. Underestimates of the number of people with mobility impairments limited the construction of sufficient accessible shelters and the provision of enough water, as well as other relief goods and services. As shelters and relief camps are often used to distribute goods such as food, blankets and medical supplies, people with disabilities are clearly excluded if they cannot access these facilities or services. Families may hide relatives with disabilities – especially girls – out of fear, shame, or the need to protect them. The absence of gender- and age-disaggregated data, compounded by poor knowledge of the power dynamics in communities, can complicate matters even further. For example, relatives of people with disabilities in Bangladesh consider cyclone shelters particularly unsafe for women with disabilities, as they are more vulnerable to abuse, highlighting intersecting vulnerabilities.

Humanitarian emergencies primarily occur in countries with sizeable poor populations and weak public health systems, which can result in higher numbers of people with disabilities. Lack of access to good maternal and child health care may result in higher incidents of birth-related impairments. Poor nutrition and inadequate access to preventive health care measures, such as vaccinations, may increase the likelihood of long-term impairments even before a disaster strikes. There is a lack of systematic data on how emergencies affect adults and children with pre-existing as well as new disabilities, and on the physical, social and economic impacts on individuals, their families and communities. In an emergency situation, those considered 'disabled' can vary enormously. Social norms and political history affect public perceptions and understanding of disability. Some groups, such as war veterans who fought on the 'right side' of a war, may be considered more 'socially acceptable' than those who did not. This affects their ability to make demands, and claim entitlements such as compensation and other welfare support.

## Inclusive humanitarian and development policies

United Nations bodies, including United Nations High Commissioner for Refugees, United Nations Children's Fund and the WHO, international non-governmental organisations and donors such as Australian Department of Foreign Affairs and Trade and the UK Department for International Development are supporting policies on disability inclusion. There has also been increased awareness and action at national level, including by Disabled People's Organisations (DPOs) and other civil society groups. However, the reality is that very little is being turned into practice so far. One of the biggest challenges is that few policies and guidelines are legally binding. Even the UNCRPD has limited legal status; it is operationalised through domestic legislation and general human rights law. In times of recognised international armed conflicts, international humanitarian law applies. This has implications for international interventions, as well as legal recourse (for example, determination of refugee status). Finally, there is often a lack of national-level recourse mechanisms for people with disabilities.

## Implementing inclusive policies

While there are now a number of positive examples of inclusive humanitarian responses, including some in Syria, these are often partial. A lack of indicators in policy instruments by which to measure inclusion raises the questions of what effective and active 'inclusion' looks like. Merely inviting people with disabilities to participate in cluster meetings, or ticking boxes in a checklist, should not be taken as indicators of inclusion. While internationally recognised guidelines such as the Sphere standards emphasise disability as a cross-cutting issue, they stop short at specific indicators, though the work of the Start network on ageing and disability inclusion standards may go some



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way to redressing this imbalance. There has only been limited progress with developing common vulnerability and capacity assessments to ensure representation of the spectrum of age, sex and disability, including in the initial assessments immediately after a disaster. This means that there is little baseline data to underpin standards and indicators.

It is important to follow a twin-track approach, having both accessible mainstream responses as well as dedicated responses for specific needs. Donors could also make the inclusion of people with disabilities a mandatory component of response funding or earmark funding for disability. More work is also required to make field staff in humanitarian responses aware of disabled people's needs and of the resources available for them. As crises have demonstrated, people with disabilities and disabilities' organisations are still rarely involved in designing, implementing and evaluating emergency responses. Even if they are included, the response may be planned in such a way that makes it difficult for many affected people to participate. DPOs may not be used to working in emergency responses, but they do have expertise on people with disabilities in the affected areas, and are ideally placed to support an inclusive response and to reach out to their members, their families and communities. The capacity of DPOs inevitably varies. Some groups, for example women with multiple disabilities and people with intellectual impairments, tend to be underrepresented by national DPOs, compared to those with sensory or physical impairments. Therefore, it is critical that those implementing humanitarian responses take into consideration the most marginalised adults and children with disabilities, who may lack family members or other representatives who are willing or able to speak out on their behalf in emergencies.

## Recommendations

To ensure inclusive emergency relief efforts that fully recognise the rights and needs of all people with disabilities the following measures need to be taken:

1. Develop an agreed set of meaningful indicators for identifying needs and capacities of people with different types of disabilities to ensure they are included in responses.
2. Establish incentives and funding mechanisms that incentivise inclusive humanitarian programming.
3. Design and offer essential training packages that include tools to develop awareness, skills and competencies on disability inclusion for humanitarian practitioners, policymakers and donors, and that can be adapted for different contexts and scenarios.
4. Support the involvement of DPOs and the development of accessible technology to facilitate the inclusion of disability issues across the humanitarian cycle, including in long-term reconstruction and rehabilitation.
5. Advocate for the inclusion of indicators to promote the rights and needs of all people with disabilities across the new Post-2015 Framework for Disaster Risk Reduction.

## Further reading

Kett, M., Stubbs, S., & Yeo, R. (2005). *Disability in Conflict and Emergency Situations: Focus on Tsunami-affected Areas*. Working: International Disability and Development Consortium

Emma Pearce (2013) *Disability Inclusion in the Syrian Refugee Response in Lebanon*. Women's Refugee Commission

Brigitte Rohwerder (2013) *Intellectual disabilities, violent conflict and humanitarian assistance: advocacy of the forgotten* *Disability & Society* Vol. 28, No. 6, 770–783

Fred Smith, Emma Jolley and Elena Schmidt (2012) *Disability and disasters: The importance of an inclusive approach to vulnerability and social capital* *Sightsavers*

## Credits

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