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# Addressing the disability data gap in humanitarian action

## Network Paper

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# Introduction

The inclusion of people with disabilities has risen rapidly up the international humanitarian agenda in recent years. Calling on humanitarian actors to play their part in delivering on the new 2030 commitment to ‘leave no one behind’, the UN Secretary-General’s report for the 2016 World Humanitarian Summit noted that people with disabilities are among the most marginalised in situations of conflict and disaster and appealed for new targeted national and international efforts to address this.<sup>1</sup> Building on the 2006 UN Convention on the Rights of Persons with Disabilities,<sup>2</sup> the Sendai Framework for Disaster Risk Reduction 2015–2030 recognises the needs and contributions of people with disabilities in disasters and disaster risk reduction.<sup>3</sup> Additionally, the Charter on Inclusion of Persons with Disabilities in Humanitarian Action – signed by over 200 humanitarian stakeholders since its launch in 2016 – highlights how people with disabilities are disproportionately affected in situations of risk and humanitarian emergencies. As well as ensuring that people with disabilities are protected and assisted, the Charter seeks to galvanise efforts to ensure they are protected and enabled to participate in humanitarian response and their rights upheld in situations of crisis.<sup>4</sup> Meanwhile, a new United Nations Disability Inclusion Strategy, adopted in 2019, established ‘the highest levels of commitment and a vision for the United Nations (UN) system on disability inclusion for the next decade’. Through the Strategy, the UN will ‘systematically embed the rights of persons with disabilities into its work’.<sup>5</sup>

The recent drive to improve the protection, assistance and involvement of people with disabilities in humanitarian response stems from a growing awareness of the extent to which physical, sensory and psychosocial disabilities affect populations in crisis contexts. Coupled with this, there is growing recognition that – despite their greater difficulties in accessing assistance – people with disabilities have been overlooked and disproportionately marginalised from mainstream humanitarian programming. A range of factors account for this heightened vulnerability, including risks of stigma, discrimination and abuse, loss of support

and environmental barriers, all of which intersect with a variety of risks and needs linked to people’s age, gender and other aspects of diversity. As important as any other risk is the design and delivery of humanitarian response: without adequate attention to people with disabilities, humanitarian responses are unlikely to address or mitigate the factors that cause their vulnerability, including barriers hampering their access to assistance and protection. The results of a large-scale survey carried out in 2015 reported that people with disabilities ‘too often fall through the cracks of humanitarian response’, with three quarters reporting that they did not have adequate access to basic assistance such as water, shelter, food or health, and half unable to access specialised services such as rehabilitation or assistive devices.<sup>6</sup>

The lack of attention paid to meeting the needs of people with disabilities is at odds with the likely number of people and households affected. People with disabilities are estimated to represent 15% of the world’s population<sup>7</sup> (a figure that is even higher among populations affected by crisis) and so constitute one of the largest population groups facing heightened risks and threats from the effects of conflict or disaster. In Syria, for example, a recent disability prevalence survey found that 27% of people aged 12 and over have a disability and, in some governorates surveyed, most households had at least one member with a disability.<sup>8</sup>

## New initiatives seek to bridge the gap between policy and practice

To start bridging the gap between the rhetoric of recent declarations and new policies on disability inclusion and the realities on the ground, a number of initiatives have sought to accelerate the practical steps needed to improve the inclusion of persons with disabilities across the sector. These include the development of Humanitarian Inclusion Standards for Older People and People with Disabilities by the Age and Disability Capacity Programme (ADCAP),<sup>9</sup> disability-focused revisions of the

1 ‘One humanity: shared responsibility - Report of the Secretary-General for the World Humanitarian Summit’ (A/70/709): (<https://reliefweb.int/report/world/one-humanity-shared-responsibility-report-secretary-general-world-humanitarian-summit>).

2 In particular, Article 11 relating to situations of risk and humanitarian emergencies, according to which: ‘States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters’.

3 United Nations (2015) ‘Sendai Framework for Disaster Risk Reduction 2015-2030’ ([www.undrr.org/publication/sendai-framework-disaster-risk-reduction-2015-2030](http://www.undrr.org/publication/sendai-framework-disaster-risk-reduction-2015-2030)).

4 Charter on inclusion with disabilities in humanitarian action (<http://humanitarianinclusioncharter.org/>).

5 United Nations Disability Inclusion Strategy (2019) ([www.un.org/en/content/disabilitystrategy/](http://www.un.org/en/content/disabilitystrategy/)).

6 Handicap International (Humanity & Inclusion) (2015) *Disability in humanitarian context: views from affected people and field organisations* ([www.un.org/disabilities/documents/WHS/Disability-in-humanitarian-contexts-HI.pdf](http://www.un.org/disabilities/documents/WHS/Disability-in-humanitarian-contexts-HI.pdf)).

7 WHO and World Bank (2011) *World report on disability*. Geneva: WHO, Chapter 2 ([www.who.int/disabilities/world\\_report/2011/report/en/](http://www.who.int/disabilities/world_report/2011/report/en/)).

8 Humanitarian Needs Assessment Programme for Syria (2019) *Disability: prevalence and impact: a nationwide household survey using Washington Group methodology*. HNAP for Syria ([www.globalprotectioncluster.org/wp-content/uploads/Disability\\_Prevalence-and-Impact\\_FINAL-2.pdf](http://www.globalprotectioncluster.org/wp-content/uploads/Disability_Prevalence-and-Impact_FINAL-2.pdf)).

9 ADCAP (2018) *Humanitarian inclusion standards for older people and people with disabilities* ([www.helpage.org/resources/publications/](http://www.helpage.org/resources/publications/)).

Sphere Handbook,<sup>10</sup> DFID's Guidance on Strengthening Disability Inclusion in Humanitarian Response Plans,<sup>11</sup> and – most recently – the launch of the Inter-Agency Standing Committee (IASC) Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action.<sup>12,13</sup> For the wider UN system, the new disability inclusion strategy contains a detailed accountability framework with a comprehensive set of indicators, timetables, technical guidance and allocation of responsibilities to ensure full implementation of the policy by all parts of the UN system. This aims to make the 'concerns and experiences of persons with disabilities an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all ... spheres so that persons with disabilities benefit equally'.<sup>14</sup>

Despite these efforts, there remains a long way to go to fully address the inclusion deficit in humanitarian policy and programming. A joint agency analysis of humanitarian stakeholders' self-reporting against Agenda for Humanity commitments concluded that humanitarian actors are 'challenged to modify their responses to promote the protection and equitable inclusion of persons with disabilities and consider their experience and capacities' and suggests that 'this requires a fundamental rethink of the way humanitarian actors work, their policies, practices, processes and assumptions'.<sup>15</sup>

## The lack of disability-related data is hampering progress

Chief among the challenges hampering progress is a chronic and widespread lack of reliable disability-related data and analysis to inform policy and practice across the sector. Although there is increasing awareness about the difficulties and risks facing people with disabilities in affected populations, humanitarian actors generally lack even the most basic information, including how many people are affected, their needs, the threats and barriers that they face and their access to services.

As the familiar adage goes, what isn't counted doesn't tend to count. In seeking to ensure that people with disabilities are no longer overlooked, all recent declarations and policies on disability inclusion call for action to improve

the collection, analysis and use of disability data in humanitarian response. For state actors, the Convention on the Rights of Persons with Disabilities (CRPD) establishes obligations to collect appropriate information on people with disabilities and to disaggregate and use this data to assess and support measures to ensure the protection and safety of people with disabilities in humanitarian action (Articles 3 and 11).<sup>16</sup>

Despite the weight and ambition of the various commitments and advice being advanced at the global level, however, there remain very significant gaps and weaknesses in the collection, analysis and use of disability-related data in practice. The consequent lack of information about the numbers, vulnerabilities, capacities, experiences and needs of people with disabilities is recognised as a major stumbling block to improving disability inclusion in humanitarian responses.<sup>17</sup> In fact, many humanitarian actors lack basic knowledge about how to collect, analyse and use this data and are without adequate systems to support this. Since information about the needs of people with disabilities and their access to assistance is so fundamental to ensuring a needs-based and non-discriminatory humanitarian response, this lack of data and information represents a profound challenge to the impartiality of humanitarian action. It also undermines humanitarian actors' accountability to affected populations, since this rests on seeking to ensure that assistance delivers the best possible outcomes for everyone affected by crisis, including those at risk of being marginalised from the mainstream response.

## Outline of this report

This Network Paper explores the challenge of improving the collection, analysis and use of disability data to support more inclusive, impartial and accountable humanitarian action. It considers both the obstacles in this area and the potential opportunities for improving practice going forward.

The paper draws directly on the experience and outcomes of a recent UK Aid-funded multi-partner action research project led by Humanity & Inclusion

10 *The Sphere handbook: humanitarian charter and minimum standards in humanitarian response* (<https://spherestandards.org/handbook/editions/>).

11 DFID Humanitarian Investment Programme (2019) *Guidance on strengthening disability inclusion in Humanitarian Response Plans* ([https://reliefweb.int/sites/reliefweb.int/files/resources/Guidance\\_on\\_strengthening\\_disability\\_inclusion\\_in\\_Humanitarian\\_Response\\_Plans.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/Guidance_on_strengthening_disability_inclusion_in_Humanitarian_Response_Plans.pdf)).

12 IASC (2019) *Guidelines: inclusion of persons with disabilities in humanitarian action, 2019*. IASC Task Team on Inclusion of Persons with Disabilities in Humanitarian Action. Endorsed by IASC October 2019 (<https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>).

13 Further disability-focused guidance includes: UNICEF (2018) *Guidance on including children with disabilities in humanitarian action* (<http://training.unicef.org/disability/emergencies/index.html>); and UNHCR (2019) *Need to know guidance: working with persons with disabilities in forced displacement* ([www.unhcr.org/publications/manuals/4ec3c81c9/working-persons-disabilities-forced-displacement.html](http://www.unhcr.org/publications/manuals/4ec3c81c9/working-persons-disabilities-forced-displacement.html)).

14 United Nations Disability Inclusion Strategy (2019).

15 CBM, Humanity & Inclusion and International Disability Alliance (2018) 'Inclusion of persons with disabilities in humanitarian action: Update on 2017 progress' ([www.agendaforhumanity.org/sites/default/files/resources/2019/Jan/2018%20Initiatives%20Updates\\_Disabilities\\_Final\\_January%202019.pdf](http://www.agendaforhumanity.org/sites/default/files/resources/2019/Jan/2018%20Initiatives%20Updates_Disabilities_Final_January%202019.pdf)).

16 UN Convention on the Rights of Persons with Disabilities (2006) ([www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)).

17 Cf., for instance, the UN Disability Inclusion Strategy, which states: 'The lack of disability-related data, including qualitative and disaggregated data, is one of the major barriers to the accurate assessment of disability inclusion in the development and humanitarian contexts'.

(HI),<sup>18</sup> which explored how the use of the internationally validated Washington Group Questions on Disability<sup>19</sup> can support the collection of more reliable and comparable quantitative data on persons with disabilities in humanitarian settings.

Based on a broader desk review of practice-based reports and case studies, this paper also draws on a further range of methods and approaches that have been taken to collect, analyse and use data and information to support inclusion of people with disabilities across different stages of the humanitarian programming cycle, focusing particularly on instances where qualitative information is used in combination with quantitative data. The paper looks at the collection and use of data on the accessibility and inclusiveness of humanitarian programmes, as well as data on the number, needs and capacities of persons with disabilities.

Chapter 1 explores the key gaps, flaws and challenges in collecting and using statistical and disaggregated disability data in humanitarian responses. It highlights some unique difficulties facing humanitarian actors collecting data on disabilities in crisis response contexts, and explains why the Washington Group Questions on Disability are increasingly seen as the preferred framework to overcome them. Inclusive humanitarian programming requires a lot more than statistics on disability, however.

While the Washington Group Questions have been shown to support and improve disability data collection across many humanitarian settings, the kind of quantitative data they can generate cannot on its own provide the full breadth and depth of information that humanitarian actors need to inform and support inclusive programming. Although helping to identify people with disabilities more reliably, the Washington Group Questions cannot provide any information about their needs and vulnerabilities or the barriers that they face

in accessing or participating in humanitarian assistance and protection. Chapter 2 explores the much wider range of qualitative data that is needed to capture the lived experiences of people with disabilities in crisis contexts, and discusses how this information can be collected and analysed alongside statistical data to provide a fuller picture of the situation and how people's needs might be responded to.

Wherever assessments have focused on the needs of people with disabilities, findings highlight significant access and inclusion barriers to humanitarian programmes that substantially compound the risks, threats and vulnerabilities of people with disabilities affected by crises. Chapter 3 considers how humanitarian agencies need to assess, monitor and address these barriers in their operations that make it difficult or impossible for people with disabilities to properly access and participate in assistance and protection.

Looking ahead, the conclusion reflects on one of most significant institutional barriers to the inclusion of people with disabilities in humanitarian action: without proper data, there is no meaningful accountability for disability inclusion across the humanitarian sector. There is a clear lack of accountability for humanitarian actors to systematically identify people with disabilities and to understand their needs and capacities, or to identify how and why people with disabilities might be excluded from assistance. There is also limited guidance on how to use this information to actively strengthen inclusive programming or how this exclusion can be addressed. Data is crucial not only to inform humanitarian actors about what they need to do to reach people with disabilities and ensure their inclusion, but also for holding humanitarian actors to account for what they do or do not do and what they achieve in this regard. Without accountability for disability inclusion, accountability for the impartiality of programming across the humanitarian system is significantly weakened.

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18 See: <https://humanity-inclusion.org.uk/en/projects/disability-data-in-humanitarian-action>.

19 See: [www.washingtongroup-disability.com](http://www.washingtongroup-disability.com).

# Chapter 1 Ensuring disability counts in humanitarian programming

To make progress towards operationalising the Charter on Inclusion of Persons with Disabilities in Humanitarian Action and other commitments to disability inclusion, humanitarian actors must understand why there has been such a serious deficit in attention to and information about people with disabilities in humanitarian programming up to now. Only then can they begin to address the gaps in the collection and analysis of disability data as a matter of urgency.

## 1.1 Gaps, flaws and challenges in disability data

A rapid review of the evidence on approaches to reaching people with disabilities through humanitarian programmes conducted for DFID in 2019 identified a host of environmental, attitudinal and institutional barriers to the inclusion of people with disabilities. Most prominent among these were barriers stemming from a lack of understanding, knowledge, skills and expertise among humanitarian staff, and negative attitudes, stigma and discrimination among both staff and affected populations.<sup>20</sup> The review points to the common misconception that people with disabilities are the concern of specialist agencies and do not require access to mainstream services. It cites a rapid qualitative study of the Nepal earthquake response that found much lower awareness of discrimination based on disability than on gender or social hierarchy.<sup>21</sup> The Nepal study highlights the influence of social and cultural attitudes and norms that can lead to a devaluing of the lives of many people with disabilities, with stigma and discrimination sometimes resulting in them being ‘hidden away, physically restrained and frequently neglected’ within households.<sup>22</sup> In addition to gaps and flaws in data collection processes, discussed below, the institutional barriers identified in the DFID review include a lack of disability inclusion expertise or disability mainstreaming across sectors, a lack of targets or indicators to monitor access and inclusion, a disregard of people with disabilities in vulnerability and

capacity assessments, and general exclusion of people with disabilities from consideration or participation in planning processes by humanitarian actors.<sup>23</sup> Unsurprisingly, the greater the barriers faced by people with disabilities, the lower their visibility in the data and systems underpinning humanitarian programmes, and the weaker the institutional imperatives to pay attention to their needs and to ensure or account for their inclusion in humanitarian programmes.

When collecting the basic data needed to inform inclusive policy and practice, there is a further technical challenge that is exacerbated by the lack of overall knowledge, skills and expertise in disability inclusion across the humanitarian sector. Simply put, collecting data about people with disabilities and their lives can be difficult and poses unique problems, whether for humanitarian programming or for any other purpose. According to the World Health Organization (WHO), compared to other areas of social statistics, disability statistics are particularly vulnerable to distortions of data due to a combination of definitional and methodological challenges. Worldwide, prevalence rates vary substantially, and in most countries, official disability statistics are extremely unreliable (see, for example, Box 1). In the Asia Pacific region, for instance, reported percentages of people with disabilities in the population range from as low as 0.7% in the Cook Islands and 1% in Singapore to 20% in Australia, with the majority reporting figures below 5% (well below the international average 15% estimated by the WHO).<sup>24</sup> Although some differences can be accounted for by variation in contextual factors, such as differing rates of disease, nutritional status or exposure to conflict and environmental hazards, it is highly unlikely that the extreme variation in disability percentages reflects reality. It is far more likely to result from different countries or surveys using divergent concepts and definitions of disability and varying ways and means of collecting this data (see Box A1).<sup>25</sup>

Humanitarian actors are therefore faced with a triple problem when it comes to collecting and using quantitative data on the numbers or prevalence of people

20 Holden, J., Lee, H., Martineau-Searle, L. and Kett, M. (2019) *Disability inclusion in humanitarian programming*. Disability Inclusion Helpdesk Research Report No. 9. London: Disability Inclusion Helpdesk. ([https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/833579/query-9-evidence-humanitarian-response1.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/833579/query-9-evidence-humanitarian-response1.pdf)).

21 Searle, L., Flint, J. and Munyeki, M. (2016) *Inclusive humanitarian action: a study into Humanitarian Partnership Agreement (HPA) agency practice in the Nepal earthquake response*. Melbourne: Humanitarian Advisory Group.

22 Women's Refugee Commission (2008) *Disabilities among refugees and conflict-affected populations*.

23 Holden et al. (2019): 7-9. See also Rohwerder, B. (2017) *Disability inclusive humanitarian response: operational practice paper 1*. Brighton: Institute of Development Studies; Twigg, J. (2014) ‘Attitude before method: disability in vulnerability and capacity assessment’ *Disasters* 38(3): 465-482; and Pearce, E. and Sherwood, E. (2016) *Working to improve our own futures: inclusion of women and girls with disabilities in humanitarian action*. New York: Women's Refugee Commission.

24 WHO & UN Economic and Social Commission for Asia and the Pacific (UNESCAP) (2008) *Training manual on disability statistics*. Bangkok: UN ([www.unescap.org/sites/default/files/Training-Manual-Disability-Statistics-E.pdf](http://www.unescap.org/sites/default/files/Training-Manual-Disability-Statistics-E.pdf)). See also: UN Disability Statistics Database (DISTAT) (<https://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp>).

25 Note that the UN's DISTAT database includes the warning that ‘[d]ue to differences in the concepts and methods used to identify persons with disabilities, prevalence rates should not be compared across countries’.

## Box 1 National disability statistics in Ethiopia

### Persons with physical, sensorial, intellectual and mental disabilities

In Ethiopia, as per 2007 National Population and Housing Census, ‘a person who [is] unable to carry out or limited in carrying out activities that others can do due to congenital or long-term physical/mental disabilities was identified as a disabled person. [...] In general, a person was defined as disabled if due to physical or mental injuries could not fully perform activities that other healthy person could do.’ This definition focuses on the person’s impairments but does not raise the issue of their rights or how their disability hinders their social participation as stipulated in the Convention on the Rights of Persons with Disabilities (CRPD). Furthermore, existing legislation and policies use derogatory terms to refer to persons with disabilities, such as ‘insane’, ‘infirm’, ‘deaf-mute’. In Ethiopia, there are no reliable, up-to-date national statistics available on disability. The most recent national census in 2007 found only 805,492 persons with disabilities in Ethiopia, merely 1.09% of the total population of 86 million (and less than what was reported in the 1994 census: 1.9%). Commentators in the disability arena generally regard the census data as skewed by under-reporting, due to the formulation of census questions, lack of disability-related knowledge among those involved in census data collection and analysis and the application of a narrow definition of disability.

The World Report on Disability, published jointly by the World Bank and WHO in 2011, estimated that there were 15 million persons with disabilities in Ethiopia, representing 17.6% of the total population at that time. According to the Ministry of Labour and Social Affairs, 95% of persons with disabilities in the country live in poverty – the vast of majority in rural areas, where basic services are limited and the chances of accessing rehabilitative or support services are remote.

Source: *Humanitarian Needs Overview for Ethiopia, 2020 (p.19)*

with disabilities in affected populations, whatever its purpose: not only do humanitarian agencies usually lack expertise in disability data collection, but there tends to be little or no reliable secondary data they can use, and collecting new primary data is far from straightforward.

This means the majority of humanitarian programmes have been planned and delivered without reference to any disability data, or use flawed data that substantially under-reports and misrepresents the prevalence and range of disabilities in the affected population. For example, a 2018 report from Humanity & Inclusion (HI)<sup>26</sup> on the barriers to accessing humanitarian services in camp settings in Iraq reported that information about people with disabilities was scarce. Assessments of three internally displaced persons (IDP) camps found staff had not been trained to identify different impairments and were using binary yes/no questions directed to heads of household or identified persons with disabilities through visual observation, both of which would lead to substantial under-reporting of disability prevalence. Less than 2% of the population of two camps were identified as having a disability, whereas surveys conducted by HI using the Washington Group Questions subsequently identified 17% with disabilities and found that most households had at least one member with a disability in at least one domain (seeing, hearing, walking, cognition, self-care and/or communication).<sup>27</sup>

In Jordan, UNHCR’s standard registration system (Profile Global Registration – ProGres) had only identified 2.36% of registered refugees as having a disability, whereas a pilot trial of the Washington Group Short Set (WG-SS) of questions in 2016 with 98 refugee households found that 27.55% had a disability – a figure that is almost certainly more realistic.<sup>28</sup>

Given the dearth of reliable secondary data, the IASC Guidelines advise that, when robust quantitative data do not exist, humanitarian actors should assume that 15% of an affected population has a disability<sup>29</sup> so as to inform planning, resourcing and monitoring access to assistance. It should be kept in mind, however, that – on its own – this estimate indicates nothing about the diverse range of physical, sensory, intellectual and psychosocial disabilities within this population, nor does it take into account the possibility of a higher disability rate or changed prevalence of particular disabilities in crisis-affected contexts. This is an important limitation; not only will crises and disasters usually cause new disabilities and therefore a higher prevalence overall (e.g. new psychosocial and physical disabilities resulting from trauma), but the sudden adverse changes in the social and physical environment can also significantly affect how people with pre-existing or new impairments are able to cope, participate and access support. Depending

26 Humanity & Inclusion (2019) *Disability assessment among internally displaced persons (IDPs) in 3 Ninewa camps*. Disability Survey Report (Iraq, March 2019). HI ([www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/assessments/2019\\_disability\\_assessment\\_report\\_ninewa\\_handicap\\_international\\_vf.pdf](http://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/assessments/2019_disability_assessment_report_ninewa_handicap_international_vf.pdf)).

27 Humanity & Inclusion (2019).

28 Humanity & Inclusion (2016) ‘Disability universal indicator to assist identification’ (HI & UNHCR co-chaired Disability Task Force, Jordan) (<https://humanity-inclusion.org.uk/sites/uk/files/documents/files/2016-11-disability-universal-indicator-jordan-unhcr.pdf>).

29 Based on the WHO’s 15% global estimate; see WHO and The World Bank (2011). DFID’s new guidance on strengthening disability inclusion in Humanitarian Response Plans (HRPs) also advises that it is preferable to use to assume that 15% of total persons in need have disabilities, rather than using flawed secondary data where the risk of under-identification is high; see DFID Humanitarian Investment Programme (2019).

## Box 2 Intersectional prevalence data on disability in Syria

In June 2019, the joint UN Humanitarian Needs Assessment Programme for Syria (HNAP) conducted a national household survey on the prevalence of persons with disabilities (aged 12+) throughout Syria by area, age group and population type, including: resident, or non-displaced host communities; IDPs; and households returning from displacement (returnees) within 2019.<sup>1</sup> The survey used the Washington Group Questions on disability and the data was triangulated with other responses in the survey, allowing for a more comprehensive understanding of social aspects, such as access to education, employment, and income coping strategies. In doing so, it built on institutional understanding of social inclusion for persons with disabilities across Syria.

The HNAP reports that the impacts of disabilities are compounded inside Syria where individuals with disabilities experience increased threats of violence and limited access to essential income-generating activities and medical assistance. Disabilities increase individual and household vulnerability through exclusion in social, economic and political areas, which can further the cycle of exclusion and poverty, especially for vulnerable population groups like IDPs and returnees. In terms of employment, the survey found that 62% of persons with a disability are out of work, compared to 48% of those without a disability. Two districts in Homs, Qabu and Shin – where 5% and 7% of the total population had disabilities, respectively (mobility difficulty being the most common type) – had no person with a disability working. Meanwhile, in Deir-ez-Zor Governorate, 82% of persons with disabilities were out of formal employment, and 12% of the Deir-ez-Zor population reported ‘a lot of difficulty’ or ‘cannot do at all’ regarding mobility and self-care respectively.

1 See HNAP (2019). See also: Humanity & Inclusion and iMMAP (2018) ‘Removing barriers: the path towards Inclusive access disability assessment among Syrian refugees in Jordan and Lebanon: Jordan report’ (<https://reliefweb.int/report/jordan/removing-barriers-path-towards-inclusive-access-jordan-report-july-2018>).

on the nature of the crisis and other intersecting causes of risk or vulnerability, some disability groups may require particular responses to be prioritised more than others (e.g. targeted or adapted responses for people with new physical injuries versus those with psychosocial disabilities, or differentiated programming for older people, young children or adolescent girls with disabilities). As discussed further in Chapter 2, disability always intersects substantially with other sources of risk, discrimination or social disadvantage, such as age, gender, sexuality, ethnicity, poverty, or legal status, which may affect needs and access to humanitarian assistance programming (see Box 2). An intersectional approach to programming, which recognises and responds to the multiple and interacting sources of vulnerability among affected populations, depends on the collection of disability data so that key assessment and other population data can be disaggregated by (at a minimum) sex, age and disability.<sup>30</sup>

### 1.2 Collecting and disaggregating data using the Washington Group ‘Short Set’ of Questions on Disability

Although there is plenty of evidence of difficulties, limitations and gaps in the data and in other aspects of disability inclusion in humanitarian programming, with so little previous positive experience, the evidence on what works (or what has worked) to include people with disabilities effectively in humanitarian responses is scarce.<sup>31</sup> The wide range of frameworks and methodologies that have been developed to collect data on disability prevalence and other population-level aspects of disability reflects the underlying complexity of disability both as a concept and as an aspect of lived human experience. This, in turn, complicates any assessment of what works best for humanitarian programming.<sup>32</sup>

However, based on evidence from recent field studies, and in order to promote a common standardised and validated approach to quantitative/disaggregated data collection and data-sharing, recent inclusion guidelines<sup>33</sup> for humanitarian actors reflect a growing consensus that the most appropriate tool is the WG-SS. This widely used and internationally endorsed set of six targeted questions on individual functioning is designed to be added to

30 IASC (2019), p.27.

31 Holden et al. (2019).

32 In addition to the Washington Group Question sets discussed in this chapter, some of the most recognised disability survey instruments include the WHO Disability Assessment Schedule Version 2.0, the WHO Model Disability Survey (and a recently developed additional ‘Brief Version’ of the MDS), and the Rapid Assessment of Disability (RAD) developed by the Nossal Institute for Global Health (<https://mspgh.unimelb.edu.au/research-groups/nossal-institute-for-global-health/inclusive-health-and-development/the-rapid-assessment-of-disability-rad>). For comparisons of the main WG and WHO frameworks, see Groce, N. et al. (2018) *Which one to use? The Washington Group Questions or Model Disability Survey*. Working Paper Series 31. London: UCL; and DFID Humanitarian Investment Programme (2019) Annex 3.

33 Including IASC (2019); European Civil Protection and Humanitarian Aid Operations – ECHO (2019) *The inclusion of persons with disabilities in EU-funded humanitarian aid operations*. DG ECHO operational guidance (February) ([https://ec.europa.eu/echo/sites/echo-site/files/dg\\_op\\_guidance\\_inclusion\\_gb\\_liens\\_hr.pdf](https://ec.europa.eu/echo/sites/echo-site/files/dg_op_guidance_inclusion_gb_liens_hr.pdf)); and DFID Humanitarian Investment Programme (2019).

**Figure 1 Washington Group tools and domains by age group**

Child Functioning Module		Modified Extended Set
Age 2–5	Age 5–17	Age 18+.
	Seeing	
	Hearing	
	Walking	
	Communication	
		Self care
	Learning	
	Controlling behaviour	
	Remembering	Cognition (remembering or concentrating)*
	Concentrating	
		Anxiety
		Depression
Playing	Making friends	Upper body 1&2**
Fine motor	Accepting change	Fatigue

\* Domains covered by the Short Set.

\*\* Upper body 1 is difficulty raising a 2-litre bottle of water or soda from waist to eye level and 2 refers to difficulty using hands and fingers, such as picking up small objects.

Source: HI and iMMAP (2018), p. 15.

existing population-based censuses and surveys to identify people with disabilities in any given population group (see Box A2).

A key source of evidence supporting a widening endorsement of the use of WG-SS in humanitarian programming is a UK Aid-funded study led by HI from 2016 to 2019, in collaboration with the WG and the International Disability Alliance. The study tested and assessed the WG question sets through action research with a range of operational partners in Syria, Jordan, the Philippines and the Democratic Republic of Congo.<sup>34</sup> It supported a range of humanitarian actors<sup>35</sup> working

in different sectors<sup>36</sup> and contexts<sup>37</sup> to integrate the WG-SS questions into their existing practices and explored the practicalities and utility of the questions for generating useful and reliable data on disability among affected populations. The findings are strongly corroborated by further indicative evidence from other organisations' use of the WG-SS in a range of settings, including, for example:

- A 2017 joint agency assessment of the experiences of people with disabilities in Vanuatu during and after Tropical Cyclone Pam using the Rapid Assessment of Disability Tool, which incorporates the WG-SS.<sup>38</sup>

34 Detailed information and all outputs from this project, including guidance and e-learning resources are available at: <https://humanity-inclusion.org.uk/en/projects/disability-data-in-humanitarian-action#9>. Key outputs include: Humanity & Inclusion and Leonard Cheshire (2018) *Disability data collection: a summary review of the use of the Washington Group Questions by development and humanitarian actors*. London: Humanity & Inclusion and Leonard Cheshire; and Humanity & Inclusion (2019) *Data on persons with disabilities in humanitarian action: collecting quantitative data with the Washington Group Questions*. London: Humanity & Inclusion.

35 Including UN agencies, INGOs, local NGOs, government agencies and disabled people's organisations (DPOs).

36 Including multi-sector, food security and livelihoods, WASH, protection, health and disaster risk reduction.

37 Including sudden onset emergencies, displacement and refugee emergencies, protracted crisis and disaster-prone contexts.

38 CBM & Nossal Institute for Global Health (2017) 'Disability inclusion in disaster risk reduction: experiences of people with disabilities in Vanuatu during and after Tropical cyclone Pam and recommendations for humanitarian agencies' ([https://mspgh.unimelb.edu.au/data/assets/pdf\\_file/0011/2567576/WEB-DIDRR-Report-14112017.pdf](https://mspgh.unimelb.edu.au/data/assets/pdf_file/0011/2567576/WEB-DIDRR-Report-14112017.pdf)).

### Box 3 Varying disability prevalence rates reported among Syrian refugees in Lebanon with and without using the WG-SS

In 2017, the joint agency Vulnerability Assessment of Syrian Refugees in Lebanon (VASyR) defined disability to include physical, sensorial and mental/intellectual impairments, and found an overall disability prevalence of 3.5%, with 2.3% among children.<sup>1</sup>

In 2014, HI and HelpAge International studied Syrian refugees with specific needs, including persons with impairments plus injuries and chronic diseases, in five daily activities. The study found 21.4% had impairments, 16.2% had chronic diseases and 4.5% had significant injuries in Bekaa and Baalbek-Hermel. UNHCR data had previously reported in 2013 that only 1.4% of registered Syrian refugees in Lebanon had disabilities, based on self-identification against its own categories covering a number of impairments: physical (moderate and severe), mental (moderate and severe) and visual, hearing and speech impairments.<sup>2</sup>

Using the WG-SS, a joint HI & iMMAP assessment found a disability prevalence of 22.9% in Lebanon, with 59.9% of sampled households including at least one member with disabilities, compared with only 14% of households identified in the previous VASyR assessment.

Source: HI and iMMAP (2018).

1 UNHCR, UNICEF and WFP (2017) *Vulnerability assessment of Syrian refugees in Lebanon: VASyR 2017* (<https://data2.unhcr.org/fr/documents/download/61312>).

2 Cf. HelpAge International and HI (2014) *Hidden victims of the Syrian crisis: disabled, injured and older refugees* (<https://reliefweb.int/report/syrian-arab-republic/hidden-victims-syrian-crisis-disabled-injured-and-older-refugees>).

- An assessment of service accessibility for people with disabilities in Bentiu Protection of Civilian (PoC) site in South Sudan, carried out by IOM and HI in South Sudan in 2017.<sup>39</sup>
  - A series of pilot projects undertaken by Sightsavers that use the WG-SS to disaggregate data on disabilities among service users, including in India, Tanzania and Ghana<sup>40</sup>.
  - The integration of the WG-SS into numerous sectoral assessments conducted by REACH among Rohingya refugees in Cox's Bazaar in 2019.<sup>41</sup>
- the increase in overall numbers of people identified has been so great that organisations have been left wondering how to respond. HI reports that some partner organisations appeared overwhelmed and perplexed by the results and were prompted to question their role in the light of the data they had collected. As concluded by HI, if, through the use of the WG-SS, disability prevalence is found to be orders of magnitude higher than previously assumed, this should have a direct impact on programme planning and implementation and may raise potentially far-reaching questions about how organisations understand and operationalise disability inclusion. Key outcomes of the HI action research project that are explored in the following two chapters centre on what the disability data means for humanitarian programming in practice – not only the WG data, but also other forms and sources of qualitative data that are needed to properly inform inclusive humanitarian programming.

While challenges should not be underestimated, there is little doubt overall that where the WG-SS questions have been introduced into data collection processes, the reliability of quantitative data on people with disabilities has been significantly improved (see for example Box 3). In some cases – due to previous substantial under-reporting

39 International Organization for Migration (IOM) and Humanity & Inclusion (2017) *Access to humanitarian services for people with disabilities. Situational analysis in Bentiu protection of civilians site, South Sudan* ([https://displacement.iom.int/system/tdf/reports/22052018\\_DTM\\_HI\\_Joint\\_Assessment\\_Bentiu\\_PoC\\_Dec2017.pdf?file=1&type=node&id=6969](https://displacement.iom.int/system/tdf/reports/22052018_DTM_HI_Joint_Assessment_Bentiu_PoC_Dec2017.pdf?file=1&type=node&id=6969)).

40 See: [www.sightsavers.org/programmes/everybody-counts/](http://www.sightsavers.org/programmes/everybody-counts/).

41 REACH (2019) 'Rohingya refugees with disabilities: prevalence, meaningful access, and notes on measurement'. REACH Brief. ([www.impact-repository.org/document/reach/d4b0d4b1/REACH\\_BGD\\_Brief\\_Disability\\_Nov2019.pdf.pdf](http://www.impact-repository.org/document/reach/d4b0d4b1/REACH_BGD_Brief_Disability_Nov2019.pdf.pdf)). Note that some important methodological problems were identified in the course of this study, which resulted in a likely under-reporting of disability among the Rohingya population surveyed.

## Chapter 2 Assessment data on the situation and needs of people with disabilities

Among the most notable outcomes from humanitarian organisations' recent use of the Washington Group Questions has been an increase in disability awareness among staff involved in data collection and analysis using the questions. There was also heightened awareness within organisations of gaps in their capacities and systems to support inclusive data collection and remaining gaps in the data that need to be filled in order to deliver more inclusive humanitarian responses.<sup>42</sup> As already discussed, the Washington Group Questions do not on their own provide a framework for needs or vulnerability and capacity assessments, nor do they inform organisations about the specific barriers facing people with disabilities or the enabling factors that help people with disabilities in a crisis response situation. Inclusive programming depends on agencies collecting and using a combination of statistical and qualitative data, which, when analysed together, can provide a full picture of the number and circumstances of people with disabilities in a population and inform the necessary responses.

The IASC Guidelines set out four main types of information collection and analysis that agencies need at each phase of the programme cycle:

1. identifying the population of people with disabilities (for which use of the WG-SS is key);
2. analysing the risks they face and the factors contributing to those risks;
3. identifying the barriers that impede persons with disabilities from accessing humanitarian assistance; and
4. understanding their roles and capacities in the humanitarian response (see Box A4).

To gain a full understanding of the risks and barriers affecting people with disabilities, data needs to support explanatory (rather than simply descriptive) analysis. It will be necessary to recognise and analyse the intersectional drivers and processes leading to these risks and barriers in order to design and deliver effective and inclusive programmes.<sup>43</sup>

Arriving at reliable, valid and usable information for all the purposes listed in the IASC Guidelines and to support explanatory analysis of this kind may seem challenging.

Given the low base of existing information that agencies will usually be starting from, this process will need to be incremental and (ideally) shared among organisations within and between clusters or sectors. This will not only promote the shared use of the data between agencies, but also strengthen the quality and breadth of the data and analysis – including intersectional analysis linking across to data on age, gender, socioeconomic factors and other diversity characteristics (see Box 4). As with data collection generally, organisations must only collect the data they will use to support decision-making and enable quality and accountability in their programming, and they should mainstream data collection and analysis on people with disabilities into existing processes and tools.<sup>44</sup>

### 2.1 The use of official and secondary data

In the majority of crisis response contexts, there is a lack of available official and secondary data that reliably captures the size and diversity of the population of persons with disabilities. The risks and other factors affecting this population represents a significant institutional barrier to disability inclusion from the earliest stages of a crisis response. Although humanitarian actors are requested to share data on people with disabilities through OCHA's Humanitarian Data Exchange (HDX),<sup>45</sup> data available via this and other general humanitarian data portals remains variable and patchy for reasons outlined earlier. In response to this, a Disability Data Portal was set up by Leonard Cheshire in 2018 for the Global Disability Summit, providing a one-stop snapshot of available data on people with disabilities in 40 countries. The Portal lists a number of limitations that users need to be aware of before seeking to interpret or compare its data, including possible lack of available data, outdated data, problems with comparability, methodological issues and limited verification.<sup>46</sup> In a humanitarian response context, organisations face the additional problem that the crisis may have brought about changes in disability prevalence, which immediately renders any pre-crisis data out of date, regardless of its quality.<sup>47</sup> Consequently, while the collection and analysis of

42 Humanity & Inclusion and Leonard Cheshire (2018).

43 On the importance of explanatory analysis, see ACAPS (2019) *Lessons learned: needs assessments in Cox's Bazar*. NPM-ACAPS Analysis Hub Thematic Report (April) ([www.acaps.org/sites/acaps/files/products/files/20190404\\_acaps\\_npm\\_coxs\\_bazar\\_analysis\\_hub\\_needs\\_assessments\\_lessons\\_learned.pdf](http://www.acaps.org/sites/acaps/files/products/files/20190404_acaps_npm_coxs_bazar_analysis_hub_needs_assessments_lessons_learned.pdf)); and ACAPS (2020) *South Sudan analysis ecosystem: strengthening the information landscape in South Sudan*. Thematic report (March) ([www.acaps.org/sites/acaps/files/products/files/2020311\\_south\\_sudan\\_analysis\\_ecosystem.pdf](http://www.acaps.org/sites/acaps/files/products/files/2020311_south_sudan_analysis_ecosystem.pdf)).

44 Cf. DFID Humanitarian Investment Programme (2019), p.6.

45 See: <https://data.humdata.org/>

46 See: [www.disabilitydataportal.com](http://www.disabilitydataportal.com). See also BOND (2019) *Disability data lab learning paper: a practical guide to disability data*. London: Bond Disability and Development Group ([www.bond.org.uk/sites/default/files/ddg\\_outcome\\_document\\_final.pdf](http://www.bond.org.uk/sites/default/files/ddg_outcome_document_final.pdf)).

47 As noted in the previous chapter, where no reliable statistical data is available, the IASC Guidelines and other guidance on disability inclusion recommend that humanitarian agencies should use a 15% disability prevalence estimate to inform planning and to monitor access to assistance rather than use unreliable secondary data.

## Box 4 Disability-sensitive needs analysis as an incremental and joint process

Initial analysis should give an idea of the extent to which people with disabilities may be at additional risk compared to the rest of the population, and provide some pointers to identify broad priorities. If initial data indicates that people with disabilities are particularly marginal and invisible and have no functioning safety networks, it will be clear that they should be given higher priority when designing further assessments and response programmes. The assessment team should have some prior knowledge of what to be alert to in terms of potential risks (based on previous experience and/or through staff training and sensitisation on disabilities). As the quantity and depth of the available information increases over time, the breadth and depth of analysis can increase. In general, disability-related risk analysis should guide the process of setting strategic objectives and designing programmes so that any pre-existing condition of invisibility, marginality and exclusion is not worsened by humanitarian assistance.

*Source: Adapted from: HelpAge International (2012) Ensuring inclusion of older people in initial emergency needs assessments, pp.19–20.*

*Note: In the main, the approaches recommended to initial needs assessment for older people can be applied equally well to people with disabilities. It is also important to remember that analysis of the situation of people with disabilities in a crisis should always have a significant intersectional component, with analysis disaggregated by age group, gender and other diversity characteristics. Given the high prevalence of frailty and disability among older people, there is substantial intersectional overlap between old age and disabilities in terms of risks and needs in the population, and also in terms of inclusive programme responses. For further insight into the links between age- and disability-sensitive programming, see ADCAP (2018).*

available data on people with disabilities remains a crucial element of preparedness action, this is just as likely to result in the reporting of a lack of available data – an important finding, nonetheless, to inform subsequent data collection at later phases in a response (see for example Box 5).<sup>48</sup>

As disability inclusion becomes more established across mainstream programming, disability-focused data collected previously by humanitarian agencies may become increasingly important in informing humanitarian responses. DFID's guidance on strengthening disability inclusion in HRP's points to a number of potential sources of data, including accessibility audits, post-distribution monitoring data, feedback and complaints mechanisms, needs assessments, participatory assessments and protection monitoring systems.<sup>49</sup> However, the lack of attention to people with disabilities in these mechanisms to date means that, until disability data collection is mainstreamed more routinely, a review of these sources may reveal more data gaps than data that can be used. These gaps are, nonetheless, important to record and share to inform priorities for subsequent primary data collection as a response evolves.

Where available data can be trusted, its collection and use can make a significant positive difference to the early stages of analysis and to subsequent assessments and programme planning (cf. Box 4). For example, in a disability-inclusive situational analysis to inform the response to Tropical Cyclone Gita in Tonga in 2018, CBM-NZ and the Pacific Disability Forum report how the

Government of Tonga had used the WG-SS questions in the 2016 census to provide a more accurate indication of pre-cyclone disability prevalence. This in turn contributed to increased attention to people with disabilities by government departments: the Ministry of Internal Affairs' disability allowance register, for instance, was used by some responders to distribute food and essential non-food items, contributing to 55% of survey informants receiving assistance within the first fortnight after the cyclone.<sup>50</sup> Following an escalation in violence in Gaza in 2018, ACAPS drew on a range of secondary data sources to inform a situation analysis that contained significant detail on the prevalence and situation of people with disabilities, such as numbers and range of injuries and psychosocial trauma. The data also included important detail on health service capacities and damage sustained by health facilities and the scale of injuries to health personnel. Much of the quantitative data threw light on the situation and risks facing people with disabilities rather than reporting prevalence data per se. For example, the analysis found that at least 700 children had been injured; 60% of children recently surveyed by NRC suffered from traumatic nightmares and showed signs of psychosocial deterioration; an estimated 200,000 children required psychosocial support; 35% of children with disabilities were not attending school; and 49,000 people with disabilities faced protection needs.<sup>51</sup> The collection and analysis of secondary data on the socioeconomic, political and legal situation for people with disabilities in the context concerned is particularly important to inform strategic planning and assessments at any stage in a response (see for example Box 6).

48 Cf. HelpAge International (2012).

49 DFID Humanitarian Investment Programme (2019), p.11.

50 CBM New Zealand & Pacific Disability Forum (2018) *Tropical Cyclone Gita: disability inclusive situational analysis, Tonga* ([https://cbm-nz.org.nz/images/pdfs/Tropical\\_cyclone\\_Gita.pdf](https://cbm-nz.org.nz/images/pdfs/Tropical_cyclone_Gita.pdf)).

51 ACAPS (2018) *Gaza: most pressing needs and vulnerabilities*. Thematic report (7 May) ([www.acaps.org/sites/acaps/files/products/files/20180504\\_acaps\\_thematic\\_report\\_needs\\_and\\_vulnerabilities\\_in\\_gaza\\_0\\_0.pdf](http://www.acaps.org/sites/acaps/files/products/files/20180504_acaps_thematic_report_needs_and_vulnerabilities_in_gaza_0_0.pdf)).

## Box 5 Reporting gaps in secondary qualitative data to inform responses to the needs of Rohingya refugee children

In 2019, ACAPS conducted a child-focused secondary data review for the Rohingya response, with the aim of giving an overview of children's needs both inside and outside the camps and to identify child-related information gaps, in order to inform the design and methodology of a subsequent primary data collection exercise to be led by Save the Children. As regards children with disabilities, the review reported that: 'Information on the specific needs and barriers of ... children and youth with disabilities is limited. This impacts assistance and services provision to these groups, without the relevant information targeting is difficult and these groups are at risk of being missed. For example, health clinics are reporting that adolescent boys are not attending the clinics however, there is a lack of information that investigates why that is and how to overcome this problem. The lack of data on ... children and youth with disabilities means that their specific needs are going unmet.'

Source: ACAPS (2019) Rohingya refugee response: child-focused secondary data review. Thematic report (November) ([www.acaps.org/sites/acaps/files/products/files/20191121\\_acaps\\_coxs\\_bazar\\_analysis\\_hub\\_child\\_focused\\_sdr\\_0.pdf](http://www.acaps.org/sites/acaps/files/products/files/20191121_acaps_coxs_bazar_analysis_hub_child_focused_sdr_0.pdf)).

## Box 6 Use of secondary data on the socioeconomic situation of people with disabilities in crisis-affected contexts

In an assessment of service accessibility for people with disabilities in the Bentiu Protection of Civilians Site in South Sudan, carried out jointly by IOM and HI in South Sudan in 2017, a review of secondary data showed that the needs of people with disabilities – estimated to number more than 1.2 million people – were not prioritised in national plans, and people with disabilities experienced widespread discrimination. This limited their participation in community activities and restricted their access to income-generation opportunities, vocational training and education compared to their peers without disabilities.<sup>1</sup> The review noted that South Sudan has yet to ratify the UN Convention on the Rights of Persons with Disabilities.

A joint HI and iMMAP disability access assessment among Syrian refugees in Lebanon in 2018 drew on a secondary data review to inform understanding of issues affecting livelihoods and access to education for those with disabilities. The review cited a recent study revealing widespread exclusion from livelihood opportunities, with 80% of Syrian refugees with disabilities over the age of 18 reporting that they were unemployed. A joint UN agency report from 2017 had found that the expenditure level of 80% of households with children with disabilities did not meet the minimum expenditure threshold. A Human Rights Watch report was also cited, which highlighted the extent to which, in practice, children with disabilities are excluded from education despite their legal entitlement to access public education under Lebanese law.<sup>2</sup>

1 IOM and Humanity & Inclusion (2017), citing: *National Disability Assessment: Eastern Equatoria, Jonglei, & Western Bahr el-Ghazal States*, Forcier consulting for MGCSW, September 2012.

2 HI and iMMAP (2018).

## 2.2 Primary data collection in initial and rapid needs assessment and analysis

Needs assessment is one of the most critical components of a humanitarian agency's response to a crisis, with the quality of the assessment largely determining the quality of programming. If vulnerable groups are not directly considered from the earliest stages of a response, the likelihood that they will be included in initial programming or later assessments is

substantially reduced.<sup>52</sup> However, as cautioned in the IASC's guidance on coordinated assessments, the success of an assessment depends partly on the timeliness of the findings – it is therefore important to seek a balance between the quality of data, the level of detail and the timeliness of results (during the initial phase, gathering purposive data quickly is more important than collecting 'statistically representative' data).<sup>53</sup> Given the paucity of disability data generally, the collection, analysis and use of data on people with disabilities should be approached as an incremental process; initial data will not tell the

52 HelpAge International (2012), pp.4–5 and p.21.

53 IASC (2012) *Operational guidance for coordinated assessments in humanitarian crises*, p.12 ([https://interagencystandingcommittee.org/system/files/legacy\\_files/operational\\_guidance\\_for\\_coordinated\\_assessments\\_in\\_humanitarian\\_crises.pdf](https://interagencystandingcommittee.org/system/files/legacy_files/operational_guidance_for_coordinated_assessments_in_humanitarian_crises.pdf)).

## Box 7 Prioritising protection considerations and identifying intersecting factors in assessments: lessons learned from needs assessments in Cox's Bazar

A review of needs assessments in the Rohingya refugee response in Cox's Bazar conducted by ACAPS in 2019 highlighted the following findings:

- Protection considerations and a do-no-harm approach must always be prioritised over the need for good data; training is essential to ensure culturally sensitive approaches to gathering data by assessment teams.
- In order to understand the specific needs of women, girls, the elderly, disabled people and minorities, such groups should be specifically targeted by assessment activities, and data collection, sampling and analysis processes need to be designed around disaggregating differences accordingly. Some assessments pose generic questions without differentiating how particular population groups are affected by a specific problem.
- Even when age, gender and diversity considerations are incorporated into assessment design and questionnaires, capturing the experiences and needs of marginalised groups can be challenging. For example, due to safety considerations and cultural practices, adolescent girls often remain in their shelters during the day and have little contact with humanitarian workers.

*Source: ACAPS (2019) Lessons learned: needs assessments in Cox's Bazar. For a further assessment of the barriers, risk and situations of exclusion facing people with disabilities in Cox's Bazar, see Humanity & Inclusion (2019) Inclusive access to services for persons with disabilities: barriers and facilitators assessment report Jadimura Camp, Teknaf (January) (<https://data.humdata.org/dataset/inclusive-access-to-services-for-persons-with-disabilities/resource/be02365a-4037-4fa5-8269-6e88736030fd>) (discussed further in Chapter 3).*

whole story, but will inform subsequent planning and implementation, and can also promote inclusion from the outset.

The IASC's Operational Guidance for Coordinated Assessments in Humanitarian Crises advises that priority vulnerable groups and target populations should be addressed during contingency planning and initial assessments. The Guidelines on Inclusion of Persons with Disabilities includes a long list of expectations of different humanitarian stakeholders in strategic response planning that depend on the availability and/or collection of a range of data and information on people with disabilities at an early stage in the response. This not only includes statistical prevalence data, but also information about the needs of and risks and barriers affecting people with disabilities, to inform response planning and the design of disability-inclusive programmes (see Box A5).

Detailed household-level assessments (including assessments using the Washington Group Questions to gather quantitative data) are unlikely to be practical at the earliest stages of a response, so the most important form of primary data at this stage is likely to be collected through community-level assessments involving key informant interviews, focus group discussions (FGDs) and direct observation.<sup>54</sup> The IASC Guidelines advise that, for a needs assessment to be inclusive, persons with disabilities must be included as key informants and must participate in FGDs, and organisations representing people with disabilities should be involved. A fully inclusive and mainstreamed approach to disability-responsive programming will depend to a great extent on adapting mainstream

assessment tools to incorporate the collection of data on people with disabilities (there will of course be some limitations to data collection, which must be recognised).<sup>55</sup> Attention must be given pre-crisis at headquarters and operational levels to modifying the assessment frameworks appropriately and to putting in place awareness-raising and training to ensure that the necessary quality and mix of data is collected to inform inclusive responses. Strengthening the voices of people with disabilities in mainstream assessment systems and processes will also depend on humanitarian actors working to ensure that people with disabilities and their representative organisations can engage directly and effectively.

DFID's guidance on strengthening disability inclusion in HRP's includes a review of existing needs assessment tools with recommendations for how they could be modified to improve disability inclusion. It notes, for example, that the IASC Multi-cluster Rapid Needs Assessment (MIRA), intended to inform overarching strategic priorities, relies substantially on pre-crisis and some limited in-crisis secondary sources for quantitative data, which risks under-reporting disabilities, and includes only very limited primary data collection. The MIRA framework incorporates direct observation, key informant interviews and community group discussions as primary data collection approaches, but disability is considered only as a specialised issue in the analysis of unmet needs and key humanitarian priorities, rather than being mainstreamed throughout the assessment. The MIRA process gives no specific guidance on how best to collect primary qualitative data on people with disabilities. Whatever methodologies are used, the

<sup>54</sup> For example, a joint initiative between IOM, UNHCR, HI and Oxfam to develop and pilot disability inclusion guidance for use with the Displacement Tracking Matrix Multi-Sectoral Location Assessment (DTM MSLA) is exploring methodologies for collecting data on people with disabilities on the move using data from key informant interviews and observations. For future updates on the outcomes of this work, see <https://displacement.iom.int/dtm-partners-toolkit/disability-inclusion>.

<sup>55</sup> ECHO (2019), p. 19.

## Box 8 Building capacity of local OPDs through collaboration in assessment activities

In August 2018, a rapid assessment focusing on disability inclusion in humanitarian action was conducted in Lombok Island in Tenggara Province, Indonesia after the island had been hit by a 7.0 magnitude earthquake.<sup>1</sup> The assessment was conducted by local OPDs supported by the international organisation Arbeiter-Samariter-Bund (ASB). The assessment reported that OPDs and people with disabilities had not been consulted in communication activities prior to or during the emergency response and had not previously participated in humanitarian coordination meetings. Needs identified included substantial physical and communication barriers to assistance.

1 Arbeiter-Samariter-Bund (2018) *Lombok earthquake: disability inclusion rapid assessment report* (<https://reliefweb.int/report/indonesia/70-lombok-earthquake-disability-inclusion-rapid-assessment-report-arbeiter>).

quality of the data collected and its subsequent use – and whether basic protection and do-no-harm principles are adhered to when collecting disability data – depend on the quality and level of pre-crisis staff sensitisation and training in disability inclusion (see Box 7). The DFID guidance suggests that, if primary data is sought in an initial assessment, assessment teams should ensure that interview guidance and direct observation checklists include disability-related issues (e.g. by adapting disability-inclusive tools such as the DTM/IOM interview checklists<sup>56</sup> and Women in Displacement group discussion guides,<sup>57</sup> which address both disability- and gender-related issues). The DFID HRP guidance also recommends that, to account for the differing impact of the crisis on people with disabilities, interview participants should be selected to represent a cross-section of people with disabilities (i.e. men, women, people from a range of age groups and with different types of disabilities) in a 3/20 ratio (15%).<sup>58</sup>

In many situations, early data collection and analysis will be improved by collaboration or partnership with OPDs (local, regional or international), who may be able

to provide crucial contextual understanding of the risks to people with disabilities (including risks from data collection activities), or help identify participants, advise on accessibility considerations in assessments and help validate findings.<sup>59</sup> As warned in the IASC Guidelines, however, the role of OPDs depends on their pre-crisis capacities, their mandate and their ability to represent all people with disabilities or a specific group of people with disabilities. In many crisis-affected contexts, these capacities are extremely limited. Moreover, not all OPDs' missions align directly with humanitarian action and, in many situations, few local OPDs will have experience in or any capacity for assessing humanitarian needs or delivering assistance, nor are they likely to have experience in humanitarian coordination mechanisms or collaborating with humanitarian organisations. When OPDs are not present or existing OPDs do not have adequate capacity, the Guidelines advise humanitarian actors to establish contact with regional or international OPD networks and/or adopt alternative strategies over time to enable a range of people with disabilities to participate directly in assessments and decision-making, for example via direct engagement at community or camp level<sup>60</sup> (see, for example, Box 8).

While the consistent and effective mainstreaming of disability-focused data collection into initial assessments remains an important aspiration, and one that is rightly prioritised in the new guidance and increasingly in donor funding requirements, there currently remains a significant gap between theory and practice on this aspect of inclusion. This is partly due to continuing gaps in knowledge, skills and awareness among mainstream programmers, which will take time and sustained investment to address comprehensively. For this reason, collaboration between mainstream humanitarian organisations and international OPDs with specialist experience of disability-inclusive humanitarian programming continues to be important. Ideally, this collaboration will focus increasingly on building inclusion knowledge and capacities among mainstream agencies to support disability inclusion mainstreaming in all emergency response settings. However, in the face of immediate assessment priorities and challenges in new and ongoing humanitarian crises, there will continue to be a demand for specialist humanitarian OPDs to provide additional disability-focused assessments – including rapid assessments – that can directly inform mainstream responses in particular localities and/or sectors (see for example Box A6).

56 <https://displacement.iom.int/dtm-partners-toolkit/field-companion-sectoral-questions-location-assessment>.

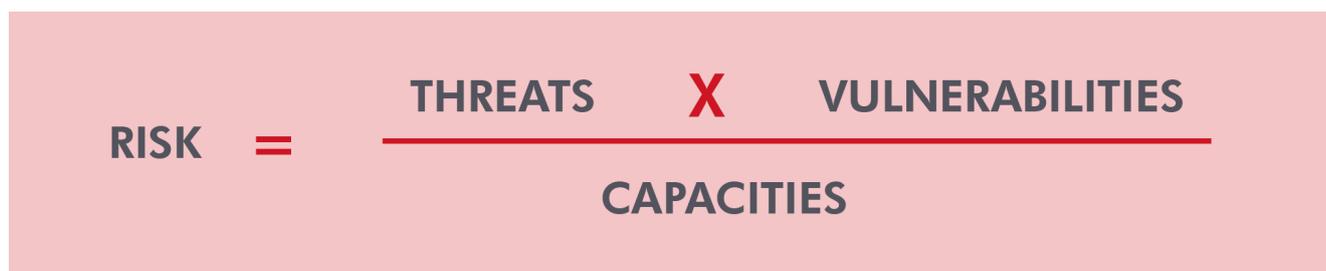
57 <https://womenindisplacement.org/>.

58 DFID Humanitarian Investment Programme (2019), Annex 4 (pp.29–30). See Annex 4 for detailed review of a range of needs assessment tools and how they could be modified to improve disability inclusion. The guidance notes that, once finalised, the the Joint Intersectoral Analysis Framework (JIAF) (which is intended as the next generation of the MIRA analysis framework) will offer a new opportunity to incorporate people with disabilities within the wider context and crisis analysis. The JIAF will produce current and forecasted priority needs/concerns according to age, gender and 'diversity groups' – which will call for strong advocacy to ensure that people with disabilities are properly considered a sub-group..

59 BOND (2019), p.8.

60 IASC (2019), p.34.

**Figure 2 Risk equation**



Source: Global Protection Cluster (2017), p.63 ([www.globalprotectioncluster.org/\\_assets/files/aors/protection\\_mainstreaming/gpc-pm\\_toolkit-2017.en.pdf](http://www.globalprotectioncluster.org/_assets/files/aors/protection_mainstreaming/gpc-pm_toolkit-2017.en.pdf)).

## 2.3 Data collection for in-depth assessments

As agencies shift towards more in-depth assessments, so the opportunities increase for collecting, sharing and comparing more detailed quantitative and qualitative data and to conduct more thorough explanatory analysis to inform programme priorities and design. While the constraints on disability data collection and use are very real in the earliest stages of an emergency response, at later stages, and particularly in protracted crises, time and resources should not pose a significant barrier. Agencies should not face significant methodological barriers, since the methodologies routinely used in vulnerability, needs and protection assessments are the same approaches needed for disability-focused assessments. As detailed in the new DFID guidance on strengthening disability inclusion in HRP, existing assessment frameworks and methodologies can be modified fairly easily to include attention to people with disabilities and intersectional risks that they face.<sup>61</sup>

The IASC Guidelines advise that, when analysing the severity of a population's needs, assessments – including Multi-Sector Needs Assessments (MSNA) – should examine the impact of a situation on people with disabilities and their families. When carrying out household surveys, data should be collected in a way that enables it to be disaggregated by disability. The Guidelines also recommend that separate data collection exercises that focus on people with disabilities should be conducted where it is relevant and feasible to do so, noting that separate data collection can be particularly valuable when analysis has flagged that people with disabilities experience specific risks or accessibility gaps.<sup>62</sup>

Both the HI-led action research project to field-test the use of the Washington Group Questions and the EU's operational guidance on the inclusion of people with

disabilities in humanitarian aid operations suggest that protection mainstreaming is often a good entry point for data collection on persons with disabilities.<sup>63,64</sup> Drawing on the Global Protection Cluster's risk equation (Figure 2), the EU guidance recommends a continuous disability-focused risk assessment, identifying context-specific threats, vulnerabilities and capacities and avoiding generalisations or assumptions.<sup>65</sup>

In protection mainstreaming, it is crucial to identify the barriers that hinder people with disabilities from accessing and participating in humanitarian assistance and protection. Such barriers lead to exclusion, which increases the likelihood of people with disabilities facing threats and vulnerabilities at a higher level than the rest of the crisis-affected population. Any risk analysis should take into account the likelihood that, as a person may face an intersectionality of risk and barriers that may change through the course of a crisis, ongoing risk analysis is of great importance (see Box 9).<sup>66</sup>

However, a recent rapid evidence review of disability inclusion in humanitarian programming found that few humanitarian actors are currently collecting assessment data on people with disabilities in any systematic way.<sup>67</sup> It notes the outcomes of a previous 2014 review of 28 vulnerability and capacity assessments (VCAs), which found that disability is largely disregarded within the VCA process, with over half failing to mention disability at all, and only two raising issues of disability-related exclusion.<sup>68</sup> More recently, a 2017 rapid assessment of disability and age inclusion in the Rohingya refugee response in Cox's Bazar, Bangladesh found that few actors were collecting gender-, age- and disability-disaggregated data, and there was limited awareness and practice of identifying people with disabilities in the response.<sup>69</sup> Similarly, when conducting rapid targeted assessments of the needs of IDPs in camps in Iraq

61 In addition to the MIRA, this includes the Needs Assessments for Refugee Emergencies checklist (NARE/UNHCR), the Vulnerability Assessment Framework (VAF/UNHCR), the Humanitarian Emergency Settings Perceived Needs Scale (HESPER/WHO), the Displacement Tracking Matrix (DTM/IOM) and the JIPS Essential Toolkit (Joint IDP Profiling Service). See DFID Humanitarian Investment Programme (2019).

62 IASC (2019), pp.27–28.

63 Humanity & Inclusion and Leonard Cheshire (2018), p.19. See also [www.globalprotectioncluster.org/themes/protection-mainstreaming/](http://www.globalprotectioncluster.org/themes/protection-mainstreaming/).

64 ECHO (2019).

65 It also advises agencies to remain aware that people with disabilities are particularly at risk of gender-based violence (GBV), violence, abuse and exploitation.

66 Ibid., p.8.

67 Holden et al. (2019).

68 Twigg (2014), cited by Holden et al. (2019), p.8.

69 Arbeiter-Samariter-Bund (2017) *Rohingya refuge crisis in Bangladesh: age and disability inclusion – rapid assessment report*. Published with support from Centre for Disability in Development Bangladesh and Aktion Deutschland Hilft (cited in Holden et al. (2019), p.8).

## Box 9 Intersectional assessment of protection risks, needs and barriers affecting people with disabilities

In 2014, the Women’s Refugee Commission led a participatory study to examine the intersections between sexual and reproductive health (SRH) and disability in humanitarian contexts in Kenya, Nepal and Uganda.<sup>1</sup> The study explored the specific risks, needs and barriers for people with disabilities accessing SRH services, including maternal and newborn health, family planning, sexually transmitted infections (STIs) (including HIV) and GBV. The study gathered information from refugee women, men and adolescents aged 15–19 with physical, intellectual, sensory and mental impairments in refugee settings in each country.

Findings showed that that refugees with disabilities demonstrated varying degrees of awareness around SRH, especially regarding the reproductive anatomy, family planning and STIs. Among barriers to accessing services, lack of respect by providers was reported as the most harmful. Pregnant women with disabilities were often discriminated against by providers and scolded by caregivers for becoming pregnant and bearing children; marital status was a large factor in determining if a pregnancy was accepted. Risks of sexual violence prevailed across sites, especially for people with intellectual impairments. The ability of women with disabilities to exercise their SRH rights was mixed. Refugees with disabilities showed a mixed understanding of their own rights in relationships and in the pursuit of opportunities.

1 Tanabe, M., Nagujjah, Y., Rimal, N., et al. (2015) ‘Intersecting sexual and reproductive health and disability in humanitarian settings: risks, needs, and capacities of refugees with disabilities in Kenya, Nepal, and Uganda’ *Sexuality and Disability* 33(4): 411–427 ([www.ncbi.nlm.nih.gov/pubmed/26594076](http://www.ncbi.nlm.nih.gov/pubmed/26594076)).

between 2016 and 2018, HI reported that information about the number and needs of people with disabilities was scarce among humanitarian actors, with most lacking information and knowledge on collecting information on their needs or those of other vulnerable groups at high risk of exclusion.<sup>70</sup>

The IASC Guidelines suggest some questions to ask about the situation of people with disabilities:

- Do persons with disabilities experience any specific forms of discrimination or targeted violence?
- What barriers do persons with disabilities face when they attempt to access assistance?
- What formats and channels of communication are most accessible to persons with disabilities?
- Are specific services that persons with disabilities require (such as assistive technologies) available/ not available?
- What are the beliefs and practices of the affected population in relation to persons with disabilities? Are harmful beliefs and practices prevalent?

The majority of disability-focused assessments that have been carried out – often led or supported by an INGO or OPD with expertise in disability inclusion in humanitarian programming<sup>71</sup> – have combined qualitative and quantitative data collection in a single assessment exercise. While most used the WG-SS, the methodology differed across assessments according to whether questions were asked at the household or individual level. The WG questions are designed for use with individual respondents; indeed HI-led field-testing of the questions confirmed the best and most dignified measurement for disability requires speaking directly to individuals regarding their own levels of ability in each functional domain. However many assessments in crisis contexts collect data at the household level. Evidence suggests that collected data on individuals by proxy, while deemed acceptable by the WG, can result in under-reporting as respondents may be reluctant to discuss disabilities among individual household members (see for example Box 10).<sup>72</sup>

However, while data on disabilities at household level may be less reliable and more difficult to analyse and use than individual-level data, other considerations – including the assessment objectives and time available to collect data – will determine survey design and methodology.<sup>73</sup> Moreover, at times, for strategic planning, resource mobilisation or other programming purposes, household-level disability data may be as important as individual-level data. A HNAP for Syria survey of disability prevalence conducted in 2019, for example, was specifically interested in the prevalence of households headed by a person with a disability, since previous assessments had indicated that household resilience and income are further undermined by heads of household having a disability. This survey found that 25% of returnee households had a head of household with a disability, compared with 38% of displaced households, and in highly affected areas such as Ar-Raqqa this rose to 56%. Other data collected in the assessment confirmed that the entire household can be negatively impacted if a head of household has a disability. In two areas surveyed –

70 Humanity & Inclusion (2018) *Disability in humanitarian context: a case study from Iraq*, pp.2–3 (<https://reliefweb.int/report/iraq/disability-humanitarian-context-case-study-iraq>).

71 E.g. HI, CBM, ASB, Women’s Refugee Commission, REACH, IRC, IFRC.

72 A disaster risk reduction-focused assessment of the impacts of Cyclone Pam on people with disabilities in Vanuatu in 2017 recommended an adjustment to the assessment methodology to mitigate for possible under-reporting of disability due to the household-level survey design. See CBM & Nossal Institute for Global Health (2017).

73 See HI Factsheet 2: ‘Collecting data in humanitarian action using the Washington Group Questions at household level’ ([https://humanity-inclusion.org.uk/sn\\_uploads/document/2019-01-Factsheet-2-Collecting-data-using-the-WGQs-at-household-level.pdf](https://humanity-inclusion.org.uk/sn_uploads/document/2019-01-Factsheet-2-Collecting-data-using-the-WGQs-at-household-level.pdf)).

Ein Halaqim and Easter Bari in Hama – 90% or more of households had one or more people with disabilities.<sup>74</sup>

In some cases, specific questions on disability – including the WG – have been integrated into in-depth sectoral assessments to allow for disaggregation of survey findings by disability. In Bangladesh in 2019, for example, REACH conducted a number of sectoral assessments, including an education needs assessment and a WASH household survey. Both included disability components, with the WG-SS (in households with children) and the WG Child Module questions asked by proxy for each household member (cf. Box 10), supplemented by FGDs. The education survey found that children with disabilities were reportedly attending learning centres at lower rates than peers without disabilities, particularly in the youngest age group. A key limitation of this study, however, was that these sectoral assessments were not specifically designed to capture in-depth experiences of people with disabilities in any holistic way. For example, the WASH household survey identified a gap in access to support services for people with physical or cognitive impairments, but the survey’s format did not allow for this finding to be further explored to inform an appropriate response.<sup>75</sup>

By contrast, an in-depth qualitative assessment of livelihood challenges for very poor people with disabilities in the southwest coastal region of Bangladesh in 2013 used in-depth interviews and FGDs to explore the range and context of livelihood challenges they faced and the complex forms of deprivation they experienced. This qualitative research was supplemented by quantitative Save the Children baseline data collected in 2009 and 2010 and a disability screening survey conducted by the team in early 2012 to identify types of disability, causes of disability, difficulties doing daily activities, and the use of assistive devices. Supplementary questions about the project intervention and access to social safety nets were also included in these surveys.<sup>76</sup> The findings confirmed that, overall, people with disabilities faced significant challenges in maintaining their livelihood activities. The most common limitation identified was an inability to do physical work over long periods due to physical impairments, resulting in prospective employers not wanting to recruit people with disabilities. A number of respondents with physical and mental disabilities also experienced wage discrimination within the workplace.

A joint IOM and HI assessment of the situation of people with disabilities in Bentiu PoC site in South Sudan in 2017 combined qualitative and quantitative data collection methods, including a household-to-household individual survey, key informant interviews, semi-structured

## Box 10 Variations in quantitative data on disability using the WG-SS at household level or using responses by proxy: evidence from Cox’s Bazar, Bangladesh

A comparison of disability prevalence estimates among Rohingya refugees in Cox’s Bazar, conducted by REACH in 2019,<sup>1</sup> indicates that asking the WG-SS questions by proxy for each individual household member resulted in higher rates of reporting of disabilities compared with asking the questions once for the whole household. However, asking the WG-SS by proxy for each individual, rather than asking the questions directly, may still have resulted in under-reporting due to the considerable stigma attached to disability – and especially psychological disability – in Rohingya communities.

The WG-SS questions asked by proxy for each individual estimated that 14% of households had a member with a disability, whereas the fifth round of the UNHCR/REACH Settlement and Protection Profiling assessment, conducted in July and August 2019 using the WG-SS questions, produced a lower estimate of 9% of households with at least one individual with a disability.

Findings from assessments that ask respondents to report on ‘disability’ more generally, without specifying specific domains of disability, tends to lead to even lower estimates. The UNHCR Key Demographic Indicators dataset, for example, estimates roughly 5% of Rohingya refugee households have an individual with a disability.

These findings suggest that asking WG-SS questions at the household level may not fully capture the presence of individuals with disabilities, compared to an individual-level approach to measurement.

1 REACH (2019).

discussions and direct service observations across a range of sectors.<sup>77</sup> The assessment included people with disabilities and their caregivers and families, who also face risks, vulnerabilities and barriers as a consequence of caring for or living with a person with disabilities. The individual survey gathered information on living conditions as well as the needs and access to available services of community members. It was developed to

74 Humanitarian Needs Assessment Programme, Syrian Arab Republic (HNAP) [joint UN assessment initiative] (2019) *Disability: prevalence and impact. A nationwide household survey using Washington Group methodology* ([www.globalprotectioncluster.org/wp-content/uploads/Disability\\_Prevalence-and-Impact\\_FINAL-2.pdf](http://www.globalprotectioncluster.org/wp-content/uploads/Disability_Prevalence-and-Impact_FINAL-2.pdf)).

75 REACH (2019).

76 Nokrek, P., Alam, M.A. and Muzzafar A. (2013) ‘Livelihood challenges for extremely poor disabled people in the southwest coastal region of Bangladesh’. Shiree Working Paper No. 12. Dhaka, Bangladesh: Shiree ([www.gov.uk/dfid-research-outputs/livelihood-challenges-for-extremely-poor-disabled-people-in-the-southwest-coastal-region-of-bangladesh-shiree-working-paper-no-12](http://www.gov.uk/dfid-research-outputs/livelihood-challenges-for-extremely-poor-disabled-people-in-the-southwest-coastal-region-of-bangladesh-shiree-working-paper-no-12)).

77 IOM and Humanity & Inclusion (2017).

identify socio-demographic barriers and facilitators of access to mainstream services, and to collect information on people with disabilities' access to disability-related health and nutrition services. Individuals were found in randomly selected households with various household characteristics. A pre-identification of disability was done with all household members (above five years old) in addition to the collection of socio-demographic household information. Key informant interviews gathered information on barriers and facilitators of inclusion and accessibility, and on key challenges and good practices expressed by service providers working at field and coordination level. Service provision observations collected information on the barriers evident, reported or suspected. Semi-structured discussions with both service users and service providers were used to go deeper into certain issues and to explore the possibilities for people with disabilities in Bentiu PoC site.<sup>78</sup>

A common theme across the findings of household- and individual-level assessments is that those assessed face additional risks, vulnerabilities and barriers compared with people without disabilities. The Bentiu PoC assessment found, for instance, that people with disabilities experienced greater challenges in meeting their basic needs. Barriers ranging from discrimination

and lack of information on services and absence of physical accessibility are compounded by aid workers' lack of knowledge on the prevalence and the needs of people with disabilities, as well as by an absence of disability representation in leadership positions and sectoral committees. On the positive side, facilitators to inclusion, such as special queues during food distributions, the employment of people with disabilities and the construction of accessible latrines, were reportedly providing momentum for aid workers to take people with disabilities into consideration when providing services.<sup>79</sup>

Humanitarian actors need more information and data on their own responses and the institutional barriers within mainstream humanitarian programming that risk excluding and marginalising people with disabilities. Although attention needs to be given to disability prevalence and the experiences of affected populations, humanitarian actors must also turn the spotlight back on themselves to identify and understand the many barriers on their side that directly or indirectly discriminate against people with disabilities. Without this information, humanitarian actors cannot know whether their programming is impartial with regards to assistance and protection for people with disabilities.

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78 For a similar assessment using this combination of methods that produced similar findings, see also IOM and Humanity & Inclusion (2019) *Wau PoC AA disability and inclusion survey* (<https://displacement.iom.int/system/tdf/reports/IOM%20DTM%20SSD%20Wau%20Disability%20Inclusion%20Report%2020191030.pdf?file=1&type=node&id=6901>).

79 Ibid., p.43–45.

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## Chapter 3 Data and information on programming barriers and enabling factors affecting inclusion of people with disabilities

The IASC Guidelines advise that people with disabilities must be able to access humanitarian assistance and interventions on the same terms as other members of the population. This requires a twin-track approach that combines inclusive mainstream programmes with targeted interventions for persons with disabilities. In addition to addressing people with disabilities' specific needs – for example, by delivering food and non-food items to people who have difficulty reaching distribution sites – mainstream programme planning, design, implementation and evaluation need to include people with disabilities.<sup>80</sup> This means that humanitarian agencies need to actively assess, monitor and address the barriers preventing access and participation of people with disabilities in humanitarian assistance and protection.<sup>81</sup>

Yet, wherever assessments have paid close attention to the situation of people with disabilities – including the assessments discussed in the previous chapter – the findings reveal significant accessibility and inclusion barriers in humanitarian programmes that substantially compound the risks, threats and vulnerabilities experienced by people with disabilities. A recent evidence review that scrutinised barriers to inclusion in humanitarian programming uncovered multiple factors that limit or exclude people with impairments from accessing humanitarian services and programming. These include a catalogue of significant environmental, attitudinal and institutional barriers to access and inclusion in programming. For the most part, agencies are likely to be oblivious to these barriers without focused attention given to identifying and monitoring them (see Box A7).

### 3.1 Service accessibility assessments and integrating data into protection mainstreaming approaches

Because people with disabilities so regularly face barriers to accessing assistance and support, recent disability-focused assessments often include significant attention to barrier assessments. The objectives of HI's 2013 rapid participatory assessment of the situation of children, youth and adults with disabilities within and around Domiz IDP camp in northern Iraq, for example, were to identify the needs of refugees with disabilities and the barriers they face when accessing humanitarian services, and to examine the resources and capacities

of service providers regarding disability inclusiveness in their service provision. The assessment found that most service providers were passively excluding people with disabilities; there were few mechanisms to address barriers and minimal active inclusion. Most had not consulted people with disabilities in planning or designing services, nor had they established targets for the numbers of people with disabilities that they should be reaching. Service providers reported no knowledge on how to make their services accessible, or how to reach or communicate with people with disabilities. They also said they lacked the financial resources to support such work and reported that disability inclusion would slow down the work of the organisation when under time pressure to meet targets. Informed directly by input from people with disabilities, the assessment identified a number of priorities for organisations to improve the accessibility of their services, including expanding accessible livelihood opportunities, providing affordable and diverse transport options to access education and health services, enabling children with disabilities to participate in school and child-friendly spaces, insulating shelters, improving the physical accessibility of the camp, and introducing mechanisms to support coordination around disability issues.<sup>82</sup>

Similarly, an HI-led access to services assessment of Jadimura Camp in Cox's Bazar, Bangladesh in 2018 looked at what barriers, risks and situations of exclusion faced people with disabilities when accessing different services, and what systems and processes humanitarian actors had in place to address these.<sup>83</sup> Drawing on previously developed assessment tools (including from the Domiz Camp assessment<sup>84</sup>), data collection was from two main sources: a survey of people with disabilities (based on a random selection from a list of people receiving assistance from HI) using the WG-SS questions, and structured interviews with representatives of 11 local and international NGOs working in Jadimura Camp. The findings were analysed and reported by sector. For instance, it found a very high reliance on food distributions among people with disabilities, as is the case for most of the refugee population in the camp, but those with disabilities were struggling to access distributions, with 56% reporting that they could not access food distributions at all, and 41% reporting a lot or some difficulty.<sup>85</sup> A number of methodological limitations meant that the findings could not be generalised to the wider population of Rohingya refugees with disabilities – for example, a convenience sampling methodology biased

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80 IASC (2019), p.19.

81 ECHO (2019), p.4.

82 Handicap International [Humanity & Inclusion] (2013).

83 Humanity & Inclusion (2019) *Inclusive access to services for persons with disabilities*.

84 Handicap International [Humanity & Inclusion] (2013).

85 *Ibid.*, p.16.

the findings towards people with physical disabilities rather than other domains. However, this assessment provides a potential model for similar service accessibility assessments to be conducted more widely going forward.

In some cases, accessibility assessments included or recommended structured audits of programme or service accessibility. In the case of HI's assessment of IDPs in and around Domiz camp in Iraq, for instance, service providers identified that an audit of barriers and facilitators would help to strengthen inclusion.<sup>86</sup> For a disability-inclusive situational analysis to inform the response to Tropical Cyclone Gita in Tonga in 2018 (led by CBM-NZ and the Pacific Disability Forum), audits on accessibility and usability of shared facilities were conducted at four evacuation centres.<sup>87</sup> The IASC Guidelines include accessibility audits of organisations, programmes, projects and services as a key element of inclusive monitoring and evaluation. They could be considered a key preparedness action to identify potential environmental, attitudinal and institutional barriers, such as those identified in Box A7.

Service accessibility assessments should also identify factors that *enable* access for people with disabilities. For example, the joint IOM and HI assessment at Bentiu PoC site in South Sudan in 2017, identified a number of factors helping people with disabilities to access services, some of which had been implemented as a direct response to a previous 2016 accessibility assessment. These included site residents helping people to collect water, prioritising people with disabilities at food distribution sites and provision of wheelbarrows to help people to carry food, recruitment of people with disabilities into the site staff, and the establishment of a community-based representative group for people with disabilities with support from the Danish Refugee Council.<sup>88</sup>

As cautioned in the IASC Guidelines, it is important for assessments to take into account – and to pay close attention to – persons with the same impairment experiencing barriers differently, due to their gender, age, culture or socioeconomic status. The collection and analysis of data in service accessibility assessments should be disaggregated by gender, age and, where appropriate, other key status factors, to fully capture how service barriers may affect people with disabilities according to other intersecting risks. A joint IOM and HI disability and inclusion survey of Wau PoC Adjacent Site in South Sudan reported, for example, that women and girls with disabilities fared worse than men and boys in terms of accessing livelihoods. The assessment also

found that tailored assistance in food distribution did not respond to the needs of people of different ages and dietary requirements, with no targeted outreach support or monitoring system to ensure they could access food effectively. With only one distribution centre in the PoC site to serve all camp members, those with mobility difficulties living in the zones furthest away from the distribution centre had the most problems in accessing food, often selling part of their food to pay for transportation, leaving an insufficient amount to last until the next distribution cycle. Those living further away were also at higher risk of having their food rations stolen on the way back to their shelters. Long queues and the lack of resting spots added to the difficulties faced by people with disabilities, and those with hearing, understanding, communication or learning difficulties often missed key information about the distribution schedule.<sup>89</sup>

The barriers to assistance and protection for households and individuals affected by disabilities, often in combination with other intersecting risks and vulnerabilities, should also be considered in service accessibility assessments. A 2015 Save the Children study of multi-purpose cash assistance (MCA) to Syrian refugees in Lebanon, for example, identified households with members with disabilities who were facing added protection risks but ultimately did not receive MCA.<sup>90</sup> Case studies highlighted the inadequacy of MCA assessments to capture or incorporate protection risks that can arise from multiple risk factors associated with living with disabilities and being female and being separated from caregivers. One case study profiled an 18-year-old woman with a mental disability who was legally married with a child and a missing husband. While living with other family members, her position (a single, female-headed household responsible for a small child, with finances being a major concern) put her at risk of exploitation. Other case studies highlighted children with disabilities whose families were unable to pay their medical bills or enrol them in school, and experienced harassment or discrimination by doctors and pharmacies when attempting to access services. The study highlighted that, without access to education or other opportunities, children with disabilities and their families are often at risk of exploitation and abuse. These risks can be heightened without access to MCA to supplement their medical expenses.

Of course, the purpose of identifying barriers is to inform organisations about how these can be addressed to minimise exclusion and actively strengthen inclusion of people with disabilities in humanitarian programmes. This underlines the importance of harmonising or even standardising key questions and methodologies for

86 Handicap International [Humanity & Inclusion] (2013).

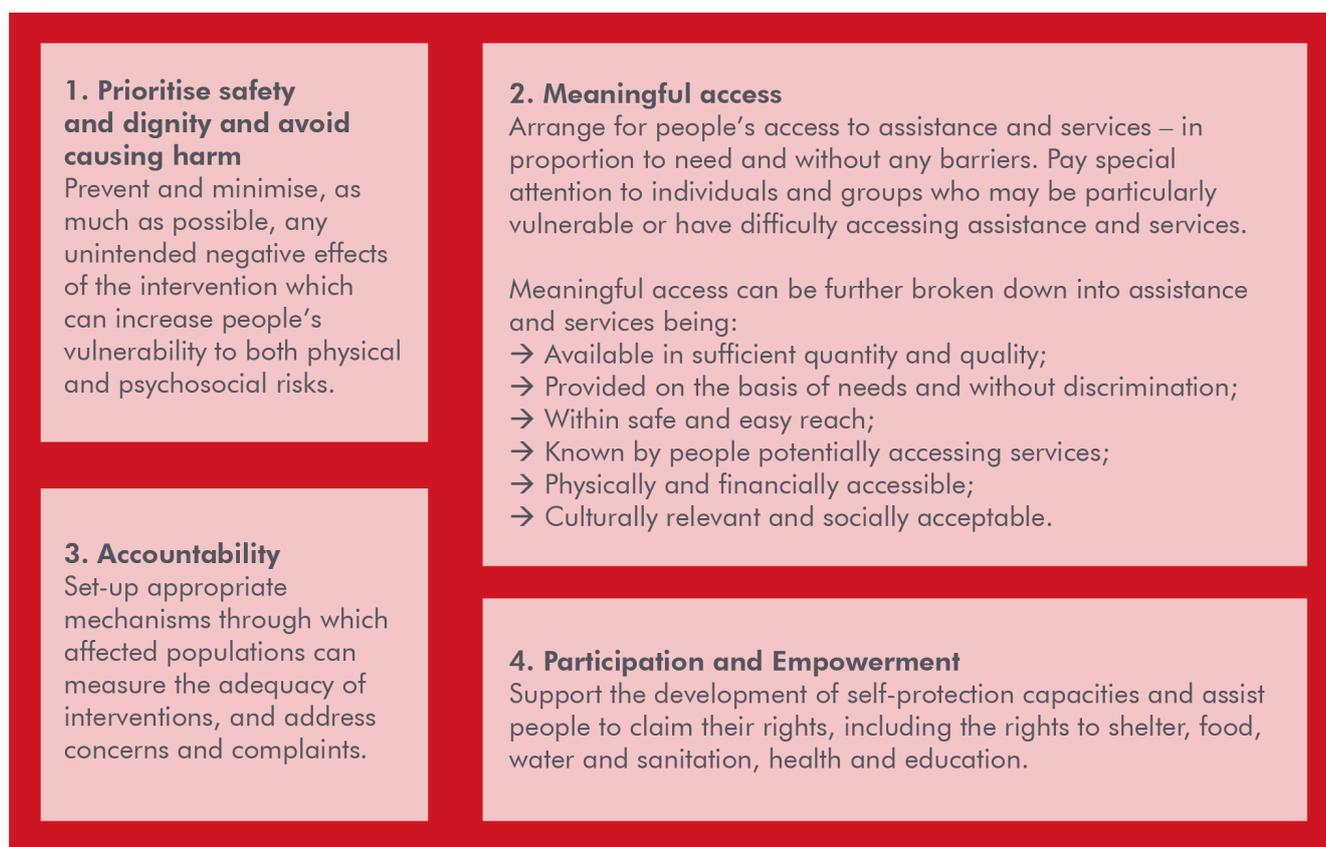
87 A checklist template for the accessibility audit of evacuation was compiled specifically for Tropical Cyclone Gita using guiding documents: CBM (2017) 'Humanitarian hands on action tool (HHoT)'; CBM (2015) Inclusive post-disaster reconstruction: building back safe and accessible for all. 16 minimum standards; and IFRC (2015) All under one roof, disability-inclusive shelter and settlements in emergencies; and CBM New Zealand & Pacific Disability Forum (2018), p.10 and p.34.

88 IOM and Humanity & Inclusion (2017).

89 IOM and Humanity & Inclusion (2019) *Wau PoC AA disability and inclusion survey* (<https://displacement.iom.int/system/tdf/reports/IOM%20DTM%20SSD%20Wau%20Disability%20Inclusion%20Report%2020191030.pdf?file=1&type=node&id=6901>)

90 Save the Children/Lebanon Cash Consortium (2015) *Impact of multipurpose cash assistance on outcomes for children in Lebanon* (November) (<http://data.unhcr.org/syrianrefugees/download.php?id=10526>); cited in Women's Refugee Commission (2017) *Vulnerability- and resilience-based approaches in response to the Syrian crisis: implications for women, children and youth with disabilities* (<https://reliefweb.int/report/syrian-arab-republic/vulnerability-and-resilience-based-approaches-response-syrian-crisis>).

**Figure 3 The four key elements of protection mainstreaming**



Source: ECHO (2019), p.12.

collecting data across organisations and/or within clusters or sectors in order to support and strengthen the shared use and comparability of data. As noted previously, a mainstreaming approach is recommended to identify and address the numerous barriers that people with disabilities face in humanitarian response situations. Importantly, the protection mainstreaming framework should ensure that organisations not only look at meaningful access for people with disabilities, but also at their participation and empowerment, safety and dignity. They should also investigate organisations' accountability for the adequacy of interventions and responses to concerns and complaints raised (see Figure 3) – and that they use a community-driven participatory approach to collect this data.<sup>91</sup>

Using this framework, the EU guidance suggests how data on specific barriers can be translated into more general enabling factors to strengthen inclusive programming. In prioritising the safety and dignity of people with disabilities, barriers may be identified<sup>92</sup> in GBV prevention and response programmes – for example, people with disabilities may be excluded because the credibility of what they report is doubted (attitudinal barrier) or they may be unable to communicate what has happened to them (communication barrier). Once identified, these barriers can be translated into enabling responses; for example, raising awareness on rights and

non-discrimination, including respect for people with disabilities in organisational policies and codes of conduct and tailoring prevention activities to include people with disabilities. These responses can be further supported by more general measures to promote safety and dignity and do no harm, such as systematically engaging OPDs in assessments, ensuring that risk assessments are conducted/updated regularly and include identifying risks faced by people with disabilities, and ensuring that targeting is protection-sensitive and inclusive and that relevant criteria are determined in consultation with people with disabilities (see Tables A1 and A2 for suggested examples of how this approach could be taken to ensuring meaningful access and participation and empowerment of people with disabilities).

### 3.2 Monitoring inclusion

A key mechanism through which humanitarian agencies can be alert to access barriers affecting people with disabilities and assess the effectiveness of efforts taken to mitigate them is ongoing performance monitoring using disability-disaggregated data. As highlighted by the IASC Guidelines (and emphasised again in the conclusion to this report), donors have a crucial part to

91 ECHO (2019); and, for an example of the identification of barriers through a bottom up approach, citing (at p.30): EDR, West Bank, Palestine (2017) *Emancipatory disability research* ([www.aics.gov.it/wp-content/uploads/2017/04/Emancipatory\\_Research\\_2017.pdf](http://www.aics.gov.it/wp-content/uploads/2017/04/Emancipatory_Research_2017.pdf)).

92 To help identify barriers to accessing services and assistance, the guidance recommends that organisations carry out a beneficiary baseline assessment (tool #B1 in the GPC Protection Mainstreaming Toolkit) supported by a protection and risk mitigation measures matrix (tool #B2 in the GPC Protection Mainstreaming Toolkit).

## Box 11 Monitoring access to assistance and services

In the absence of any systematic disaggregation of monitoring data by disability by humanitarian actors, an HI-led access to services assessment of Jadimura Camp in Cox's Bazar, Bangladesh in 2018 had to use a survey to collect data on the access of refugees with disabilities to socioeconomic empowerment programmes supported by humanitarian actors. The results showed that no working-age people with disabilities surveyed were participating in cash for work, vocational or skills training programmes. Moreover, no people with disabilities reported that anyone in their household was participating in these programmes or receiving cash assistance.

This data was cross-referenced with qualitative data collected from people with disabilities to gain an insight into the reasons for such low participation in these programmes. The most significant barriers identified through the qualitative research were lack of access to training and cash for work opportunities and difficulties reaching work sites, with 84% reporting that the cash for work opportunities were not inclusive of people with disabilities. The findings indicated that a lack of information was not the main barrier for those included in the survey (biased towards people with physical disabilities due to sampling constraints): no people included in the survey reported a lack of awareness or information about these programmes.

### Monitoring access to health services

In 2014 and 2015, Sightsavers conducted a pilot to disaggregate service access monitoring data by disability (and gender and age), focusing on access to eye health and neglected tropical disease programmes in India and Tanzania. The monitoring data revealed that people with disabilities were not accessing services in the same proportion as people who did not have disabilities. The data also showed that barriers to access seemed to be more important in secondary/tertiary health centres and affected women with disabilities more in India. The data from Tanzania also showed that people with disabilities were using Trachomatous Trichiasis camps as an opportunity to get health information, treatment or referrals that would otherwise not be available to them.

*Source: Humanity & Inclusion (2019) Inclusive access to services for persons with disabilities; Sightsavers (2016) Everybody counts: disability disaggregation of data pilot projects in India and Tanzania – final evaluation report ([www.sightsavers.org/wp-content/uploads/2017/09/everybodycounts\\_brochure\\_accessible\\_web.pdf](http://www.sightsavers.org/wp-content/uploads/2017/09/everybodycounts_brochure_accessible_web.pdf)).*

play in requiring humanitarian actors to disaggregate data by disability (and gender and age), to deliver results frameworks that include specific outputs or outcome indicators for people with disabilities, and to use resource tracking markers to identify projects that are disability-inclusive.<sup>93</sup>

The IASC guidance on coordinated assessments emphasises that humanitarian actors should ensure that needs assessment are linked effectively with monitoring. Ideally, initial data on needs can be used as baseline data for comparison with data subsequently drawn from monitoring systems to show whether interventions have succeeded in responding to identified needs.<sup>94</sup> Implementation monitoring should help to identify whether and how humanitarian assistance reaches people with disabilities and their changing needs through the course of the crisis, with disaggregated monitoring data identifying barriers and gaps in access to assistance and protection by people with disabilities.<sup>95</sup> The IASC Guidelines note that when monitoring flags up gaps or potential barriers, more targeted assessment exercises involving direct engagement with people with disabilities (through FGDs, key informant interviews, etc.) and with

service providers or other humanitarian stakeholders should be carried out to understand the nature of the barriers and identify measures to mitigate or remove them (see for example Box 11).

To ensure that implementation monitoring is systematic across the response, all implementing partners should be required to report on the number or proportion of people with disabilities they have reached, through contracts and monitoring templates. Situation reports, dashboards and other reporting mechanisms should record progress in reaching people with disabilities, including the use of disaggregated data.<sup>96</sup> DFID's guidance on strengthening disability inclusion in HRP's emphasises the importance of setting targets for inclusion of people with disabilities and requiring reporting on inclusion using disaggregated monitoring data at the programme and project design stage, including in cluster-level output indicators. Indicators can reflect actions to improve accessibility of assistance, to promote participation or to provide targeted support to people with disabilities. Annex 6 of the guidance provides examples of how output indicators can be formulated to reflect inclusion across a range of sectors and thematic areas, based on the key commitment areas

93 IASC (2019), p.27.

94 IASC (2012), p.10.

95 IASC (2019), p.28.

96 Ibid.

in the Charter on Inclusion of Persons with Disabilities in Humanitarian Action (Participation, Inclusive Policy, Inclusive Response and Services, and cooperation and Coordination) (see for example Table A3).<sup>97</sup>

While these suggested output-level indicators are specific to activity and outputs specific to people with disabilities, the IASC Guidelines advise that outcomes on equal access and inclusion may be identified more clearly by analysing disaggregated data in the course of general monitoring, i.e. by disaggregating general monitoring questions by disability, rather than including a specific indicator on disability, as this may better flag discrepancies between general access and participation and the access and participation of those with disabilities across different groups.

As we have seen, when robust quantitative data does not exist, it is recommended to assume that 15% of an affected population has a disability. In this case, rather than using process indicators (e.g. percentage of beneficiaries (disaggregated by gender, age and disability) reporting that humanitarian assistance is delivered in a safe and accessible manner), the IASC Guidelines advise that disability-related considerations will be reflected most meaningfully at the output indicator level, revealing the effectiveness (or not) of actions taken to improve accessibility to assistance, to measure participation or to provide targeted support to people with disabilities.<sup>98</sup>

### **3.3 Preparing for disability-specific and disaggregated data: investing in skills and modifying information management systems, funding requirements and evaluations**

The HI-led action research project to test humanitarian actors' use of the WG questions identified limited data analysis skills in-country, with some organisations not carrying out data analysis at all. Scrutiny revealed problems with correctly manipulating data, with staff sometimes struggling to determine and apply the relevant WG question cut-off points or to disaggregate the data. These difficulties did not apply only to use of the data based on WG-SS – they reflected shortcomings in general data literacy skills internally, including the ability to disaggregate any data. Organisations were inconsistent in whether they recognised skills gaps or flawed analysis

and interpretation of the data. A recent initiative by the International Rescue Committee to step up disability data collection and inclusive programming also pointed out the importance of skills and training, and has trained disability and data champions to support this work.<sup>99</sup>

Regarding the WG questions specifically, an action research project and a recent disability-focused inclusion assessment at Jadimura Camp in Cox's Bazar, Bangladesh found that organisations' information management systems are not aligned to the WG-SS or collection of disability data more generally. The Jadimura assessment recommended that service providers not only introduce more rigorous and systematic collection of disability data, but also link this data collection effectively with referral pathways and defined processes on how to use the data to promote more inclusive programming.<sup>100</sup>

To promote the requisite organisational preparation and investment in the necessary skills and systems internally, the HI-led action research project found that having an inclusion adviser at headquarters and/or a person in the field with a specific interest in disability facilitated disability data collection. In some cases, the motivation to collect data came very much from the field, but often organisations took a more top-down approach, requesting or requiring field teams to collect data on disability to fulfil donor requirements.

Overall, the HI-led project confirmed the importance and influence of donor requirements for leveraging increased attention to and investment in collecting and using disability data. Better data on people with disabilities is crucial to hold humanitarian actors to account for their progress and success (or not) in effectively including people with disabilities. Donors, therefore, have a central role to play in ensuring that the organisations they fund and contract are systematically collecting data on people with disabilities and disaggregating it by gender, age and disability, and monitoring and reporting on a range of data and indicators, including on the accessibility of their programmes, the removal of barriers and the quality of services from an inclusion point of view. Donors can also require implementing partners to design and include strategies on inclusion as part of funding requirements, as well as making funding for inclusive programming a priority.<sup>101</sup> Likewise, the inclusion of people with disabilities should be a standard component of the terms of reference for humanitarian evaluations, with each of the core evaluation criteria scrutinised from a disability-related perspective (see Table A4).

97 DFID Humanitarian Investment Programme (2019) pp.20–23.

98 IASC (2019), p. 27. See also see Annex 5 for examples of output-level indicators. On indicators to measure disability inclusion, see also ECHO (2019), pp.20–21.

99 BOND (2019), p.16.

100 Humanity & Inclusion (2019) *Inclusive access to services for persons with disabilities*.

101 Cf. IASC (2019), p.63.

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## Chapter 4 Conclusion

The past 5–10 years have proved pivotal for the disability inclusion agenda in the humanitarian sector – not only because of the raft of new declarations, standards and guidelines that have come into play and shone a light on the issue at the global level, but also through painstaking practical efforts on the ground that have sought to address gaps in practice through testing and demonstrating how better inclusion can and should be done. This practical work has been led by disability organisations but, crucially, has also involved key donors and an ever-widening range of mainstream agencies who recognise the imperative to start doing things better when it comes to including people with disabilities in humanitarian responses.

Early work to develop new inclusion standards and guidance for the sector quickly identified data collection and analysis as the weakest link in current practice. It needed to be addressed swiftly in order to provide humanitarian actors with the basic information they need to underpin all other aspects of disability inclusion. The work that has been done to test and demonstrate how humanitarian actors can best approach disability data collection has not only shown the sector that it is possible to collect this data, but also that it *must* be. As the quality of data has improved through this work – including through the use of the WG questions – so the data has started to reveal to the wider sector that the numbers and needs of people with disabilities are far greater than previously recognised, affecting upwards of 15% of individuals and (particularly in crisis contexts) a much higher percentage of households in the populations that humanitarian actors are seeking to help.

In interaction with a range of other factors that affect people’s needs and capacities in a crisis – including gender, age and socioeconomic status – this new data shows that disabilities play a major part in the dynamics of risk and vulnerability in affected populations. Moreover, in terms of design and implementation, humanitarian programming has been found to contribute substantially to the risks for people with disabilities in crisis contexts, due to the range of attitudinal, environmental and institutional barriers that make it difficult for them and their households to access assistance and protection. The extent of vulnerability and exclusion associated with disability that is emerging from this recent data highlights disability inclusion and its intersections with gender and age as posing a major challenge for humanitarian impartiality going forward. This challenge has become all the more urgent in the context of the Covid-19 pandemic, which introduces a new and potentially devastating intersecting factor of vulnerability for crisis-affected populations.

However, the needed step-change in disability data collection and analysis and wider strengthening of disability inclusion will not come about simply because the data shows that it should. While the evidence emerging from the ground and the global declarations of good intent create a new moral imperative for humanitarian actors to act, it is only when ‘should’ becomes ‘must’, through more robust accountability frameworks, that humanitarian practice will start to shift in this regard. The new UN-wide disability inclusion strategy, which contains a detailed accountability framework, is a significant step in this direction. There have also been positive moves by a number of donors towards strengthening accountability for disability data collection, including by DFAT, DFID and ECHO, which have all brought in new expectations and requirements of implementing partners regarding the collection, use and reporting of disability data in mainstream humanitarian programming. This will need to become fully established and recognised as a key marker of good humanitarian donorship and a routine aspect of donor practice. This new accountability will also need to follow through and across all the chains of contracting and subcontracting between UN agencies, international NGOs, national and local organisations to ensure that accountability for disability inclusion is mainstreamed.

Similarly, and as recommended in the new IASC Guidelines, the terms of reference for evaluations should, as standard, require data disaggregated by disability and the input of people with disabilities as informants, with evaluation questions that seek specific information on people with disabilities. For example, how have people with disabilities accessed assistance and participated in the programme cycle, and how has the response reduced the risks they face and enhanced their resilience? Evaluations should also identify good practice regarding inclusion, and expect to be able to scrutinise progress-, outputs- and outcomes-specific indicators.<sup>102</sup>

As with protection mainstreaming – and, indeed, as an integral aspect of protection itself – the mainstreaming of disability inclusion needs to extend across every level and cluster/sector of humanitarian programming, every part of the programme cycle and every phase of humanitarian action, from risk reduction and preparedness through to emergency and protracted crisis responses, and recovery and ‘nexus’ programming. To support this, good data and information on disabilities and barriers to inclusion is needed, as is stronger coordination among humanitarian actors in collecting, sharing and using this data. This will require substantial investment across the sector to equip and resource systems and staff accordingly. Humanitarian actors must adopt

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102 IASC (2019), p.28.

a fully inclusive approach to the collection of this data and to the decisions and practices that will be informed by it, ensuring that people with disabilities are fully involved at every stage. Ultimately, it is

only when the sector begins to put its money where its mouth is on disability inclusion that people with disabilities will genuinely start to count in humanitarian programming.

## Annex 1 Additional boxes

### Box A1 Varying concepts of disability affecting disability data

Defining disability for the purposes of data and statistics is complex and controversial. What is understood as a disability – and therefore who is counted (and who counts themselves) as having a disability – tends to reflect differing and, in many respects, socially and culturally constructed concepts of disability.

Previously, disability statistics have often been conceived as a matter of counting people who fall into specific groups such as ‘the blind, ‘the deaf’ or ‘wheelchair users’ – with the focus tending to be on identifying people who fall into a few discrete categories of physical or sensory impairments. Using fixed labels in this way fragments and distorts the data by assuming that people with a disability fit neatly into one of a few clearly bounded categories. More recently, however, disability is understood to include a much more diverse and varying range of physical, sensory, cognitive and/or psychosocial impairments which, in interaction with the environment, can have highly variable impacts on people’s functioning and participation in daily life.<sup>1</sup>

Traditionally – and in many administrative data collection systems – disability has been approached as a binary ‘yes’ or ‘no’ matter. This dichotomous ‘minority’ model of disability assumes that everyone either is or is not a person with a disability. Who is considered to be a person with a disability – and therefore a member of a discrete ‘disability’ grouping – will often depend on how disability is understood in a specific cultural context. For example, in many situations, mental health conditions, impairments caused by chronic disease, age-related impairments or injuries resulting from conflict or disaster, may not be considered disabilities as such. In many contexts, stigma – often particularly relating to mental/psychosocial and cognitive impairments – will inhibit some people from identifying themselves or a family or household member as having a disability. Moreover, the term disability may be understood as relating only to severe impairments, thereby excluding more moderate or hidden impairments that may nevertheless impact on people’s functioning and participation. Therefore, direct questions seeking a binary yes/no answer to the question ‘do you have a disability?’ tend to significantly under-report disability prevalence.<sup>2</sup>

By contrast, universal models of disability – such as the model underpinning the WHO’s International Classification of Disability (ICF) – approach disability as a continuum. This model is based on the understanding that everyone has some degree of functional limitation at the body, person or societal levels, and people experience this to varying extents along the continuum. According to this model, disability prevalence within a group or population depends on threshold decisions about where to draw a line to identify those with a disability on a continuum of difficulty or severity.

Two major, competing models of disability have dominated disability policy and literature: the ‘medical model’, which focuses on impairments (requiring treatment, cure, rehabilitation or adaptation to society), and the ‘social model’, which focuses on the social, physical, informational and institutional barriers that contribute to the disability caused by a person’s impairment(s). From a statistical point of view, the medical model falls short: impairment information provides only a partial picture of how disability is experienced, since the effects of impairments on people’s lives and participation differ radically depending on individual factors and their social/environmental context.

The WHO’s ICF rejects any dichotomy between the medical and social models of disability, adopting instead a ‘bio-psycho-social’ model that sees functioning and disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental. Disability is understood as an umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and their contextual factors (environmental and personal factors). This definition is in line with the Convention on the Rights of Persons with Disabilities, which stresses that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others’. Defining disability as an interaction means that ‘disability’ is not an attribute of the person per se, but instead the consequence of this interaction. Progress on improving social participation can be made by addressing the barriers that hinder persons with disabilities in their day-to-day lives.<sup>3</sup>

1 WHO and United Nations Economic and Social Commission for Asia and the Pacific (2008), p.2.

2 Ibid., p.70; and DFID Humanitarian Investment Programme (2019), p.15.

3 WHO and The World Bank (2011), p.4.

## Box A2 Disability measurement and monitoring using the Washington Group Short Set of Questions on Disability

Because not all people have the same understanding of what disability means, and due to the stigma associated with disability, it is important that the questions used to obtain disability data are appropriately designed and implemented.

Designed by the Washington Group on Disability Statistics under the UN Statistical Commission, the Washington Group Question sets are intended to facilitate the comparison of data on disability cross-nationally. They are derived from the WHO's bio-psychosocial concept of disability and its ICF.

The Washington Group (WG) has developed a number of tools including four main question sets:

- the Short Set of Disability Questions;
- an Extended Set (expanding on Short Set questions with 39 additional questions on different aspects of functioning, including psychosocial functioning, fatigue and pain);
- an Enhanced Short Set (including the Short Set and three additional questions on anxiety, depression and upper body functioning); and
- the WG/UNICEF Module on Child Functioning (specific to the needs of children aged 2–4 and 5–17).

Additional sets of WG-related questions are in development but not yet fully validated, including questions on participation and alternative questions on psychosocial disabilities.

The WG-SS is designed to be used in conjunction with other measurement tools within a larger survey or registration process to enable disaggregation of other population measures (e.g. age or sex) by disability status. Although originally designed for use in censuses and other large-scale surveys of the general population, the focus on functioning and the brevity of the tool<sup>1</sup> mean it can be relatively easily used in a variety of settings, including, potentially, humanitarian response contexts.

The questions intentionally do not use the word 'disability', but instead ask people how much difficulty they have performing basic universal activities in each domain (walking, seeing, hearing, cognition, self-care and communication), with answers categorised into 'no difficulty'/'some'/'a lot'/'cannot do it at all':

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual language, do you have difficulty communicating (for example understanding or being understood by others)?

(Disability is determined, according to the WG-SS, as anyone having at least 'a lot of difficulty' on at least one of the six questions.)

It is important to note that the WG-SS does not identify health conditions or diagnostic categories but rather captures the possible impact of these conditions on functional abilities. Additional questions can be added to a survey containing the Short Set to obtain information on the cause of the functional difficulties.

The WG-SS will identify most but not all people with disabilities. There are two important limitations of the WG-SS to note:

- It does not include questions on mental health/psychosocial functioning (the longer Extended Set does). Alternatively, questions on depression and anxiety ('affect') can be added by using the 'Enhanced Short Set'.<sup>2</sup>

1 The WGQSS is estimated to add approximately two minutes per survey.

2 For a detailed consideration of prevalence data on psychosocial functioning in conflict-affected contexts, see: Charlson, F. et al. (2019) 'New WHO prevalence estimates of mental disorders in conflict settings: a systematic review and meta-analysis' *The Lancet* 394(10194): 240-248 ([www.thelancet.com/journals/lancet/article/PIIS0140-6736\(19\)30934-1/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)30934-1/fulltext)).

## Box A2 Disability measurement and monitoring using the Washington Group Short Set of Questions on Disability (continued)

- While the WG-SS may identify many children with disabilities, it can miss a significant number of children with developmental or psychosocial issues and is therefore not recommended for use with children. To identify a fuller range of childhood disability for children and youth aged 2–4 and 5–17, the WG has developed a Module on Child Functioning in conjunction with UNICEF, which has now been incorporated into the Multiple Indicator Cluster Surveys (MICS) for use in humanitarian settings.<sup>1</sup>

By integrating the WG-SS into existing surveys, humanitarian organisations can:

- Understand the prevalence of people with disabilities in a given area, which can inform strategic planning frameworks such as Humanitarian Needs Overviews (HNOs) and HRPs (see, for example, the Syria HNO 2019).<sup>2</sup>
- Measure and monitor access to services by people with disabilities, for example by adding the WG-SS to case management or registration data, with potential for further disaggregation by sex, age or other relevant characteristics to highlight potential barriers for specific groups (for example, Sightsavers' Everybody Counts pilot studies).<sup>3</sup>
- Disaggregate programme indicators by disability to better understand the situation of people with disabilities and the effectiveness of humanitarian programmes (for example, WFP's use of the WG-SS in a food security outcome monitoring (FSOM) survey among Syrian refugees in Jordan, which revealed that households with a member with disabilities were resorting to more severe coping mechanisms).<sup>4</sup>

Source: [www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions](http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions).

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1 For further information and resources on the Module on Child Functioning, see: [www.washingtongroup-disability.com/washington-group-question-sets/child-disability](http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability). See also Mactaggart, I., Cappa, C., Kuper, H., et al. (2016) 'Field testing a draft version of the UNICEF/Washington Group Module on child functioning and disability. Background, methodology and preliminary findings from Cameroon and India' *Alter, European Journal of Disability Research* 10(4): 345-360 (<https://doi.org/10.1016/j.alter.2016.09.003>).

2 OCHA (2019) *Humanitarian Needs Overview: Syrian Arab Republic* [EN/AR] (<https://reliefweb.int/report/syrian-arab-republic/2019-humanitarian-needs-overview-syrian-arab-republic-enar>). The Syria HNO reports the findings of a joint agency health assessment among adults in western Aleppo, Idlib and Ar-Raqqa governorates, which indicated an average prevalence rate of 30%, double the global average, and which revealed that an average of 45% of surveyed persons injured during the Syria crisis are expected to sustain a permanent impairment (e.g. amputation, spinal cord injury, brain injury) (p.27). See also: 'Turkey Hub Health Cluster Bulletin', December 2018, p.6 ([https://reliefweb.int/sites/reliefweb.int/files/resources/turkey\\_health\\_cluster\\_bulletin\\_december\\_2018.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/turkey_health_cluster_bulletin_december_2018.pdf)).

3 See: [www.sightsavers.org/programmes/everybody-counts](http://www.sightsavers.org/programmes/everybody-counts).

4 E.g. WFP Jordan (2019) 'Food security outcome monitoring Q3 2019': Factsheet ([www.wfp.org/publications/food-security-outcome-monitoring-q3-2019](http://www.wfp.org/publications/food-security-outcome-monitoring-q3-2019)).

## Box A3 Findings from the field on the collection and analysis of disability data using the WG-SS questions

Key findings on data collection using the WG-SS included:<sup>1</sup>

### Staff training needs and the sensitisation of staff to disability issues

- All projects and assessments reported the importance of staff training, particularly for technical advisers, programme staff, monitoring and evaluation (M&E) staff and enumerators. The outcomes of Sightsavers' pilot projects and the HI-led action research project highlighted the importance of all-staff training on sensitisation on disability and inclusion more broadly, as well as technical training on data collection using the WG-SS tool. This ensures cross-organisational understanding of the purposes of disability data and supports effective linking of data collection to programming. A key outcome of the HI project is an e-learning tool to support staff training on disability data in humanitarian action, including use of the WG-SS.<sup>2</sup>
- The HI and Sightsavers projects both identified significant in-country skills gaps and a need for training in disaggregated data analysis. Despite WG software to assist analysis, the HI project found that many organisations were carrying out limited or flawed analysis of the WG-SS data, and some were not analysing it at all. Most of the practical issues encountered related to the disaggregation of populations generally rather than to issues specific to the disability/WG data.
- All projects and assessments identified significant positive impacts on overall understanding of disability and changed perceptions among staff towards people with disabilities as a consequence of using the WG-SS.

### The need for staff/organisations to understand the purposes of the WG-SS data on disability:

- Both the HI and Sightsavers projects found there was potential for staff to misunderstand what the WG-SS are designed for and how the data can be used, sometimes with an incorrect assumption that the WG-SS can provide diagnostic data rather than being limited to showing prevalent trends to inform programming.
- The HI project found that risks or misunderstandings over the purposes of the WG-SS depended partly on specific programming approaches in different sectors, for example, the food security/livelihoods sectors seeking to use WG-SS to identify people for targeted assistance, and the health sector considering its use to identify cases for referral to health services. However, the WG questions were not designed for targeting or referrals and are not sufficiently detailed for use in accurately diagnosing individuals or determining eligibility for disability programmes.<sup>3</sup> More detailed and robust individual assessment data using other tools is needed for these purposes.

### A lack of data on mental health

- The HI project reported frustration among some organisations that the WG-SS questions are not sufficient to identify people with psychosocial disabilities. A mental health and psychosocial support project by International Medical Corps in Jordan used the Enhanced Short Set that includes additional questions on anxiety and depression. They found that, of those identified with mental health disabilities using the Enhanced Short Set, only 51% were identified by the WG-SS alone.

### Identification/relevance of the cause of disability

- In Jordan, HI's action research asked people when their difficulties started, revealing that 40% of Syrian refugees reported experiencing difficulties as a result of the humanitarian situation. This research highlighted that, for the purposes of humanitarian programming, the specific cause or duration of the disability may not be relevant (not only long-term disabilities, but also temporary or recent disabilities may restrict people's access and participation).

1 For an overview of the findings of the HI action research project, see Humanity & Inclusion and Leonard Cheshire (2018).

2 Fifty-nine staff from 29 different organisations working in 22 different countries were consulted to inform the development of the learning toolkit. Combined with the findings from the action research, this feedback informed what materials were to be developed, for what audiences, and by what priority. Specific focus was given to the development of open source materials that are accessible with screen readers, on mobiles and in hard-to-reach locations. Subject matter experts have supported the development of the content, which has since been tested across 13 countries by nine organisations. The toolkit can be accessed at: <https://humanity-inclusion.org.uk/en/projects/disability-data-in-humanitarian-action#9>.

3 On how the WG-SS differs from disability eligibility determination, see Mont, D. (2017) 'How does the WG-SS differ from disability eligibility determination?' Blog, 5 May ([www.washingtongroup-disability.com/washington-group-blog/wg-ss-differ-disability-eligibility-determination/](http://www.washingtongroup-disability.com/washington-group-blog/wg-ss-differ-disability-eligibility-determination/)).

## Box A3 Findings from the field on the collection and analysis of disability data using the WG-SS questions (continued)

### Practicalities of collecting data using the WG-SS, including in sudden-onset emergencies

- The HI project showed that enumerators were often sceptical about the WG questions before using them, but after a short experience of administering the questions in the field, the reported ease of using them increased. No major difficulties with enumerators administering the questions were reported. The Sightsavers studies and IOM and HI Bentiu PoC assessment found that disabilities were under-reported when enumerators had not been sufficiently trained.
- The time taken to administer the questions was identified as a potential issue. HI found a significant discrepancy between perceived time needed to ask the questions (seven minutes) compared with the actual average time (three minutes); however, this did pose challenges when administered to all individuals in a household. HI notes that, when time constraints are an issue, it is possible (within WG guidance) to ask just four questions (on seeing, hearing, walking/climbing steps and remembering/concentration). Enumerators involved in the Sightsavers Ghana pilot reported that some older respondents and people with cognitive or sensory impairments often needed longer to answer the questions.
- The HI project explored issues around when to use the WG questions in different ways at certain points in the programming cycle and across various sectors. The project confirmed that the WG-SS may not be suited to the initial stages of programming in a sudden-onset emergency, so collecting data during the preparedness stage is important (although pre-crisis data on disabilities may not reflect the post-crisis situation). Data can be collected more readily at household and/or individual levels at later stages in a humanitarian response and in protracted crises responses, or in registration processes in displacement and refugee emergencies.
- In the case of the REACH assessment of disabilities among Rohingya refugees, the joint agency assessment of people with disabilities in Vanuatu, and a number of pilots included in the HI project, organisations used the WG-SS questions in a household survey format where heads of household answered on behalf of everyone in the household. In all cases, this was recognised as potentially problematic. The HI project observed that the utility and/or feasibility of applying the questions at individual or household level depended on the programme context.

### Cultural, language and context issues

- HI investigated the impact of the WG questions on affected populations; data from pilots in the Philippines and Jordan showed that most people felt comfortable with the questions. However, the REACH disability assessment among Rohingya refugees found that disabilities may have been under-reported due to the stigma attached to disability in Rohingya communities, particularly psychosocial disabilities. Despite the neutral language used by the WG-SS, respondents were possibly reluctant to discuss disabilities. The Sightsavers pilot project in Ghana found that some people were offended when asked the self-care question, and some were reluctant to answer questions that would expose the limitations they experience in the community due to fear of discrimination.
- HI reports that the answers to the questions on seeing and hearing were affected when respondents had no access to glasses or hearing aids. These questions were reported by some organisations as potentially problematic as they raised expectations of support among respondents. Both the HI and Sightsavers projects underlined the importance of clarity in telling people why the data is being collected and how it will be used.
- Language and translation problems were reported across all projects and assessments. HI reports, for instance, that the word 'concentration' was frequently misinterpreted to mean memory. Where the WG-SS were used in Vanuatu, the Philippines (HI project), questions had not been translated into local languages. This led to enumerators translating the questions themselves, potentially affecting the validity of the data due to lack of consistency and lack of cognitive testing of the translated words and phrases used.<sup>1</sup> HI also reports that on some occasions, the equivalent of the term 'disability' was mentioned directly by enumerators, potentially rendering the data invalid (stigma associated with the term could potentially impact answers). In the Sightsavers pilot project in Ghana, some respondents with cognitive or sensory impairments were unable to understand the questions.

<sup>1</sup> An accurate translation that conveys the context or conceptual meaning (rather than a literal translation) of the WG SS is crucial. The WG has collected translations of the questions in several languages. If a country has appropriately translated the Short Set for use in their national census, use this version. It is desirable for all programmes in a country to use the same translation. Further information on translating the WG-SS into other languages can be found in the WG Translation Protocol: [www.washingtongroup-disability.com/washington-group-question-sets/translations/](http://www.washingtongroup-disability.com/washington-group-question-sets/translations/).

## Box A4 Quantitative and qualitative data needed

The IASC Guidelines identify a range of forms and uses of quantitative and qualitative disability data through all stages of the humanitarian programme cycle:

### **Quantitative data (information that can be measured and calculated) may be used:**

- To identify individuals with disabilities and calculate the number of persons with disabilities in an affected population (via registration data, household surveys, household estimates, etc.).
- To determine the number and location of accessible and inaccessible facilities.
- To disaggregate data on needs and risks (for example, the number or proportion of food insecure households that are headed by persons with disabilities).
- To monitor access to assistance (for example, establish the number or proportion of participants in livelihood programmes who are persons with disabilities).
- To monitor protection concerns (for example, establish the number of human rights violations, or types of human rights violation, experienced by persons with disabilities).

### **Qualitative data (information that is descriptive) may be used:**

- To collate the views and priorities of persons with disabilities, for example via feedback and complaint processes.
- To understand the risks and barriers that persons with disabilities face, as well as enabling factors, for example via focus group discussions and key informant interviews.
- To identify specific risks, barriers and enablers to accessing assistance that persons with disabilities encounter, for example through policy and document reviews.
- To monitor protection concerns, for example by privately interviewing persons with disabilities about the human rights violations they have experienced.
- To obtain detailed information about the knowledge, attitudes and perceptions of humanitarian actors and local communities with regard to persons with disabilities, for example via surveys or interviews.
- To map OPDs and accessible services, for example by gathering 5W data (who does what, when, where and for whom?).

*Source: IASC (2019).*

## Box A5 IASC Guidelines on inclusion of persons with disabilities

### Roles and responsibilities of different stakeholder groups in strategic response planning to support persons with disabilities

#### Governments:

- Involve organisations of persons with disabilities (OPDs) in strategic response planning.
- Take steps to ensure that strategic response planning includes persons with disabilities and adopts a human rights-based approach that complies with national, regional and international legal instruments and frameworks.

#### Humanitarian leadership (Emergency/Resident Coordinator, Humanitarian Country Team):

- Include disability in the strategic and results frameworks of response plans; ensure that reporting reflects the diversity of persons with disabilities.
- Ensure that all strategic response plans (HRPs, rapid response plans, etc.) include all persons with disabilities who are in need.
- Describe in the plan how the response will address factors that heighten the risks faced by persons with disabilities.
- Involve OPDs in developing the HRP.

#### Cluster and sector leads:

- Involve OPDs representing the diversity of persons with disabilities in strategic response planning processes, including analysis of information relating to persons with disabilities.
- Develop and use appropriate indicators to measure the inclusion of persons with disabilities, applying the recommendations of these guidelines.
- Design a twin-track approach and response strategy, including standard operating procedures (SOP), based on sector-specific guidelines and standards on inclusion of persons with disabilities. These should take into account the intersectionality of gender, age, disability and other diversity factors.

#### Programmers (in humanitarian and development organisations):

- Make sure that meeting the requirements of persons with disabilities is among the objectives of the HRP. Design and include indicators that measure the inclusion of persons with disabilities.
- Adopt a twin-track plan to implement projects and strategies that ensure that persons with disabilities enjoy equitable access to assistance and protection. For this purpose, consider outreach, home-based services, accessible infrastructures, reasonable accommodations, etc.
- Liaise and develop partnerships with disability-focused organisations, service providers and OPDs that represent the diversity of persons with disabilities

#### Donors:

- Require implementing partners to design and include strategies on disability inclusion as part of funding requirements.
- Promote and assist partners to develop approaches that identify, analyse and address the risks facing persons with disabilities.

## Box A6 An OPD-supported rapid assessment in an ongoing refugee response

In 2013, HI commissioned a rapid needs assessment focused on the experiences of refugees with disabilities within and around Domiz camp in northern Iraq. The assessment sought to identify the needs of refugees with disabilities and the barriers they faced in accessing humanitarian services across all key sectors, and to examine the resources and capacities of service providers to include people with disabilities in their service provision. The assessment used a combination of secondary data review, FGDs, key informant interviews and surveys among people with disabilities and service providers.

Among the findings was the observation that the majority of refugees with disabilities had long-standing disabilities and therefore there was minimal need for acute rehabilitation and medical care. However, psychological trauma was identified as a significant problem, affecting 67% of persons with disabilities. Significantly fewer unregistered refugees were accessing health services compared with registered refugees.

The assessment noted important constraints on the collection and analysis of the rapid needs assessment data that required mitigation, including:

- Due to the sensitive nature of discussing sexual and gender-based violence (SGBV), time constraints and the lack of confidentiality in FGDs, SGBV experiences may not have been identified and explored adequately.
- Some assessors had limited assessment experience or exposure to disability issues in a post-crisis situation, and there was insufficient time to provide extensive training.
- Information collected on people with disabilities was biased against people without visible impairments. This was due to bias towards visible impairments in the lists of people with disabilities provided by sector leads and UNHCR.

*Source: Handicap International [Humanity & Inclusion] (2013) Rapid needs assessment: situation of children, youth and adults with disabilities, within and around Domiz, northern Iraq (December) (<https://reliefweb.int/report/iraq/rapid-needs-assessment-situation-children-youth-and-adults-disabilities-within-and>).*

## Box A7 Environmental, attitudinal and institutional barriers identified in humanitarian programmes

In 2019, DFID commissioned a rapid review of the evidence on approaches to ensuring people with disabilities are reached through humanitarian programmes, including evidence on barriers to access and the impact on participation and outcomes to support more inclusive programmes going forward. Drawing on a range of sources, the review found considerably more evidence on barriers than on enabling factors in mainstream humanitarian programming. These included:

### Individual factors and intersecting vulnerability affecting inclusion in assistance and protection

- People with psychosocial disabilities and mental health conditions are more likely to be excluded from access to information and services than those with physical and sensory disabilities. A 2008 Women's Refugee Commission (WRC) study in five refugee settings found that people with intellectual and psychosocial disabilities are more stigmatised and tend to be especially 'invisible' in refugee and IDP assistance programmes.<sup>1</sup>
- Field research with refugee survivors of SGBV with communication disabilities in Rwanda found that people with communication disabilities are at increased risk of SGBV and face particular barriers in accessing SGBV prevention and response interventions.<sup>2</sup>

### Environmental barriers

Numerous examples of environmental barriers were identified, including:

- **Lack of accessible information:** A 2015 study by HI found that lack of accessible information was one of the main barriers faced by people with disabilities in accessing services; almost a third of the 484 people with disabilities surveyed (30% and 32%) did not know where to find available services or what types of services existed.<sup>3</sup>
- **Physical inaccessibility:** For example, inaccessible food distribution points and lengthy wait times; inaccessible school buildings and WASH facilities; the design, layout and location of camps; and inaccessible housing – all of which present mobility difficulties for many people with disabilities.<sup>4</sup>
- **Long distances and lack of accessible transport:** These present barriers to accessing services, especially for people with physical impairments.<sup>5</sup>
- **Lack of specialist services and equipment:** These include lack of special food rations or prioritisation in food distribution systems; unmet needs for assistive devices such as wheelchairs and specialised medical care, including treatment for chronic physical and mental health conditions; and lack of rehabilitation services, such as physical and occupational therapy. Such services often tend to be viewed as specialist and complex, and outside the remit of a sector focused on providing short-term emergency aid and basic primary care.<sup>6</sup>
- **SGBV and other safety issues:** Research undertaken by HI in Yemen found that more than half of all respondents reported feeling unsafe when accessing services.<sup>7</sup>

### Attitudinal barriers

- **Negative attitudes among service providers and staff:** For example, a WRC-led participatory study on the SRH needs of refugees with disabilities in Kenya, Nepal and Uganda found that negative attitudes of service providers were the most significant barrier to accessing services.<sup>8</sup>
- **Lack of awareness of disability issues and misconceptions among humanitarian actors:** For example, a rapid qualitative study of the Nepal earthquake response found that awareness of discrimination based on disability status was generally much lower than awareness of discrimination based on gender or social hierarchy.<sup>9</sup> Staff

1 Women's Refugee Commission (2008).

2 Marshall, J. and Barrett, H. (2018) 'Human rights of refugee-survivors of sexual and gender-based violence with communication disability' *International Journal of Speech-Language Pathology* 20(1): 44–49. DOI: 10.1080/17549507.2017.1392608.

3 Handicap International (2015).

4 Women's Refugee Commission (2008).

5 Handicap International (2015).

6 Women's Refugee Commission (2008); Shivji, A. (2010) 'Disability in displacement' *Forced Migration Review* (Theme Issue: Disability and Displacement)

35: 4–7; Mirza, M. (2015) 'Disability-inclusive healthcare in humanitarian camps: pushing the boundaries of disability studies and global health' *Disability and the Global South* 2(1): 479–500.

7 Humanity & Inclusion (2018) 'Inclusion factsheet: Shelter/NFI/CCM – Yemen, 2018' ([www.sheltercluster.org/sites/default/files/docs/inclusion\\_of\\_people\\_with\\_disabilities\\_other\\_vulnerable\\_in\\_shelter\\_response-yemen\\_factsheet.pdf](http://www.sheltercluster.org/sites/default/files/docs/inclusion_of_people_with_disabilities_other_vulnerable_in_shelter_response-yemen_factsheet.pdf)).

8 Tanabe et al. (2015).

9 Searle et al. (2016).

## Box A7 Environmental, attitudinal and institutional barriers identified in humanitarian programmes (continued)

often have misconceptions that people with disabilities require specialist care and that specialist care and adaptations are prohibitively expensive.<sup>10</sup>

### Institutional barriers

- **Lack of disability mainstreaming across sectors:** Humanitarian agencies tend to refer people with disabilities to service providers for health, rehabilitation and provision of assistive devices, sometimes failing to recognise their needs in social dimensions – such as their lack of inclusion in schools, shelter, livelihoods and protection programming.<sup>11</sup> The needs of people with psychosocial disabilities and mental health conditions were less likely to be integrated within mainstream programmes such as education and livelihood activities.<sup>12</sup>
- **Exclusion of specialised health services from ‘basic bundle’ of care:** Research in southern Africa found that disability-specific health services were consistently excluded from the ‘basic bundle’ of healthcare.<sup>13</sup>
- **Lack of disability-disaggregated data and lack of assessment of needs:** For example, the findings of an ASB rapid review of disability and age inclusion on the Rohingya refugee response in Cox’s Bazar found limited awareness and practice of identifying people with disabilities in the response and few actors collecting gender-, age- and disability-disaggregated data.<sup>14</sup>
- **Lack of disability inclusion expertise:** A 2016 global mapping with humanitarian actors found that staff perceive that they do not have the capacity and know-how to ensure the inclusion of women and girls with disabilities.<sup>15</sup>
- **Lack of accountability mechanisms, gaps in policy development and implementation, exclusion from official planning processes, and lack of indicators and targeting:** For example, VCA manuals and guidelines, ‘while promoting the general idea of inclusiveness, are insufficiently aware of the difficulties in achieving this in practice, and do not give enough guidance on how to reach and include disabled people’<sup>16</sup> Policies and commitments (including those on education provision and on gender equality and women’s protection) often lack specific reference to women and girls with disabilities.<sup>17</sup> A 2016 qualitative study on inclusive humanitarian response to the Nepal earthquake found that none of the 12 agencies included in the study were intentionally and systematically undertaking meaningful consultation with and feedback from people with disabilities.<sup>18</sup> A lack of specific targets or indicators for the participation of people (including women and girls) with disabilities in humanitarian activities presents significant challenges to monitoring of access and inclusion in implementation.<sup>19</sup>

10 Trani, J.F., Kett, M., Bakhshi, P. and Bailey, N. (2011) ‘Disability, vulnerability and citizenship: to what extent is education a protective mechanism for children with disabilities in countries affected by conflict?’ *International Journal of Inclusive Education* 15(10): 1187–1203.

11 Rohwerder, B. (2017) *Women and girls with disabilities in conflict and crises*. Brighton: K4D Helpdesk; Pearce, E. (2015) ‘I see that it is possible’: building capacity for disability inclusion in gender based violence programming in humanitarian settings. WRC & IRC; and 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.

12 Women’s Refugee Commission (2008).

13 Mirza, M. (2015).

14 Arbeiter-Samariter-Bund (2017) *Rohingya refuge crisis in Bangladesh: age and disability inclusion – rapid assessment report, 2017*. Published with support from Centre for Disability in Development Bangladesh and Aktion Deutschland Hilft.

15 Pearce and Sherwood (2016).

16 Twigg (2014).

17 Pearce and Sherwood (2016).

18 Searle et al. (2016).

19 Pearce and Sherwood (2016).

## Annex 2 Additional tables

**Table A1 Strengthening meaningful access for people with disabilities through integration of disability data in protection mainstreaming**

Examples of barriers	Specific enabler
Food distribution is organised in a location characterised by having to travel long distances on a muddy, impassable road, making it inaccessible to persons with disabilities (physical barrier).	Ensure that accessible locations, means of distribution and delivery are in place; make sure there are priority lanes and resting areas, or organise home deliveries.
Children with disabilities are not allowed to access school (policy barrier), are not seen as welcome in school (attitudinal barrier) or the school and its facilities are not physically accessible for children with disabilities (physical barrier) or educational material used at school is not accessible.	The prior is to be addressed by advocacy and the second by raising awareness of staff, students, families, teachers and community members to ensure that education is provided based on individual needs and strengths without discrimination. Ensure accessibility through universal design and reasonable accommodation in order to render the school physically accessible.
Persons with sensory, mental and intellectual disabilities are not aware of available services and assistance as information on these is not provided in a language and format that everyone can understand (information and communication barrier).	Ensure that information is provided through accessible channels, accessible formats, in appropriate languages and locations so that it reaches everyone in line with universal accessible standards.
Eligibility for cash assistance is based on having a disability certificate, which requires paying a fee to the medical facility and paying for transport and accommodation to the facility (economic barriers).	Support fees, costs and, if needed, provide legal assistance for obtaining documentation required to have access to assistance.
Receiving cash assistance requires a bank account. Yet, national legislation provides that people deprived of their legal capacity need a guardian to act on their behalf. Due to the crisis, the guardian system has collapsed (legislative/regulatory barrier).	Find a temporary manner of providing cash assistance outside the banking system to all persons on an equal basis.
<b>General enablers and capacities for ensuring meaningful access</b>	
Consult persons with disabilities as they are the best placed to identify strategies to overcome the barriers they face.	
Engage DPOs and community-based organisations (CBOs), particularly from the local area, as they often possess unique knowledge about the location of persons with disabilities, about the diversity of disabilities and about the possible solutions to overcoming the barriers.	
Ensure that all relevant information on rights, access to services and assistance is provided through accessible channels, accessible formats and in appropriate languages and locations so that it reaches everyone. Make sure provision for this is included in the budget.	
Provide mobile/outreach services to facilitate access to services and delivery of assistance. Outreach also supports identification of persons with disabilities.	
Ensure accessibility where possible following universal design of all buildings and facilities, and ensure that activities are physically and financially accessible and reachable.	
Allow persons with disabilities to be accompanied by a person of their choice if they require such support.	
Ensure a functional referral system for support to accessing individual protection assistance (accompaniment, legal assistance and case management) and specialised services (e.g. rehabilitation) is in place and that all actors know where to refer persons with disabilities.	

Source: ECHO (2019), p.14

**Table A2 Strengthening participation and empowerment of people with disabilities through integration of disability data in protection mainstreaming**

Examples of barriers	Specific enabler
Persons with disabilities are not aware of ongoing consultations and decision-making processes (information and communication barrier).	Ensure that information is provided through/in accessible channels, formats, languages and locations (e.g. places where persons with disabilities often come).
Persons with disabilities are not included in consultations and decision-making as their contributions and capacities are not considered relevant by the community and/or by humanitarian actors (attitudinal barrier).	Raise awareness of households, communities and staff on rights and non-discrimination and include respect for persons with disabilities in organisational policies and codes of conduct. Actively empower persons with disabilities to participate.
Persons with disabilities are not able to participate in consultations and decision-making because they cannot access the venue (physical barrier) or because support is not provided to overcome communication barriers (information and communication barrier).	Ensure the venue is accessible, that support is available and that capacities of DPOs are developed to become equal partners in the system.
DPOs are not invited to participate in humanitarian coordination mechanisms as they are not considered to have a relevant contribution (attitudinal barriers).	Raise awareness among humanitarian actors on the importance of DPO participation and on the right of persons with disabilities to be active actors in the coordination system.
DPOs are not involved in humanitarian coordination mechanisms as they cannot access the venue (physical barrier), or because support is not provided to overcome communication barriers for persons with sensory, mental or intellectual disabilities (information and communication barrier), or because they are not aware of how the humanitarian coordination system works and how they can engage (legislative barriers).	Ensure the venue is accessible, that support is available to overcome communication barriers, and that capacities of DPOs are developed to become equal partners in the system.
<b>General enablers and capacities for ensuring participation and empowerment</b>	
In consultation with persons with disabilities and in collaboration with DPOs, identify and address barriers preventing persons with disabilities from participating in consultations and decision-making.	
Arrange meetings in a manner that encourages participation of persons with disabilities, including by ensuring that the venue is accessible, that reasonable accommodation is provided, and that information needed to ensure meaningful participation is provided through accessible channels and formats and in appropriate languages so that it reaches everyone.	
In collaboration with DPOs, identify and build the capacities of persons with disabilities to fully and meaningfully participate in decision-making processes	
Ensure presence of persons with different kinds of disabilities and provide necessary support to overcome e.g. communication barriers.	
Ensure that DPOs are automatically included in humanitarian coordination mechanisms and that their participation is facilitated through reasonable accommodation.	
Raise awareness in the community on the rights of persons with disabilities to have full and meaningful participation in consultations and decision-making	

Source: ECHO (2019), p.16

**Table A3 Examples of output-level indicators by thematic area**

<b>Thematic area</b>	<b>Examples of activity/output-level indicators</b>	<b>Commitment area Aspect of vulnerability addressed</b>	<b>Means of verification Tools and methods</b>
<b>Health</b>	# of health facilities constructed or adapted in accordance with universal design standards	<b>Inclusive response and services</b> Physical barriers to safe and dignified access	<b>Accessibility audits to identify facilities that do not meet standards</b>
<b>Health</b>	# of persons with disabilities accessing health-related rehabilitation services, including assistive technology	<b>Cooperation and coordination</b> Interruption of essential health service due to disruption caused by the crisis	<b>Health post/clinic records</b> HeRAMS checklist of services may require adaption.
<b>Education</b>	# of classrooms retrofitted or constructed in accordance with universal design standards	<b>Inclusive response and services</b> Physical barriers to safe and dignified access	<b>Checklists to facilitate systematic monitoring</b> Standards (e.g. width of doors, height of tables, accessibility ramps)
<b>WASH</b>	# of toilet facilities retrofitted or constructed in accordance with universal design standards	<b>Inclusive response and services</b> Physical barriers to safe and dignified access	<b>Checklists to facilitate systematic monitoring</b> Standards (e.g. toilet fixtures, drinking water, hand-washing, signage)
<b>WASH</b>	# of hygiene messages provided in a minimum of two formats (written and oral)	<b>Inclusive response and services</b> Communication barriers prevent access to important information	<b>Checklists to facilitate systematic monitoring</b> Tips and guidance by CBM on accessible communication
<b>Food security and nutrition</b>	# of distribution points/markets retrofitted or constructed in accordance with universal design standards	<b>Inclusive response and services</b> Physical barriers to safe and dignified access	<b>Common Operational Dataset or Foundational Operational Datasets issued to identify appropriate and accessible distribution points</b> SPHERE food security – Food assistance standard 6.3: Targeting, distribution and delivery
<b>Protection</b>	# of staff, partners and communities trained in working with people with disabilities	<b>Cooperation and coordination</b> Limited capacity of protection actors to include persons with disabilities in core activities	<b>Follow-up assessment of efficacy will require a baseline of knowledge attitude and practice</b> Tips and guidance by UNICEF

Source: DFID Humanitarian Investment Programme (2019) pp.20-23.

**Table A4 Evaluation criteria through a disability-inclusive lens**

<b>Evaluation criteria</b>	<b>Definition</b>	<b>Example of disability-related considerations</b>
<b>Appropriateness, relevance</b>	The extent to which humanitarian activities are tailored to local needs, thereby increasing ownership, accountability and cost-effectiveness.	Adaptations made to improve accessibility; persons with disabilities participate in design and implementation.
<b>Effectiveness, timeliness</b>	The degree to which an activity achieves its purpose; whether it does so within an appropriate time frame.	Persons with disabilities have access; they perceive positive benefits.
<b>Efficiency, cost-effectiveness</b>	Expected qualitative and quantitative outputs are achieved from inputs; alternative outputs would not achieve the same result at lower cost.	Accessibility is addressed from the start, improving cost-effectiveness.
<b>Impact</b>	Measures the wider social, economic, technical and environmental effects of an intervention. Includes results that are intended, unintended, positive, negative, macro (sector) and micro (household).	Whether persons with disabilities benefit equally; whether persons with disabilities experienced unintended impacts.
<b>Connectedness</b>	The extent to which activities of a short-term emergency nature take into account the local context and longer-term concerns.	Impacts on the inclusiveness of national/local services. Whether local/national systems providing assistive technology, inclusive education, etc., are strengthened; whether OPDs build capacity.
<b>Coverage</b>	The extent to which major population groups facing life-threatening events were reached.	Levels of access for persons with disabilities.
<b>Coherence</b>	The extent to which policies are consistent and consider humanitarian and human rights.	The extent to which humanitarian action complies with the Convention on the Rights of Persons with Disabilities (CRPD).
<b>Coordination</b>	The extent to which the interventions of different actors are harmonized to promote synergy and avoid gaps, duplications and resource conflicts.	Level of engagement by OPDs and other disability actors in the humanitarian response; quality of coordination.
<b>Protection</b>	The extent to which affected populations are protected from violence, abuse, exploitation and other harms, taking into account their rights and capacities.	The extent to which risks faced by persons with disabilities are identified, removed or mitigated.

Source: IASC (2019), Annex 6, p.198.

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