

OPERATIONAL PRACTICE PAPER 1

December 2017

Disability Inclusive Humanitarian Response

'Too often invisible, too often forgotten and too often overlooked'.¹

The population at risk

The *World Report on Disability* estimates that about 15 per cent of the world's population have some form of disability, with disability prevalence likely to increase as a result of ageing populations and the global increase in chronic health conditions such as diabetes, cardiovascular disease, cancer and mental health disorders.² Disasters and armed conflicts can also increase the number of persons with disabilities as people acquire new impairments and/or experience a deterioration in existing impairments from injuries and/or limited access to health care and rehabilitation.³ For instance, a survey of Syrian refugees living in camps in Jordan and Lebanon found that 22 per cent had an impairment.⁴ However, accurate numbers can be hard to calculate due to lack of data disaggregation in humanitarian emergencies and differences in the way disability is defined and measured, while families may be reluctant to disclose disability due to fear of stigma and isolation.⁵ As a result, humanitarian programmes may inadequately document and consider the needs of persons with disabilities.⁶

Disproportional vulnerability in crises

People with all types of disabilities have been found to have a disproportionately negative experience of disasters, conflicts, displacement, and their response. Research has shown that within any crisis-affected community, persons with disabilities are among the most marginalised, yet often they are excluded from humanitarian assistance.⁸ Different types of impairments, and other intersecting factors such as gender, age and class, and the different barriers they face in that context, contribute to differences in vulnerability and resilience for persons with disabilities.⁹

Women, children and older persons with disabilities are particularly vulnerable to discrimination, exploitation and violence in humanitarian emergencies, but may have difficulty accessing the support and services that could reduce their risk and vulnerability.¹⁰ It is important to note that persons with disabilities are disproportionately vulnerable in crises 'primarily as a consequence of social disadvantage, poverty and structural exclusion' and a lack of knowledge and awareness of their needs, rather than because of any inherent vulnerability.¹¹

As such, vulnerability to conflicts and disasters for persons with disabilities begins before the emergency strikes. Social exclusion and poverty weaken their resilience to the negative impact of disasters, with data showing that 'people with disabilities in low- and middle-income countries are poorer than their nondisabled peers in terms of access to education, healthcare, employment, income, justice, social support and civic involvement'.¹² Preparations for emergencies

Box 1 Definition of 'disability' and commitment to inclusion in emergencies

There is no single definition of 'disability' but the Convention on the Rights of Persons with Disabilities (CRPD) defines persons with disabilities as 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', making clear that disability is not an attribute of a person but an interaction with the environment they are in.⁷

The CRPD, ratified by 174 countries as of October 2017, emphasises that persons with disabilities have the right to protection and safety in situations of risk, including armed conflict, humanitarian emergencies and natural disasters (Article 11).

are often not accessible, with a recent study by the UN Office for Disaster Risk Reduction (UNISDR) finding that 85 per cent of persons with disabilities had not participated in ongoing disaster management and risk reduction processes in their communities.¹³ Wide neglect of the needs of persons with disabilities in official planning processes for disasters has increased death rates of persons with disabilities and reduced their inclusion in disaster response.¹⁴ For example, persons with disabilities were twice as likely to die during the 2011 Japanese earthquake and tsunami than people without disabilities, as a result of inaccessible evacuation procedures that did not provide for them to escape in time.¹⁵

During humanitarian emergencies, persons with disabilities experience increased problems due to abandonment or separation from family; loss of support structures; loss of assistive and mobility devices; and difficulties with accessing information.¹⁶ For example, research by Human Rights Watch in the Central African Republic found evidence that persons with disabilities were often unable to flee the violence and were killed, while those who managed to escape faced many additional hardships while fleeing and in camps.¹⁷

Barriers to humanitarian assistance

Discrimination, prejudice and other barriers disadvantage persons with disabilities in humanitarian situations. Humanitarian aid and services, such as shelter, food distribution, WASH facilities – including menstrual hygiene management – health facilities, temporary learning spaces and child-friendly spaces, are often not built to be accessible to persons with disabilities.¹⁸ For example, 75 per cent of respondents to Handicap International's survey of persons with disabilities in humanitarian contexts reported that they did not have adequate access to basic assistance such as water, shelter, food or health.¹⁹ In addition, for one out of two respondents, the specific services that persons with disabilities may need, such as rehabilitation, assistive devices, access to social workers or interpreters were not available, further impeding their access to mainstream assistance.²⁰

The main barriers to accessing aid in crisis contexts appeared to be the lack of accessible information about services; the difficulty in accessing the services themselves due to lack of physical or financial access; limited staff knowledge, attitudes, and practices in relation to disability inclusion; distance from the

services; lack of data on disability; gaps in policy development and implementation; and negative attitudes of family members and communities.²¹ Research by Handicap International reported that only 30–45 per cent of the services provided by humanitarian actors were accessible to persons with disabilities, despite 85 per cent of humanitarian actors responding to the survey recognising that persons with disabilities are more vulnerable in times of crisis and 92 per cent estimating that they are not properly taken into account in humanitarian response.²²

Protection risks faced in humanitarian emergencies

The variety of societal, environmental and communication barriers to accessing humanitarian assistance programmes increase persons with disabilities' protection risks, including risk of violence, abuse and exploitation.²³ Research with over 600 persons with disabilities and caregivers and over 130 humanitarian actors in displacement contexts finds that key protection concerns include 'a lack of participation in community decision making; stigma and discrimination of children and young persons with disabilities by their non-disabled peers; violence against persons with disabilities, including gender-based violence; lack of access to disability-specific health care; and unmet basic needs among families of persons with multiple impairments'.²⁴ Research carried out by the Women's Refugee Commission and others, have found that in emergencies persons with disabilities, especially those with intellectual disabilities, face added risks of violence, including gender-based violence, due to multiple forms of discrimination, the breakdown in protective peer networks, and exclusion from activities which might confer access to age- and gender-appropriate information and education.²⁵ For example, in Handicap International's global survey, 27 per cent of persons with disabilities reported that they have been psychologically, physically or sexually abused.²⁶

Issues with operationalising disability inclusion

The need to include persons with disabilities, including some specific references to women with disabilities, is increasingly being recognised in policies and guidelines, including in the commitments from the World Humanitarian Summit in 2016, such as the Charter on Inclusion of Persons with Disabilities in Humanitarian Action. However, there are still significant

gaps in operationalising these at the field level in humanitarian emergencies, including in terms of ensuring appropriate human and financial resourcing; strengthening staff knowledge, attitudes, and practices; and monitoring access and inclusion with data on disability.²⁷ For example, research in Nepal found that ‘despite being understood and framed as a “crosscutting issue” and/or something that requires mainstreaming, inclusion generally remain[ed] an extra activity –

something added onto humanitarian assistance to improve it – rather than an overall approach’.²⁸ In addition, there still seems to be a tendency for humanitarian agencies to refer the vast majority of persons with disabilities to service providers for health, rehabilitation and provision of assistive devices, sometimes failing to recognise their needs in social dimensions – such as lack of inclusion in schools, shelter, livelihoods and protection programming.²⁹

LESSONS FOR IMPROVING DISABILITY INCLUSION IN HUMANITARIAN RESPONSE

■ Persons with disabilities have the same needs and rights to basic services in emergencies – it is how they are provided that matters

Persons with disabilities have the same needs and rights to basic services as others to survive and thrive – namely, nutrition, health care, education, safe water and a protective environment – and would be able to access them if service delivery is designed to be inclusive.³⁰ Making sure the provision of basic services are inclusive involves things like prior communication in different accessible methods about relief distribution; provision for those less able to queue; and using universal design for service facilities.³¹ Operational staff should be trained in disability inclusion as part of disaster preparedness activities, and in humanitarian response programmes.³² As well as addressing attitudes and stigma, capacity building

for operational staff should include practical guidance on how to make services more accessible and inclusive. Planning for accessibility from the outset is less expensive than modifying existing infrastructure.³³

■ Implementing a ‘twin track’ approach is key to inclusion

The ‘twin track’ approach, which combines mainstreaming with targeted disability-specific projects needed to achieve the full inclusion and participation of persons with disabilities, is recommended as best practice.³⁴ This approach ‘ensures that specific needs (for example, assistive devices such as wheelchairs) are met while basic needs (including health care, shelter and livelihood) are made accessible to all’.³⁵ In order to be successful, there needs to be an emphasis on both tracks (see Table 1).³⁶

Table 1 Some examples of how to address the needs of persons with disabilities in humanitarian emergencies using a ‘twin track’ approach³⁷

Disability/impairment	To meet basic needs (mainstreaming)	To meet specific needs (targeting)
Physical impairment	<ul style="list-style-type: none"> ■ Separate queues for rations and water ■ Accessible latrines ■ Universal design construction 	<ul style="list-style-type: none"> ■ Personal support ■ Provision of assistive devices ■ Adapted physical environment
Visual impairment	<ul style="list-style-type: none"> ■ Good lighting ■ Separate queues ■ Signs with large and contrasted lettering 	<ul style="list-style-type: none"> ■ Personal support ■ Hand rails
Hearing impairment	<ul style="list-style-type: none"> ■ Communication including visual signs 	<ul style="list-style-type: none"> ■ Visual aids ■ Picture exchange communication ■ Sign language
Intellectual impairment	<ul style="list-style-type: none"> ■ Speak slowly ■ Use plain language 	<ul style="list-style-type: none"> ■ Personal support

■ Data disaggregation can ensure awareness and accountability

Collecting data on persons with disabilities during all humanitarian phases, such as needs assessments and monitoring and evaluation, makes it ‘possible to identify them, assess their needs and monitor the outcomes of humanitarian interventions’.³⁸

The Washington Group Short Set of Questions has been suggested as a module to be used in surveys, censuses and registration systems to identify adults and children with disabilities, and have been piloted by humanitarian agencies.^{39, 40} The Washington Group aims to measure disability by identifying ‘persons who are at greater risk than the general population of experiencing restrictions in performing complex activities (such as activities of daily living) or participating in roles (such as working) if no accommodations were made’.⁴¹ Local disabled people’s organisations (DPOs) may be helpful in rapidly identifying persons with disabilities that they are already working with who are affected by a crisis.⁴² Developing indicators for inclusion of persons with disabilities against which humanitarian agencies and organisations must report, could strengthen accountability for inclusion of persons with disabilities.⁴³ However, research from Nepal indicated that it is important to understand that inclusion is more than disaggregated data or who is targeted for programmes and services.⁴⁴

■ ‘Nothing about us without us’ – involve persons with disabilities in humanitarian preparedness and response

Engaging with persons with disabilities and their organisations is important for understanding their priorities and capabilities, yet the leadership capabilities, resilience, creativity and innovation of persons with disabilities is a largely untapped resource.⁴⁵ Prior experience indicates that ‘persons with disabilities can be staff, consultants, advisors, volunteers or partners in all phases of humanitarian processes’.⁴⁶ First-hand experience of humanitarian workers with disabilities indicates that with their unique knowledge gained through life experience, they are ideally placed to provide insights, ideas and leadership, to supply essential data, and to fill the gaps in humanitarian response that cause the exclusion of persons with disabilities from emergency aid.⁴⁷ Placing persons with disabilities

in leadership roles in humanitarian organisations, programmes and activities, and advocacy and technical support by DPOs, has been found to improve disability inclusion by bringing appropriate expertise, demonstrating skills and capacities, and raising awareness among humanitarian actors and affected populations alike.⁴⁸

Local DPOs can be a source of support for persons with disabilities in humanitarian crises and have been known to: deliver humanitarian aid, providing health care, shelter and food until other assistance arrives; work on disaster risk reduction measures and on disaster preparedness in order to make persons with disabilities and their caretakers more resilient; and make local governments and (general) humanitarian agencies aware of reaching and including persons with disabilities.⁴⁹ However, often they have limited knowledge and experience in the issues faced by affected persons with disabilities, including refugees with disabilities, such as gender-based violence prevention, and few sustainable funding opportunities, including through the humanitarian funding system.⁵⁰ As such, it is important to increase support to DPOs in crisis-affected countries in order to develop their capacity to provide support and leadership in humanitarian response.⁵¹

■ Take a resilience-based approach that includes persons with disabilities

Vulnerability assessments for targeting humanitarian assistance were found to ‘consider persons with disabilities as a homogenous group [if they consistently considered them at all], without distinction for gender or age and without the possibility for their vulnerability status to evolve or change over time’.⁵² Such an approach ignores differences amongst persons with disabilities, misses the factors that contribute to their vulnerabilities, and any positive coping strategies or capacity they may have.⁵³ Research carried out by the Women’s Refugee Commission in relation to the Syrian refugee crisis recommends that humanitarian organisations switch instead to a resilience approach that includes persons with disabilities, helping to identify their resilience traits, strategies and approaches in order to mitigate the risks they face.⁵⁴

GUIDELINES AND OTHER RESOURCES

- The Charter on the Inclusion of Persons with Disabilities in Humanitarian Action was launched at the World Humanitarian Summit in 2016 and commits states, United Nations agencies, civil society organisations and DPOs to endorsing it to make humanitarian action inclusive of persons with disabilities, lift barriers that keep them from accessing humanitarian services, and ensure their participation.
- The Interagency Standing Committee has created a task team to develop guidelines on the inclusion of persons with disabilities in humanitarian action.
- The Sendai Framework for Disaster Risk Reduction 2015–2030 commits to mainstreaming disability in disaster risk reduction.
- The Sphere Standards, minimum rights-based standards for WASH, food security and nutrition, shelter, settlement and non-food items and health, mainstreams the rights of persons with disabilities throughout its most recent handbook.
- The Age and Disability Capacity Building Programme (ADCAP) has developed Minimum Standards for Age and Disability Inclusion in
- Humanitarian Action to inform humanitarian organisations about the actions needed to ensure that their shelter, nutrition, food security and livelihoods, education, health and protection responses are as inclusive as possible.
- The Women's Refugee Commission has developed a number of resources which can be found on their website such as a resource kit for field workers; guidance on translating disability inclusion policy into practice in humanitarian action; and capacity building for disability inclusion in gender-based violence in humanitarian settings.
- Handicap International has developed a checklist for disability inclusion in emergency response.
- The Global Protection Cluster has developed guidance on protection mainstreaming training that includes persons with disabilities.
- UNICEF and Handicap International have developed a set of six booklets full of practical actions and tips on including children with disabilities in humanitarian action. They cover: general guidance; nutrition; health and HIV/AIDS; WASH; child protection; and education.

NOTES

- 1 WRC (2008) *Disabilities Among Refugees and Conflict-Affected Populations*, New York: Women's Refugee Commission.
- 2 WHO and World Bank (2011) *World Report on Disability*, Geneva: World Health Organization: 44.
- 3 Pearce, E. (2015) "Ask Us What We Need": Operationalizing Guidance on Disability Inclusion in Refugee and Displaced Persons Programs', *Disability and the Global South* 2.1: 460, 473.
- 4 Calvot, T. (2014) *Hidden Victims of the Syrian Crisis: Disabled, Injured and Older Refugees*, London and Lyon: HelpAge International and Handicap International: 6.
- 5 Cordero, R.P.; Mitra, G. and Tucker, M. (2017) *Guidance: Including Children with Disabilities in Humanitarian Action – General*, UNICEF: 15.
- 6 *Ibid.*; NDRC Nepal (2016) *Assessing the Impact of Nepal's 2015 Earthquake on Older People and Persons with Disabilities and How Gender and Ethnicity Factor into that Impact*, Kathmandu: HelpAge International, CBM International and National Disaster Risk Reduction Centre (NDRC Nepal): 6; DCDD (2016) *Towards Disability-Inclusive Disaster Risk Management*, The Hague: Dutch Coalition on Disability and Development, Liliane Foundation, Light for the World, Karuna Foundation and Ministry of Foreign Affairs of the Netherlands: 4; Pearce (2015: 461).
- 7 UNCRPD (2006) *Convention on the Rights of Persons with Disabilities and Optional Protocol*, United Nations: 4–5.
- 8 Chaiban and Fontaine in Cordero et al. (2017: 6).
- 9 ADCAP (2017) *Inclusion of Age and Disability in Humanitarian Action: Training Course*, ADCAP: 21; Rohwerder, B. (2013) 'Intellectual Disabilities, Violent Conflict and Humanitarian Assistance: Advocacy of the Forgotten', *Disability & Society* 28.6: 770–83.
- 10 Pearce (2015: 461).
- 11 Hemingway, L. and Priestly, M. (2006) 'Natural Hazards, Human Vulnerability and Disabling Societies: A Disaster for Disabled People?', *Review of Disability Studies: An International Journal* 2.3: 57–67.
- 12 Kett, M. and Twigg, J. (2007) 'Disability and Disasters: Towards an Inclusive Approach', in *World Disasters Report 2007 – Focus on Discrimination*, Geneva: International Federation of Red Cross and Red Crescent Societies (IFRC): 87; Rohwerder, B. (2015) *Disability Inclusion: Topic Guide*, Birmingham: GSDRC, University of Birmingham: 1.
- 13 UNISDR (2014) *Living with Disability and Disasters: UNISDR 2013 Survey on Living with Disabilities and*

- Disasters – Key Findings*, Geneva: United Nations Office for Disaster Risk Reduction: 2.
- 14 *Ibid.*: 4, 12; DCDD (2016: 4).
- 15 Osamu, N. (2014) 'Japan's 2011 Earthquake and Tsunami: The Paradox of Community Living and Disaster', in D. Mitchell and V. Karr (eds), *Crises, Conflict and Disability: Ensuring Equality*, New York: Routledge: 143–44.
- 16 ADCAP (2017: 18); NDRC Nepal (2016: 7); Kett and Twigg (2007: 97, 100).
- 17 HRW (2017) *Central African Republic: People with Disabilities at High Risk*, Human Rights Watch.
- 18 Cordero et al. (2017: 15); NDRC Nepal (2016: 5–7); Pearce (2015: 470).
- 19 Handicap International (2015) *Disability in Humanitarian Context: Views from Affected People and Field Organisations*, London: Handicap International: 4.
- 20 *Ibid.*
- 21 *Ibid.*; Sherwood, E. and Pearce, E. (2016) 'Working to Improve Our Own Futures': *Inclusion of Women and Girls with Disabilities in Humanitarian Action*, New York: Women's Refugee Commission: 1, 14–15; NDRC Nepal (2016: 5).
- 22 Handicap International (2015: 4).
- 23 Pearce (2015: 461).
- 24 *Ibid.*: 460.
- 25 WRC and LASA (2017) *Working with Refugees with Disabilities: Building Peer Networks Among Refugees and Host Community Persons with Disabilities Beirut, Lebanon*, New York: Women's Refugee Commission and Lebanese Association for Self-Advocacy: 1; Sherwood and Pearce (2016: 1); Pearce (2015: 468).
- 26 Handicap International (2015: 4).
- 27 Sherwood and Pearce (2016: 1); Handicap International (2015: 4); Pearce (2015: 475).
- 28 Searle, L. (2016) *Inclusive Humanitarian Action: A Study into Humanitarian Partnership Agreement (HPA) Agency Practice in the Nepal Earthquake Response*, Melbourne: Humanitarian Advisory Group: 36.
- 29 Pearce (2015: 474).
- 30 Cordero et al. (2017: 6); Kett and Twigg (2007: 94); Calvot (2014): 4.
- 31 NDRC Nepal (2016: 6).
- 32 Searle (2016: 39).
- 33 Cordero et al. (2017: 34).
- 34 Searle (2016: 37).
- 35 CBM Emergency Response Unit (ERU) (2016) *One Year Report Nepal Earthquake 2015*, Bensheim: CBM: 3.
- 36 Al Ju'beh, K. (2015) *Disability Inclusive Development Toolkit*, Bensheim: CBM: 55.
- 37 Light for the World and Diakonie Katastrophenhilfe (2013) *Humanitarian Aid: All Inclusive! How to Include People with Disabilities in Humanitarian Action*, Vienna: Light for the World and Diakonie Katastrophenhilfe: 15.
- 38 Cordero et al. (2017: 23); Pearce (2015: 472).
- 39 For example, www.handicap-international.org.uk/page/disability-statistics-in-humanitarian-action.
- 40 Cordero et al. (2017: 25).
- 41 WG (2006) *Overview of Implementation Protocols for Testing the Washington Group Short Set of Questions on Disability*, Hyattsville MD: Washington Group on Disability Statistics (WG): 1–2.
- 42 Cordero et al. (2017: 47).
- 43 Sherwood and Pearce (2016: 2).
- 44 Searle (2016: 36).
- 45 *Ibid.*: 37.
- 46 Cordero et al. (2017: 33).
- 47 Axelsson, C. (2016) *Active Participation: Key to Inclusion – Testimonies from Humanitarian Workers with Disabilities*, CBM.
- 48 Sherwood and Pearce (2016: 2); Handicap International (2015: 4).
- 49 DCDD (2016: 4); CBM ERU (2016: 13); Sherwood and Pearce (2016: 2).
- 50 WRC and LASA (2017: 2–3); Sherwood and Pearce (2016: 2); DCDD (2016: 4); Pearce (2015: 466).
- 51 Sherwood and Pearce (2016: 2); Searle (2016: 40).
- 52 Lee, B. and Pearce, E. (2017) *Vulnerability- and Resilience-Based Approaches in Response to the Syrian Crisis: Implications for Women, Children and Youth with Disabilities*, New York: Women's Refugee Commission: 2.
- 53 *Ibid.*: 38.
- 54 *Ibid.*: 39.

Humanitarian Learning Centre

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ISBN 978-1-78118-399-1



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