INCLUDING EVERYONE

Strengthening the collection and use of data about persons with disabilities in humanitarian situations

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&inclusion

International
Disability
Alliance

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for every child

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This joint report reflects the activities of individual agencies around an issue of common concern. The principles and policies of each agency are governed by the relevant decisions of its governing body. Each agency implements the interventions described in this document in accordance with these principles and policies and within the scope of its mandate.

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Contents

Acronyms

ACAPS	Assessment Capacities Project
CRPD	Convention on the Rights of Persons with Disabilities
DTM	Displacement Tracking Matrix
ECB	Emergency Capacity Building Project
EFSA	Emergency Food Security Assessment
FAO	Food and Agriculture Organization
FTS	Financial Tracking Service
HeRAMS	Health Resources Availability Mapping System
HESPER	Humanitarian Emergency Settings Perceived Needs Scale
HPC	humanitarian programme cycle
HRIT	Heightened Risk Identification Tool
IASC	Inter-agency Standing Committee
IATI	International Aid Transparency Initiative
IDA	International Disability Alliance
JIAF	Joint Intersectoral Analysis Framework
JIPS	Joint IDP Profiling Service
MIRA	Multi-sector Initial Rapid Assessment
NARE	Needs Assessment for Refugee Emergencies
NGO	non-governmental organization
OCHA	Office for the Coordination of Humanitarian Affairs
OPD	organization of persons with disabilities
OPS	Online Project System
ProGres	Profile Global Registration System
SDG	Sustainable Development Goal
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
VAF	Vulnerability Assessment Framework
WFP	World Food Programme
WG	Washington Group on Disability Statistics
WHO	World Health Organization

Abstract

To ensure that persons with disabilities are protected and assisted during humanitarian emergencies, reliable and up-to-date information is needed on the number of individuals with a disability in the affected population and the barriers they face. The fact that disability-disaggregated data are scarce – especially in humanitarian situations – has garnered considerable political commitment to further improve data availability. However, United Nations agencies, States Parties to the Convention on the Rights of Persons with Disabilities, and humanitarian non-governmental organizations are still in the nascent stages of improving their data collection processes in humanitarian action to conform to the Convention's article 11 (protection and safety of persons with disabilities in situations of risk) and article 31 (collect appropriate information, including statistical and research data).

The slow progress towards improving disability-disaggregated data in humanitarian situations is partly a result of the wide diversity of the crises themselves. Different types of emergency contexts pose varying challenges for data collectors and impact persons with disabilities in different ways.

This publication presents four humanitarian case studies: the 2015 Nepal earthquake, the ongoing humanitarian response in Somalia, the Rohingya refugee operation in Bangladesh, and the European migrant and refugee crisis. Each example provides perspectives on the importance of disability-disaggregated data in shaping humanitarian actors' planning and implementation processes.

Current humanitarian needs assessment frameworks and guidance are also examined, considering the extent to which disability data disaggregation plays a part. Coordinated data collection efforts, such as the Joint Intersectoral Analysis Framework,[1] can be a useful starting point for improving the assessment process from the perspective of persons with disabilities.

This publication briefly documents progress in policies and guidelines related to disability data in the humanitarian sector and reviews the existing tools and mechanisms for gathering data on persons with disabilities. While there is growing commitment towards greater inclusivity in humanitarian action through better data on persons with disabilities, the question remains on how to do this. The existing tools are neither well adapted to data collection concerning persons with disabilities nor sufficient to address disability as a cross-cutting issue. With humanitarian actors working side by side in diverse settings, common data standards are needed to allow comparability and meaningful data exchange.

When data collection approaches are standardized, disaggregation of data by disability in humanitarian action is possible. Currently, only 6 per cent of the indicators in the United Nations Inter-agency Standing Committee register can be disaggregated by disability. The recommended approach for producing comparable disability data is the use of the tools developed by the Washington Group on Disability Statistics.

The ongoing reforms of the international humanitarian system offer a unique opportunity to redefine and standardize disability-disaggregated data within the humanitarian programme cycle.

Introduction: Leaving no one behind

Inclusion is an important theme throughout the United Nations' 2030 Sustainable Development Goals (SDGs) and its Agenda for Humanity. Full and effective participation and inclusion in society is also a general principle of the Convention on the Rights of Persons with Disabilities (CRPD).[2] Article 11 of the CRPD obliges States Parties 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". However, humanitarian stakeholders need to know the number of persons with disabilities in these situations, the barriers and risks they face, and whether or not they are receiving the assistance they need. Article 31 of the CRPD also specifically mentions the obligation of States Parties to collect disaggregated data to identify and address the barriers faced by persons with disabilities in exercising their rights. However, data that accurately describe the demographics of persons with disabilities are scarce, especially in humanitarian contexts.[3]

In 2011, the World Health Organization (WHO) estimated that 15 per cent of the global population are persons with disabilities. This figure has been frequently cited and continues to provide a useful starting point for discussion. However, according to WHO, "there is an urgent need for more robust, comparable, and complete data collection" in the area of disability statistics.[4]

> As the bombs fell on their neighbours' homes in Aleppo, Syria, this 13-year-old girl and her family were forced to flee. They began an arduous journey to safety, made even more challenging by the fact that this adolescent lives with cerebral palsy and has difficulty walking. When the family settled in Turkey, it was difficult to get the support she needed. Four years later, however, the girl is thriving in a Turkish public school.

The international humanitarian system recognizes the need to be more competent at data and information management. This is particularly true in the case of collecting data on persons with disabilities in humanitarian action. To improve accountability in responding to human needs in disasters and other crises, differentiating risk within affected populations is important as different segments have different needs and face different barriers to address them. One historical parallel is the now-resolved debate about the importance of understanding the needs of men and women and boys and girls separately, as one of the key drivers of effectiveness and relevance in humanitarian response. To adequately include persons with disabilities in humanitarian action, the international system first needs to count them properly.

This paper discusses challenges and opportunities related to addressing the data needs of persons with disabilities in humanitarian crises. It briefly documents progress in policies and guidelines related to disability data in the sector and reviews the existing tools for needs assessment, planning, and monitoring and evaluation in humanitarian action.

To illustrate the challenges that can influence the creation of an improved information management system for persons with disabilities, four types of crisis situations were selected to reflect the diversity of problems encountered in collecting data on this vulnerable population. Context is important because it illuminates the nuances of risks that different crises pose to persons with disabilities and the feasibility of collecting meaningful data in those situations.

The paper concludes by unpacking approaches that allow disability disaggregation and includes recommendations on how to strengthen data availability.

Recent developments in data on disability

Collecting data on persons with disabilities has progressed since the CRPD entered into force in 2008. The principle of "leaving no one behind" embedded in the SDGs is a significant indicator of the political momentum calling for improved data availability on the most-at-risk segments of society, including persons with disabilities. Several indicators in the SDG framework explicitly reference persons with disabilities, and SDG Goal 17 (Partnerships for the Goals) specifically mentions measures intended to improve disability data.[5] However, progress has been slow in view of the legal obligations on States Parties and the shared responsibility of the United Nations to place protection issues like this at the centre of humanitarian action.[6]

The Washington Group on Disability Statistics (WG) is one of the most prominent examples of a concerted effort aimed at improving data on persons with disabilities. One of the city groups established under the United Nations Statistical Commission in 2001, the WG was constituted to address the then urgent need for measures of disability that could be compared across countries. Its mandate is to promote international cooperation in health statistics focusing on disability data collection tools suitable for censuses and national surveys.[7]

The WG has designed a variety of data collection tools, of which the Washington Group Short Set of six questions is recommended for use in identifying persons with disabilities and for disaggregating the SDGs. The UNICEF/WG Child Functioning module is recommended for identifying children with disabilities in surveys and for disaggregating the SDGs that apply to children.

Since the Washington Group Short Set was adopted in 2006,[8] more than 80 countries have reported data collection activities on disability, using the recommended definitions, concepts, standards and methodologies for data about persons with disabilities.[9] Importantly, among these countries, some are considered the highest humanitarian-risk settings in the world.[10]

The Washington Group Short Set has been included in the United Nations Statistics Division's recommendations on population censuses and in the United Nations Economic Commission for Europe's Conference of European Statisticians' Recommendations for the 2020 Censuses of Population and Housing as the method for collecting information on disability. The Global Action on Disability network reaffirmed its support for the WG tools for disaggregation of the SDGs at its meeting in Helsinki in 2018. Continued efforts to promote the tools include an action research project by Humanity & Inclusion to test the use of different WG sets of questions in ongoing humanitarian response situations.[11]

In 2016, the Secretary-General's *One Humanity, Shared Responsibility* report recognized that persons with disabilities are among the most marginalized of any crisis-affected community.[12] In preparation for the World Humanitarian Summit that followed the report's release, 68 Member States, non-governmental organizations (NGOs) and other organizations made individual commitments in the Agenda for Humanity[13] related to persons with disabilities. In May 2018, the Charter on Inclusion of Persons with Disabilities in Humanitarian Action was launched, committing its signatories to "adopt policies and processes to improve quantitative and qualitative data collection on persons with disabilities that delivers comparable and reliable evidence".[14] As a follow-up to the Charter, in July 2016 the United Nations Inter-agency Standing Committee (IASC) endorsed the establishment of a task team to develop IASC guidelines on inclusion of persons with disabilities in humanitarian action, which include guidance on disaggregated data.[15]

In July 2018, the international community reaffirmed the importance of gathering and using better data and evidence during the Global Disability Summit in London, to "understand and address the scale, and nature, of challenges faced by persons with disabilities".[16] Later that year, guidance on strengthening disability inclusion in humanitarian response plans was developed and released for dissemination to inform needs assessments in 2019.[17]

While interest and commitment to improving disability data have grown, at the operational level the situation is more mixed. The CRPD requires its State Party signatories to submit initial progress reports, including on article 11 and article 31. While many of the 49 States reported positive progress in terms of specific programmes or laws to increase the protection and inclusion of persons with disabilities in humanitarian action or disaster preparedness and response as of 24 June 2017, no State highlighted improved data collection in this area.[18]

Since the CRPD came into force in 2008, the five largest United Nations entities engaged in humanitarian action have moved forward at varying speeds to develop or improve their frameworks and operational guidance to promote disability inclusion through disaggregated data. Table 1 outlines the key

operational guidance relevant to disaggregated disability data by the largest United Nations agencies working in humanitarian action developed since that time.

United Nations agencies also work side by side with other actors, including the Red Cross and NGOs. Within this space, *The Sphere Handbook*[19] is a common reference point. Its influential standards, which are voluntary, have been recently revised.

The Sphere Handbook makes a clear case for continuous data collection, where at the minimum, sex-, age- and disability-disaggregated data are collected. In the 2018 updated version, the handbook encourages disaggregation by these three factors (at the least) to design a programme built on quality and accountability. This recommendation applies to all the handbook's standards. Furthermore, three of the six technical chapters contain new specific additions that emphasize the importance of disability-disaggregated data in assessing needs or monitoring performance.

The Sphere Handbook now includes the Core Humanitarian Standard, which also references inclusion in terms of programme design, strengthened local capacity, access to information, and complaints handling, as well as the importance of data disaggregation by sex, age and disability. Through other specialist networks, complementary standards in additional humanitarian areas have been developed and are part of the Humanitarian Standards Partnership,[20] including standards on economic recovery,[21] education[22] and livestock.[23] In these complementary standards, the extent to which disability or disaggregated data is addressed varies but is minimal.

The Humanitarian Inclusion Standards for Older People and People with Disabilities are another example of complementary guidance intended to be used in conjunction with Sphere.[24] Over several years, the broad-based Age and Disability Consortium[25] developed, piloted and then finalized in 2018 these standards specifically adapted to older people and people with disabilities.[26] "Active collection of sex-, age- and disability-disaggregated data" is the first action related to the first key inclusion standard of this tool.[27] In each subsequent chapter of the guidance that discusses sector-specific standards – such as protection and water and sanitation – the first key actions always describe the collection and use of disability data. As with Sphere, compliance with this new inclusion guidance is voluntary.

TABLE 1: Large United Nations operational agencies in humanitarian action

UN agency	Humanitarian focus	Humanitarian guidance, framework or policy contribution	Year	Progress on disability disaggregation
Food and Agriculture Organization (FAO)	Households and food security at population level	• Guidance Note: Accountability to Affected Populations • Framework for Action • Phased Agriculture Livelihood Needs Assessment Framework and Tools	2009 2015 2016	Focus for humanitarian action and building resilience among populations in protracted crisis situations has led to data tools such as the Resilience Index and the Integrated Phase Classification, which are not easily disaggregated
United Nations Children's Fund (UNICEF)	Children, mothers and families	• Child Functioning module for children aged 2 to 17 years • Guidance: Including Children with Disabilities in Humanitarian Action • 2018–2021 Strategic Plan: Results Framework	2016 2017 2017	Investments in the development of child-specific data collection tools complementary to the Washington Group's Short Set and Extended Set of questions for adults. Comprehensive guidance developed to support humanitarian action for persons with disabilities
United Nations High Commissioner for Refugees (UNHCR)	Individual persons of concern	• Registration database codes • Executive Committee acknowledgement of disability inclusion • Age, Gender and Diversity Policy • Need to Know Guidance	2009 2010 2011 2011	First of the five largest operational agencies in the United Nations system to adapt its systems to identify persons with disabilities following the CRPD
World Food Programme (WFP)	Households	• Comprehensive Food Security and Vulnerability Guidance • Food Assistance for Assets for Zero Hunger and Resilient Livelihoods • Protection Guidance Manual • Corporate Results Framework	2009 2016 2016 2016	Guidance specifically addressing disability inclusion is under development. Data focus in vulnerability assessment and monitoring at household (not individual) level, although better tools to identify persons with disabilities considered to have utility for targeting populations in need
World Health Organization (WHO)	Facilities and capabilities of the public health system	• World Report on Disability • Guidance Note on Disability and Emergency Risk Management for Health • Global Disability Action Plan 2014–2021 • Operational Guidance on Accountability to Affected Populations	2011 2013 2015 2017	Advocate for more robust, comparable and comprehensive data collection for persons with disabilities, although its operational systems in humanitarian action are focused on tracking capacity and services at the facilities level

Source: Respective agency websites.

Crisis examples and their disability data implications

The humanitarian system is still in its nascent stage in terms of operationalizing improved information management for persons with disabilities. The diversity of the crises, disasters and emergencies that call for humanitarian action may in part explain this slow uptake. In some of these situations, responders have been continuously engaged for decades and are entrenched in their ways of working. In others, a sudden emergency might catch agency staff unprepared. In this section, four examples of how disability data fit into humanitarian response actions illustrate these points.

The time and place of a humanitarian response have important implications for managing information and collecting data. The type of emergency, accessibility to the affected population, time frame of the situation, speed with which the problem has escalated, and the broader socioeconomic context and local capacities all contribute to the challenges of collecting and using disability data. Issues facing persons with disabilities in different emergency scenarios also vary widely.

The following overview of four humanitarian response scenarios through the lens of disability data provides context to the subsequent section, where the data tools available in the humanitarian programme cycle (HPC) are discussed.

Nepal earthquake (25 April 2015)

Nepal's vulnerability to earthquake risk was well known before the 2015 disaster. While expected, the event occurred with no warning and caused immediate and widespread disruption. For persons with disabilities, this disaster was especially problematic given the new physical, information and communication barriers it created, together with disruptions to their existing support systems and possible separation from peer support networks. Persons with disabilities may have also faced damage or loss of their assistive devices. Many other persons acquired new impairments as a result of being caught in collapsing structures and landslides.

In the first days following the earthquake, a surge of humanitarian actors responded. Initially, understanding of the disaster scenario was poor – which communities outside of Kathmandu were most affected, the status of roads, and so on – and the initial needs assessment process was complicated by frequent and severe aftershocks.

The incoming humanitarian first responders emphasized the provision of rapid, high-quality assistance. But in their hurry to respond, many international NGOs and coordinating structures did not meaningfully include local organizations of persons with disabilities (OPDs) or other key informants.[28] A difficult trade-off existed between the need to rapidly expedite the response (e.g., to locate and rescue people trapped under rubble, or set up the logistics necessary to move supplies where they were needed) and the need for effective local participation and consultation. Humanitarian surge personnel coming in from outside of the country often did not know whom to talk to.

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Characteristics of rapid onset emergencies
(often natural disasters such as earthquakes, floods or storms)

- Massive disruption, poor understanding of the scenario, especially at the outset
- Emphasis on providing rapid, quality aid where the crisis has overwhelmed existing capacity to cope
- Quality of existing data may be questioned, but quick answers and rapid action from international community expected
- People with newly acquired impairments; damage or loss of assistive devices; separation from caregivers

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The Office for the Coordination of Humanitarian Affairs (OCHA) synchronized international humanitarian action following the earthquake. Among other information products delivered to humanitarian actors, OCHA provides ongoing tracking of *which* agencies are doing *what* work, *where*. This 3W:OP[29] analysis for operational planning gives decision makers a tool to assess where gaps may exist in the response. From a rights-based approach to disability, this analysis misses the crucial dimensions of 'how' and 'for whom'. Organizations that work with OPDs could use these two additional dimensions to lower the barriers persons with disabilities face in accessing needed services.

Before the earthquake, limited data had been collected on the situation of persons with disabilities in Nepal. Additionally, available data sources reported very low prevalence of disability[30] – far below the WHO global estimate of 15 per cent.

These limitations in available data were due to "a lack of financial and technical capacity, geographic limitations to data collection, and a variety of social stigmas that lead to underreporting".[31] Collecting data in Nepal is a complicated and expensive process bec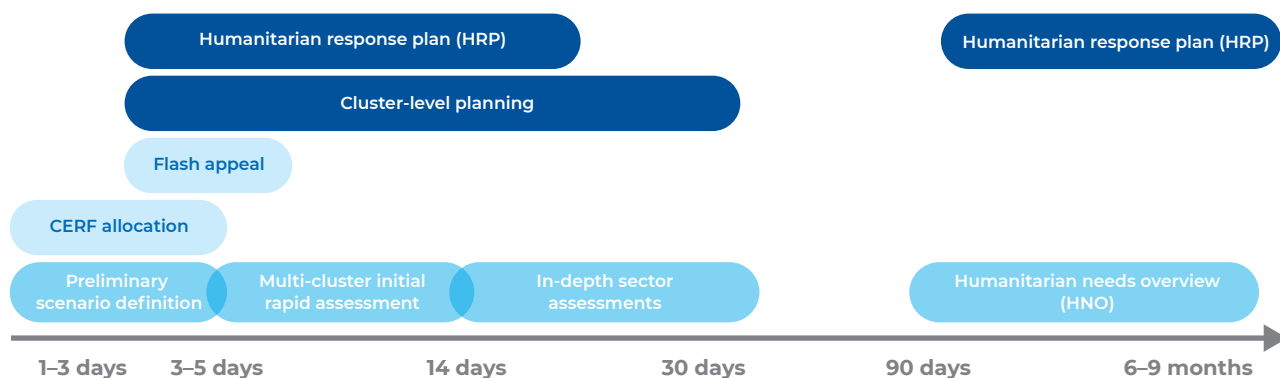ause of poor accessibility to communities outside the Kathmandu valley. Additionally, a high degree of social stigma continues to exist in Nepal that also results in underreporting related to persons with disabilities.

In the immediate aftermath of the earthquake, the availability of data did not improve, including figures on the number of persons with disabilities affected by the earthquake or on those who acquired an impairment as a result of the earthquake. Persons without disabilities may have exaggerated their situation in the hope of getting benefits. "Given widespread poverty and the rampant levels of misrepresentation and fraud that accompanied the distribution of relief materials in many areas," where disability was used as targeting criteria, persons without disabilities had an incentive to falsely represent themselves.[32]

Ensuring that good quality data are available to emergency responders following rapid onset disasters is a recurring recommendation in terms of preparedness throughout the Sendai Framework for Disaster Risk Reduction.[33] Planning tools like the INFORM risk database[34] have been established to provide humanitarian actors information on where to invest in appropriate preparedness measures, like disaggregated data collection, in the highest-risk settings.

Figure 1 illustrates a typical timeline in a rapid onset emergency like the Nepal earthquake. In this type of crisis, the time available for planning from the point when the disaster occurs is extremely short. Emergency responders have only a few days to react with flash appeals for resources and the development of a humanitarian response plan. The tools humanitarian actors use for estimates at this stage are generally based on existing, pre-crisis secondary data. Needs assessments use key informants and/or non-probability sampling techniques that do not lend themselves to producing estimates that can be disaggregated by disability and can be generalized to the overall population of persons with disabilities.

FIGURE 1: Phases of needs assessment in humanitarian action

Humanitarian response plan (HRP)

Humanitarian response plan (HRP)

Cluster-level planning

Flash appeal

CERF allocation

Preliminary scenario definition · Multi-cluster initial rapid assessment · In-depth sector assessments

Humanitarian needs overview (HNO)

| 1–3 days | 3–5 days | 14 days | 30 days | 90 days | 6–9 months |

Somalia (1991–present): Protracted and complex crisis

Somalia is one of several ongoing crises in which intensity ebbs and flows but has not disappeared over a long period of time. Unlike a transient natural disaster such as Nepal's earthquake, the underlying conflict that perpetuates Somalia's crisis continues to simmer and occasionally spikes since it began in 1991 with the overthrow of Mohamed Siad Barre. Somalia's ongoing emergency is further complicated by the fragility of its state institutions, the vulnerability of its natural environment, radicalism and geopolitics. Somalia has appealed to the international community for humanitarian assistance every year for decades.

Between 2002 and 2013, 86 per cent of all resources requested through United Nations appeals were destined to humanitarian action in conflict situations like the one in Somalia.[35]

The impact of Somalia's humanitarian crisis on persons with disabilities is enormous and widespread. This includes internal displacement, diminished livelihood opportunities and the consequent food insecurity, and absence of key services such as health and education. The conflict continues to generate additional injuries, with one estimate of 7,000 new cases annually resulting from landmines and explosive remnants of war alone.[36] While injuries should not be equated with disability, disability is seen as primarily a war issue, with attention mostly focused on veterans with acquired physical impairments. Persons with disabilities whose impairments were not caused by the conflict and persons with sensory, psychosocial or intellectual disabilities tend to be overlooked, despite the fact that they represent a "particularly marginalized and vulnerable group who are subjected to a myriad of abuse, including unlawful killings, rape, forced marriage, and other forms of sexual violence, forced evictions, and limited access to health services, food and water, and other essential services".[37]

For humanitarian actors, protracted crises present a systematic challenge. Conflict situations, which frequently characterize prolonged crises, mean humanitarian actors have limited access to the communities where the aid is needed due to security constraints. This has a negative impact on community participation in terms of consultation and design of response activities. In communities too dangerous to operate in, international humanitarian actors are forced to manage their projects indirectly or hire third-party monitors to help track activities.

Although huge volumes of aid are required to respond to the crisis year after year, the nature of the funding architecture that provides aid has focused only on short-term programming, with funding cycles rarely lasting more than a year at a time. As a result, project monitoring and evaluation seldom look far beyond the delivery of activities and outputs. In Somalia, needs assessments are carried out year after year on an annual basis. Although time is available for more in-depth needs assessments between one humanitarian response plan and the next, data collection can be hindered by security concerns and reduced mobility.

Data describing Somalia's demographics are limited because of the decades-long conflict, with the last limited census occurring in 1975.[38] Statistics on the number of persons with disabilities are non-existent. Data collection challenges are numerous. First, populations who move around a lot because of their nomadic pastoralist livelihoods, or to avoid being caught in fighting, are hard to track. Second, access to conflict areas is limited. It might simply be too dangerous to operate safely in the area. In these contexts, large-scale surveys pose major challenges.

The engagement of the international community is critical to address some of these data collection issues. In 2014, the United Nations Population Fund undertook a nationwide survey in Somalia on behalf of the Government to collect information on the characteristics of the Somali population, including sex and age but not disability.[39] In 2015, UNHCR undertook a profiling exercise to better understand the characteristics of internally displaced persons in Hargeisa, the capital and largest city in Somaliland;[40] the exercise revealed that only between 2 per cent and 5 per cent were identified as persons with disabilities. However, the questionnaire[41] used to identify the population of persons with disabilities reflects an outdated approach to measuring prevalence, which is known to underestimate the size of the affected population.[42]

Many humanitarian actors working over the long term in Somalia do have a well-established presence, usually in a specific geographic-focused area, to promote better community relationships that also improve security. The disadvantage of these arrangements is that the different service providers working across the country have different priorities, technical competencies and approaches. The humanitarian cluster system, organized by sectors and coordinated through an inter-cluster coordination group,[43] is meant to bridge this gap. However, the different technical mandates of the agencies that lead these clusters and the lack of standardized information management approaches make the integration of a cross-cutting issue like disability difficult.[44]

This is especially true for disability-related data. Large operational agencies such as UNICEF or WFP can require the smaller organizations they fund to report regularly on specific indicators describing their activities. Much progress has been made in information management but large gaps remain in collecting relevant disability data and aggregating them at the country level.

An 8-year-old boy awaits a food distribution at a feeding centre for people with disabilities in Mogadishu, Somalia. He lost his leg five months before when a bomb exploded in the city centre.

Characteristics of protracted and complex crises (often involving displacement, conflict or other complicating factors such as food insecurity or health emergencies)

- Access to affected population may be limited; many service providers with varying commitments, priorities and technical competence
- Some actors may be compromised by or implicated in fighting; international humanitarian engagement plays a unique role in delivery, protection and advocacy
- Serious data coordination issues; the humanitarian cluster system silos technical sectors, making cross-cutting issues like disability harder to integrate
- Challenges in identification and protection of the population of persons with disabilities because of stigma or social marginalization

Bangladesh (25 August 2017–present): Rohingya refugee crisis

Refugees are often a consequence of a complex emergency like the one described in Somalia.[45] Since 1991, between 5 million and 7 million people worldwide have spent more than five years in exile.[46] As of June 2019, UNHCR reports approximately 25.9 million registered refugees.[47]

The mass exodus by the minority Rohingya ethnic group in Myanmar was triggered in 2017 by violence and reprisals following coordinated attacks by militants in Rakhine State. Large numbers of people crossed into neighbouring Bangladesh seeking shelter, with 647,000 people arriving in just over four months.[48]

This rapid influx of asylum seekers – displaced into the periphery of a neighbouring country – caused an immediate humanitarian crisis. Bangladesh had no institutional structures in place with the capacity to deal with such a huge number of people, and called on the International Organization for Migration to take on the organizational leadership of the crisis, in collaboration with UNHCR, to quickly set up temporary settlements.

As refugees streamed across the border between Myanmar and Bangladesh at an average rate of more than 5,000 people per day in the early stages of the crisis, humanitarian actors prioritized meeting their basic needs: shelter, food and water. UNHCR standard operating procedure is to carry out an immediate Level 1 registration[49] of all new arrivals at the family or individual level, which includes:
• Household or family size
• Age cohorts by sex
• Physical address
• Names
• Origin
• Specific needs within the household or family

Identifying specific needs means that even at this early stage of a refugee crisis, data collection takes place with the potential for disability disaggregation. The humanitarian response plan that was prepared soon after the onset of the crisis included commentaries on the impact on persons with disabilities in a fairly systematic manner. This included, for example, rapidly mapping new settlement sites and activities from the perspective of ensuring equal access to persons with disabilities and identifying where services and shelters were not suitable or created functional barriers, placing persons with disabilities at risk.[50] The October 2017 Humanitarian Response Plan also attempted to disaggregate its response strategy by sex, age and disability, although the outcomes identified were not specifically related to persons with disabilities.

The Rohingya refugee crisis focused primarily on individuals and families. From a disability data management perspective, this created scope for follow-up and collection of additional information at later points. In UNHCR registration protocol, the initial Level 1 data collection exercise is followed by more detailed data collection where additional information is gathered, including photographs or biometric data to identify individuals. In contrast to the Somalia case study, where hundreds of humanitarian actors interact with the affected population according to their own processes and interests, this registration process in a refugee situation offers the potential for far greater data comparability. It also creates potential efficiency gains where multiple actors can share information to avoid repetition of data collection exercises.

Questions remain as to how much data sharing took place in the Rohingya crisis, especially in terms of which humanitarian actors have access to individual data collected by UNHCR. Serious data privacy and data security concerns exist with regard to individually identifiable records. However, even preliminary estimates of the prevalence of persons with disabilities would be useful to better target follow-up activities. An assessment in late 2017 that looked at age and disability inclusion reported that humanitarian actors were collecting their own data, but only limited information was disability disaggregated.[51] The same assessment alleged, "persons with disabilities and older persons had not been identified by camp management and their specialized needs were not recognized or addressed," which highlights a significant challenge implicit in the registration process.

> **Characteristics of classic refugee response operations**
>
> - Range of possible settings, with long-term displacement common in many cases (by the end of 2018 there were 15.9 million people in protected displacement)
> - Initial registration, then follow-up (opportunities for service point individual data collection)
> - Data privacy concerns
> - Access to services through the reduction of functional barriers

European migrant and refugee crisis (summer 2015)

As in the case of the Rohingya crisis, one of the origins of the European migrant and refugee crisis was conflict. The Syrian civil war had created a large refugee population congested in neighbouring Iraq, Jordan, Lebanon and Turkey that largely overwhelmed these countries' capacity to cope, even with massive assistance by the international humanitarian system. There were also real concerns that resources would run out and humanitarian actors would not be able to address refugees' basic needs. In October 2014, Jordan declared it would accept no more Syrian refugees. When it reached 1.6 million refugees, Turkey announced in November 2014 that it was unable to cope. In December, the United Nations said that it had exhausted resources to provide additional food vouchers to refugees. Because of these growing pressures, the refugees themselves were taking risks to resettle in places farther afield, sometimes involving great danger.

In May 2015, political-level discussions within the European Union about migrant quotas took place, which were soon followed by measures by some European Union members to erect physical barriers along their borders to prevent irregular migrants from crossing into their territory. In July 2015, Hungary began building a fence along its Serbian frontier to limit freedom of movement. The next month, Germany announced that Syrian asylum seekers were welcome. This led to an additional pull factor for migrants and refugees to push forward and move as quickly towards Germany as possible before their transit routes were cut off through countries on the route towards northern Europe.

Like other displacement emergencies, there was a lack of formal procedures to identify affected populations with disabilities at the various reception centres where preliminary Level 1 identification took place. Being identified as a person with a disability is key to accessing the specialized support that was being provided along the way,[52] including reasonable accommodations and adjustment[53] to procedures. But because of the speed with which the movement was happening, persons with disabilities who did not have a visible impairment often remained undetected by registration officials during these initial contacts or were sometimes undisclosed by individuals fearing the impact on their status. Various identification practices by different humanitarian actors resulted in many persons with disabilities being identified in an informal or ad hoc manner. As a result, there are no disability-disaggregated data for the crisis, and many persons with disabilities have remained unidentified in practice, according to the European Union Agency for Fundamental Rights.[54]

Characteristics of developed country emergency settings (e.g., European migrant and refugee crisis)

- Affected populations may seek anonymity, more desire (and legal obligations) for privacy; concerns about sharing of personal data putting status at risk
- Challenges linking affected people with disabilities to appropriate services; knowing what kinds of services are required and for how many

The European migrant and refugee crisis posed three unique challenges from a humanitarian data perspective. First, there was no way to accurately quantify the size of this population. No one knew how many people were leaving countries of first asylum or were already on their way. Given the informal routes that were being followed, it was difficult for humanitarian actors to differentiate migrants and refugees from host communities. The affected populations moving up the Balkans would sometimes spend only a few hours in a country before moving on to the next.[55] Given the rush to reach Germany before borders were closed, many individuals avoided service providers and other officials who might have caused a delay. Many individuals were reportedly reluctant to share personal data, a step they feared might put their status at risk.

A second major challenge was coordination. For people who were initially registered at a Greek reception centre, for example, sharing data with the other countries along the route presented difficulties. There could be no formal handoff as individuals crossed frontiers, especially when migrants and refugees entered the Schengen area where internal border controls were absent. When data were collected by a particular humanitarian actor along the way (UNICEF, for example, established child-friendly rest points), there was no mechanism for coordination, especially in terms of tracking at-risk people or the services they received in the multiple countries involved.

Third, as in the many other humanitarian contexts, the quality of data was questionable. The migrants and refugees were originating from many different countries, with Syrians being the majority, but with large numbers from Afghanistan, Eritrea and Iraq as well as many from West Africa and elsewhere.[56] The diversity of languages spoken by the migrants made it difficult for humanitarian actors to communicate. In addition, some people were reluctant to share accurate information due to the differing legal status of refugees and migrants, leading to inaccuracies or misreporting of information.

Context matters with humanitarian data collection

These four case studies illustrate important disability data issues related to a range of humanitarian response situations. It is clear that the context of the crisis matters. Several conclusions can be drawn. First, while more accurate and comprehensive pre-disaster demographic data are useful for planning a response and informing a needs assessment – especially in the early stages – such data are often sparse or unavailable. Of the four examples, only in Nepal's case did a stable enough situation exist pre-crisis where such data could have been collected. In the other three crisis examples, there was no way to know the number of persons with disabilities. In these high humanitarian-risk locations, disaster preparedness investments to produce more disability-inclusive data would pay some dividends.

A second issue is methodology. When data were being collected, different understanding and definitions of disability were used to inform the process. As mentioned earlier, in Somalia, for example, the questionnaire used by UNHCR to identify persons with disabilities only allowed respondents to report on whether they had a "physical" and "mental" disability.[57] During the European migrant and refugee crisis, due to the volume and haste in the registration process along the route, persons with disabilities were identified based on information provided by individuals themselves or as a result of observations from the personnel involved in the screening and registration processes.[58]

A 15-year-old boy using a wheelchair waits at a refugee processing centre in Vienna, where his family is applying for asylum. Refugee and migrant flows into Europe remain at an unprecedented high. Many asylum seekers are escaping conflict and insecurity in their home countries.

Data sharing and coordination were additional issues in each case. Because external actors tend to operate in silos, there are calls for agencies focused in different domains to work together more closely as part of the Grand Bargain humanitarian reform process.[59] The humanitarian system grapples with this challenge in a variety of ways. OCHA is investing in a Humanitarian Data Exchange (<www.humdata.org>) to serve as a data-sharing platform for humanitarian actors. During the Nepal earthquake response, a range of United Nations agencies and NGOs collaborated on a joint survey methodology to monitor accountability to affected populations collectively, rather than each agency investing in a separate process. OCHA has also launched the Centre for Humanitarian Data[60] to increase the use and impact of data in the humanitarian sector. Comparability of data is an issue but equally important is access to the data that another agency collects.

Finally, three of the four examples illustrate a failure of States to meet their legal obligation to collect suitable disability data under the CRPD. Somalia is not a signatory, but all the other countries involved in these crises were. The CRPD requires for States "to ensure the protection and safety of persons with disabilities in situations of risk" (article 11) and to "undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" (article 31). The four examples illustrate the challenging range of contexts in humanitarian response. Where there is only weak state capacity to meet these obligations, the international community should step in to help close the gap. In doing so, these humanitarian actors should structure their support to Member States in a way that would help them meet the commitments they have made under the CRPD.

The next section looks at the broad array of data tools and products that exist to support the HPC, the management approach that allows different actors to coordinate when addressing needs in the same crisis context.

Data and the humanitarian programme cycle

A concerted response to a humanitarian crisis is challenging. The Nepal and Somalia case studies illustrate the need for coordination among humanitarian responders. Without shared vocabulary and standard operating procedures, there is great risk of overlap, delays, conflict over leadership or competition over financing the response. One remedy has been bringing a critical mass of the international humanitarian system on board to a common programming cycle. The idea is to break down the humanitarian response into stages or steps that make up the response from actions that need to happen in preparedness for an emergency, through to evaluation of results. Known as the HPC, this process promotes better coordination and is a key element of the transformative agenda within the international humanitarian system "to improve the effectiveness of humanitarian response through greater predictability, accountability, responsibility and partnership".[61] The speed with which responders move through the steps depends on the humanitarian context. In the case of a rapid onset natural disaster such as the Nepal earthquake, it may take only months for the situation to stabilize and only a few seasons for a country to return to its pre-crisis state. But for a protracted crisis situation, such as the complex conflict in Somalia, the steps in the cycle have become entrenched in an annual routine that has been repeated for decades.

The IASC Guidelines provide a comprehensive overview of how to use and manage data in the HPC.[62] Table 2 provides examples of the kinds of instruments organized by the point in the HPC where they can be found, linking these to the different information products they are associated with.

The left columns of Table 2 describe the main humanitarian response information management products the system generates at each stage of the HPC. Time frames differ in the case of refugee emergencies,[63] rapid onset disasters and protracted humanitarian responses.[64] Although UNHCR's programme cycle is similar to that of the rest of the humanitarian community, its data collection processes, tools and information run parallel rather than in tandem with others. The column on the right includes a selection of data tools used by humanitarian actors at different HPC stages. United Nations agencies, humanitarian clusters and NGOs have tended to develop their own methods according to their missions and mandates.

Many of the tools referenced in Table 2 recommend data disaggregation in some form. The majority are specific about the need for sex and age disaggregation, with a general recommendation made to also consider the needs of other vulnerable groups, but generally without any specificity about what this should entail. In many humanitarian contexts, persons with disabilities might fall into this category of other vulnerable groups but definitions of the disability concept vary widely and are not consistent. Notable exceptions to this are UNHCR's emergency procedures,[65] including its Specific Needs Codes used in the registration process[66] as well as the current version of IASC's Humanitarian Needs Overview/Humanitarian Response Plan templates.[67] Two other tools that have elaborated disability well are the UNICEF guidance for including children in humanitarian action[68] and the Humanitarian Inclusion Standards for Older People and People with Disabilities.[69] These two resources are not included in Table 2 as they are both written to respond to different phases across the HPC.

In the HPC, the role of data generally is to provide an analytic foundation that allows key questions to be answered and inform the humanitarian response:
• Who and how many people face humanitarian risks?
• Where are these people?
• What do their survival and livelihood problems consist of?
• Why are these problems occurring (both because of immediate causes, as well as because of underlying, intersecting or structural inequalities)?
• What is being done to address these needs?
• How are the needs expected to evolve in future, based on ongoing and planned responses and other events?
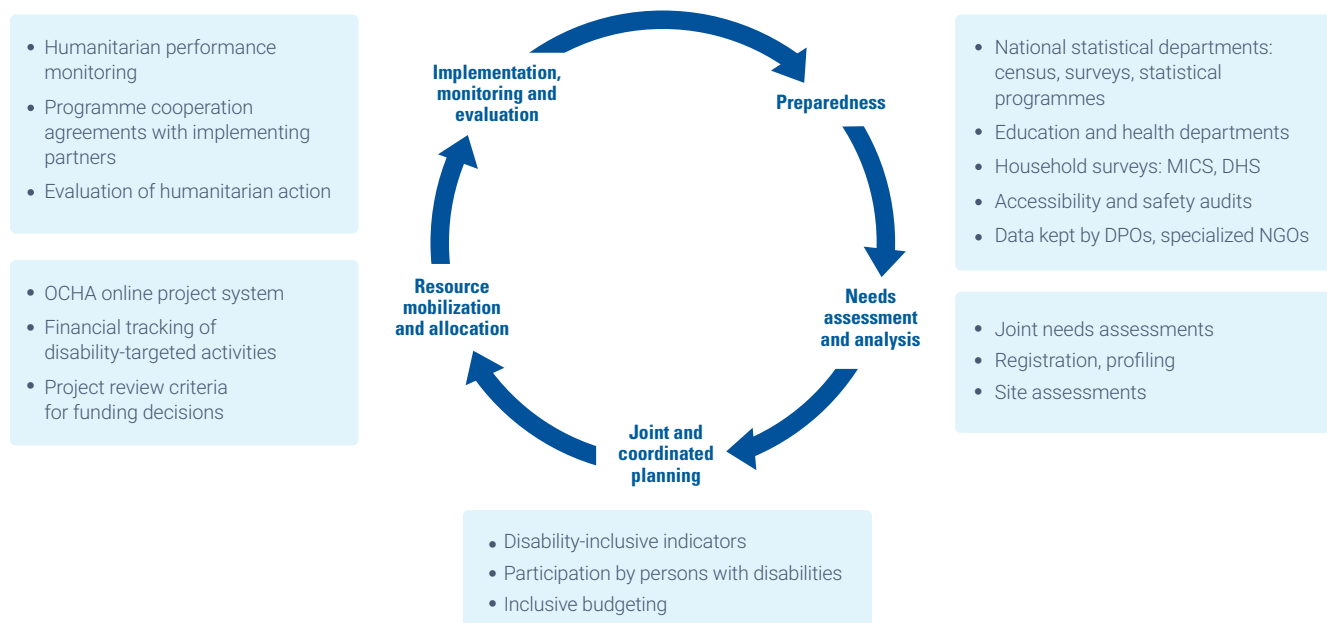
There are various entry points along the HPC where disability data would be particularly useful to answer these questions. Figure 2, on the next page, illustrates existing and potential points where disability data could feature at different stages.[70]

TABLE 2: General data tools and the humanitarian programme cycle

Humanitarian programme/operations management cycle stage, products, time frames				Tools, guidance and data sources
Preparedness • Minimum preparedness actions (needs assessment) • Advanced preparedness actions (needs assessment, scenario-based contingency plans)				• Common operational data set (OCHA, national governments) • National censuses (national statistical authorities) • Demographic and Health Surveys, Multiple Indicator Cluster Surveys or other national surveys • Early warning information management systems and risk registers • National information systems (national ministries, e.g., health, education)
	Refugee emergency	Sudden onset	Protracted crisis	
Needs assessment and analysis • Preliminary response plan (Day 3–5) • Humanitarian needs overview	Day 1–2	Day 3–14	September	• Multi-sector Initial Rapid Assessment (IASC/MIRA) • Humanitarian Needs Overview template 2020 (IASC) • Good Enough Guide (ECB project) • Needs Assessment for Refugee Emergencies (UNHCR/NARE) • Emergency Food Security Assessment (Food Security Cluster/EFSA) • Health Resource Availability and Mapping System (Health Cluster/HeRAMS) • The Humanitarian Emergency Settings Perceived Needs Scale (WHO/HESPER) • Registration database (UNHCR/proGres) • IDP profiling exercise (UNHCR) • Heightened Risk Identification Tool (UNHCR/HRIT) • Protection Mainstreaming Toolkit (Global Protection Cluster) • Survey of Surveys (ACAPS) • Joint Inter-agency Analysis Framework (JIAF/JIAG) • Vulnerability Assessment Framework (VAF/UNHCR) • Displacement Tracking Matrix (DTM/IOM) • Joint IDP Profiling Service Essential Toolkit (JIPS)
Joint and coordinated planning • Humanitarian response plan • Refugee response plan • Comprehensive Refugee Response Framework	Time available for initial planning extremely constrained	Day 14–30	November	• Humanitarian Response Plan template 2020 (IASC) • Step-by-Step Practical Guide for Humanitarian Needs Overviews, Humanitarian Response Plans and Updates (IASC) • Humanitarian Indicator Registry (IASC) • Emergency Handbook (UNHCR)
Resource mobilization and allocation • Overview of humanitarian requirements • Consolidated humanitarian appeal • Global appeal • Humanitarian Action for Children		Day 20–60	December	• Online Project System (OPS/OCHA) • Financial Tracking Service (FTS/OCHA) • Policy markers, etc. (International Aid Transparency Initiative, IATI)
Implementation, monitoring • Operational peer review • Periodic monitoring report • Situation reports • Donor reports • Cooperation agreements		Day 30–90 through Month 9	April	• Humanitarian performance monitoring (UNICEF) • Distribution monitoring (UNHCR, WFP) • Post-distribution monitoring (UNHCR, WFP) • Field monitoring checklists (WFP) • Output Tracker (Save the Children) • Community perception survey (Ground Truth) • Constituent Voice (Keystone Accountability) • Minimum monitoring requirements (WFP)
Operational peer review and evaluation • Real-time evaluation • Inter-agency evaluation • Learning review (after action review)		Month 12		• Rapid and Timely Humanitarian Evaluation (UNICEF) • Rapid Accountability Review (CARE) • Participatory Review and Reflection (ActionAid) • Post-intervention studies (Plan International) • Contribution to Change (Oxfam) • Real Time Review (Save the Children) • Response Performance Summary (CARE)

Source: Respective agency/organization websites.

FIGURE 2: Disability data entry points in the humanitarian programme cycle

- Humanitarian performance monitoring
- Programme cooperation agreements with implementing partners
- Evaluation of humanitarian action

- OCHA online project system
- Financial tracking of disability-targeted activities
- Project review criteria for funding decisions

Implementation, monitoring and evaluation

Resource mobilization and allocation

Preparedness

Needs assessment and analysis

Joint and coordinated planning

- National statistical departments: census, surveys, statistical programmes
- Education and health departments
- Household surveys: MICS, DHS
- Accessibility and safety audits
- Data kept by DPOs, specialized NGOs

- Joint needs assessments
- Registration, profiling
- Site assessments

- Disability-inclusive indicators
- Participation by persons with disabilities
- Inclusive budgeting

Source: 'Strengthening Collection and Use of Data on Persons with Disabilities for Inclusive Humanitarian Action', workshop held 9–10 May 2019, The Hague Humanity Hub, The Hague, Netherlands (<centre.humdata.org/wp-content/uploads/2019/07/DisabilityDataWorkshopReport.pdf>).

Although many tools used in the humanitarian community do not provide much guidance on disability data, there are obvious points of value addition for disability at each step in the HPC:

Preparedness

Data preparedness may involve curating existing secondary data sources, including government surveys or information on persons with disabilities collected by specialized organizations or projects, so that they are readily available in the event of a crisis. Preparedness might also involve the collection of new data relevant to persons with disabilities, such as mapping accessible public facilities.

Needs assessment and analysis

The overall IASC guidance for needs assessments recommends a more coordinated approach among humanitarian actors and across programming sectors.[71] In many humanitarian contexts, persons with disabilities should be identified as a distinct population subgroup.[72]

Data that describe the specific needs and heightened risks faced by persons with disabilities would lead to their more complete inclusion in the response. For example, what barriers do persons with disabilities face in accessing assistance? In protracted crisis situations, it may be useful to reflect on how effective the response has been in reducing vulnerability and

enhancing resilience of persons with disabilities. Also, over time, the humanitarian situation may have changed.

Despite IASC guidance to undertake a joint assessment, Table 2 illustrates how diverse the existing tools and data sources are for needs assessment. Different humanitarian actors have developed approaches closely aligned to their own technical mandates, and these might have little to do with persons with disabilities. For example, the current Emergency Food Security Assessment (EFSA)[73] tool used by the Food Security Cluster does not envisage disability disaggregation nor does the Health Cluster's Health Resources Availability Mapping System (HeRAMS).[74] The EFSA considers the impact of the crisis on food security generally, without detailed reference to specific vulnerable groups. HeRAMS is used to track the number of points where health services are delivered and although it could track accessibility of facilities to persons with disabilities, none of the currently recommended indicators actually capture this information.

The JIAF now under development following the World Humanitarian Summit in 2016 aims to complement the Multi-sector Initial Rapid Assessment (MIRA) guidance process by providing a common foundation across sectors for needs assessment analysis to occur. JIAF potentially offers an entry point for reflecting on the impact of the crisis on those with disabilities in terms of risk factors and barriers they face. The

framework will consider the broader humanitarian context, the specific event or shock that precipitated the crisis, as well as the impact of this shock on the people affected. JIAF's people-centred focus, which aims to differentiate the severity of needs, is an important value addition to the needs assessment process. Disability is proposed as one important criterion that will be used to distinguish risk factors that households face.

Joint and coordinated planning
Data disaggregated by disability can highlight the impact of disability on vulnerability to food insecurity, violence, exploitation and abuse, or other risks. Qualitative data on views and perception of persons with disabilities are important for informing the design of an inclusive and appropriate response.

Resource mobilization and allocation
Data on persons with disabilities can contribute to resource mobilization by highlighting the impact of the crisis and the specific or heightened risks for individuals with disabilities and their households, as well as total estimated number of persons with disabilities affected by the crisis and requirements for accessibility.

The humanitarian Financial Tracking Service (FTS) currently has no mechanism to track how contributions were used to aid persons with disability,[75] however, the opportunities provided to donors and humanitarian actors that join the International Aid Transparency Initiative (IATI) could provide a platform for better, more specific tracking.[76]

Implementation, monitoring
Implementation monitoring data should identify how humanitarian assistance reaches persons with disabilities and how their needs change as the crisis evolves.

Evaluation
In evaluating the overall humanitarian response, using disability data to assess the extent to which persons with disabilities accessed assistance is a relevant perspective, especially when considering whether the response reduced risk and enhanced resilience of persons with disabilities.

There are numerous entry points for disability data in the HPC as well as a plethora of existing data tools used by different actors. The type of data needed depends on the decisions or actions it will inform.

Disability-inclusive humanitarian indicators and methods

In a data taxonomy, qualitative and quantitative data are the two broadest categories. Both types of data potentially answer important questions in terms of how persons with disability experience humanitarian action.

Quantitative data, information that can be measured and calculated
• Identification of individuals with disabilities and calculation of total number of persons with disabilities among the affected population
• Determination of the number and location of accessible (or inaccessible) facilities
• Humanitarian needs and risks
• Monitoring data on access to assistance
• Protection monitoring data showing human rights violations experienced by persons with disabilities

Qualitative data, information that is descriptive
• Views and priorities of persons with disabilities
• Focus group discussions and key informant interviews with persons with disabilities to better understand risks and barriers faced and the underlying factors contributing to these
• Policy analysis and document reviews to identify specific risks faced and barriers to accessing assistance and services
• Protection monitoring data showing human rights violations experienced by persons with disabilities
• Knowledge, attitudes and perceptions of humanitarian actors and communities regarding persons with disabilities
• Mapping of service providers

To improve data on persons with disabilities in humanitarian action, two issues need to be addressed: first, broadening the types of disability questions that need answers in humanitarian action, and second, improving approaches used to collect the data so as to avoid problems of bias, discrimination and fear.

Humanitarian indicators

Through OCHA, the IASC maintains an indicator registry[77] focused on humanitarian action. As of mid-2019, the registry was very weak in its treatment of indicators applicable to persons with disabilities. Each of the IASC global clusters are responsible for proposing their own indicators. As of June 2019, the library included 428 indicators. But of these, only 25 (6 per cent) recommend disaggregation by disability. An additional 13 indicators are somewhat relevant to disability.
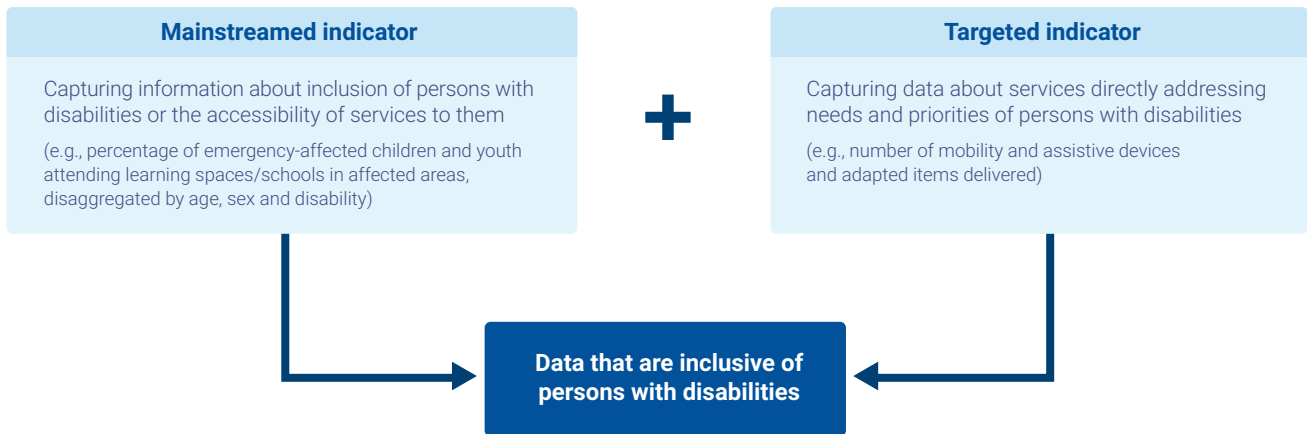
For example, a camp coordination and management cluster indicator counts the "number and percentage of displacement sites that have functioning health services within walking distance that IDP populations can attend".[78] Here, the idea of functioning and walking distance both have implications to accessibility, which has obvious relevance to persons with disabilities and their access to these services. The methodology for this indicator recommends that qualitative data be used to compare the inventory of health service sites that may not be accessible to everyone, including persons with disabilities. Although the indicator registry is currently very limited, the platform itself has considerable potential as a common indicator resource for defining data to track specific activities, outputs or results.

Some humanitarian activities are specifically designed for and targeted towards persons with disabilities. For example, a mine action project may plan on distributing assistive devices or adapted items for the benefit of a certain number of persons affected by explosive remnants of war.[79] A project's monitoring tools then tally progress against the planned activities. Currently, humanitarian projects specifically targeted at persons with disabilities use this approach with direct service delivery activities.[80]

Activities in humanitarian action that are specifically targeted towards persons with disabilities are relatively rare. However, implementation data being collected about mainstream humanitarian activities could be adapted to track targets in a way to monitor how inclusive these activities are to persons with disabilities. In the education sector indicators, for example, a mainstream activity might recommend the disaggregation of data rather than setting a specific target. The indicator, "percentage of emergency-affected children and youth attending learning spaces/schools in affected areas" could be designed to disaggregate not only by age and sex, as recommended, but also by disability.[81]

The idea of disability-specific indicators and others that are disaggregated by disability has been described as a twin-track approach, as outlined in Figure 3. A humanitarian response should include actions to improve accessibility of assistance, as well as specific actions targeting persons with disabilities. Together the two approaches should enable access to humanitarian assistance by persons with disabilities on an equal basis with others. The organization of disability data needs to follow this same approach.

FIGURE 3: A twin-track approach to disability data

Mainstreamed indicator	Targeted indicator
Capturing information about inclusion of persons with disabilities or the accessibility of services to them	Capturing data about services directly addressing needs and priorities of persons with disabilities
(e.g., percentage of emergency-affected children and youth attending learning spaces/schools in affected areas, disaggregated by age, sex and disability)	(e.g., number of mobility and assistive devices and adapted items delivered)

+

Data that are inclusive of persons with disabilities

Source: Adapted from UNICEF, Including Children with Disabilities in Humanitarian Action, 2017.

Methods

Any data collection exercise that gathers information about individuals can and should be designed to capture information about persons with disabilities. However, data collection tools currently used by humanitarian actors rely on oversimplified or partial definitions of disability and are prone to misunderstanding. For example, in Somalia a UNHCR profiling exercise to better understand the situation of internally displaced persons asked yes/no questions about whether respondents had physical or mental disabilities, or seeing or hearing impairments.[82] This resulted in a low prevalence rate of 1 to 3 per cent. Similarly, the national census in Nepal that was available to humanitarian actors following the earthquake estimated the disability prevalence rate at less than 2 per cent.[83] It asked household heads, "What is the physical or mental disability?", giving enumerators several answer code choices for each household member.

The Washington Group's Short Set methodology is intended to provide a more standard approach to collecting disability data that would overcome the types of issues seen in the Somalia and Nepal examples. The questions were designed for national censuses and surveys, and have been tested and shown to reduce issues of bias, stigma and misunderstanding. The Short Set can be used any time individual data are gathered, such as individual refugee registration or during a household survey in the course of a multi-cluster needs assessment process.

Washington Group on Disability Statistics, Short Set of questions (excerpt)

Introduction: The next questions ask about difficulties you may have doing certain activities because of a health problem.

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)?

Each question has four response categories, which are read after each question. "1. No, no difficulty; 2. Yes, some difficulty; 3. Yes, a lot of difficulty; or 4. Cannot do it at all."

Source: See <www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-2-The-Washington-Group-Short-Set-on-Functioning.pdf>.

Conclusions and recommendations

While significant political momentum exists to improve disability data, progress to conform to CRPD articles 11 and 31 at an operations level has been uneven. An important question is whose responsibility it is to collect and use disability-disaggregated data in humanitarian actions. In many crisis contexts, the affected State is at a vulnerable point with limited capacity to uphold its commitments to the CRPD. United Nations agencies aiming to fill the gap have a duty to support affected Member States to help them fulfill their responsibilities. Following this logic, the policies and guidelines that define humanitarian action for the large operational agencies need to comply with the CRPD, at the very minimum to include disability-disaggregated data.

The international humanitarian system is now at a moment of dynamic change, with ongoing work to address the many commitments made at the Global Disability Summit and the World Humanitarian Summit, including the Charter on Inclusion of Persons with Disabilities and the Grand Bargain process. The international system is becoming more united in its response to emergencies, with progressively clearer guidance on how humanitarian action needs to be undertaken and managed. This presents an opportunity to redefine how and where disability-disaggregated data fit in the HPC through processes such as Multi-sector Needs Assessments and using a JIAF that incorporates disability as an explicit factor in calculating severity of needs.

The case studies presented in this paper illustrate the kinds of recurring data challenges that responders encounter when limited time is a real constraint, including at the early stages of humanitarian action. But even in these situations, there are ways to improve data collection processes.

Data about the service and facility accessibility for persons with disabilities provide a useful complement to individual-level data. In line with the CRPD and the international community's responsibility to help affected States uphold their responsibilities, all humanitarian actions should be accessible by design. Adding specific accessibility indicators or modifying existing indicators to allow disaggregation would help humanitarian actors monitor their performance in accessibility.

Activity and output data are the most frequently used data within the humanitarian system. Very little of the available data are currently relevant to persons with disabilities as so few activities specifically target these groups. But with many mainstream activities, wide scope exists to make these data more disability inclusive.

It is critical to distinguish between different at-risk groups to uphold humanitarian principles. Insisting that different forms of disability data are used in mainstream HPC processes will help reduce the barriers to assistance persons with disabilities encounter at times when they need it the most.

Recommendations on how to strengthen the availability, quality and use of data on persons on disabilities

- **Develop guidance on strengthening data collection to enhance inclusion of persons with disabilities in humanitarian action.** Guidance for humanitarian agencies with respect to programming for persons with disabilities is growing, and disaggregated data are increasingly becoming important. But evidence confirms that the tools are applied inconsistently across humanitarian contexts.[84] Use of the WG data collection tools in the HPC and/or relevant data collection efforts should be prioritized.

- **Promote participation of and accountability towards persons with disabilities and OPDs in efforts related to data collection and decision-making processes.** Humanitarian first responders feel a strong personal and organizational imperative to deliver aid as quickly as possible in an emergency. When identifying and responding to the needs of persons with disabilities, working with local groups and organizations that intimately know the situation on the ground, including OPDs, is instrumental.

- **Strengthen collection of information on services by modifying operational management tools.** The collection of information on services that include and target persons with disabilities in humanitarian contexts could be strengthened by modifying operational management tools, such as the standard 3W:OP process, to include how services are being provided and for whom.

- **Incorporate validated data collection tools in surveys.** Integration of the WG data collection tools in surveys such as the Demographic and Health Surveys and the Multiple Indicator Cluster Surveys was an important achievement. Censuses and other national surveys in high humanitarian-risk countries represent other avenues to collect the necessary data on persons with disabilities.

- **Develop innovative data collection techniques appropriate to the situation.** Protracted crises that continue year after year present an opportunity to humanitarian actors to improve data collection methodologies. Some situations are stable enough to permit surveys that use the WG questions, although frequently the mobility of affected populations calls for innovative measures to draw random samples.

- **Adjust the humanitarian response plan format to allow disability-disaggregated data.** A simple tweak in the humanitarian response plan format requiring each cluster to say something about gender, age and disability would create an incentive in each technical area to seek out disability-disaggregated data and plan specific outcomes.

- **Monitor regularly.** The foundation for evaluation efforts is regular monitoring and other basic data collection efforts, such as registration processes in refugee situations. Terms of references for evaluations that require disability-disaggregated data would provide a powerful incentive for humanitarian actors to collect improved routine data.

- **Integrate data on persons with disabilities from a multitude of sources.** The Humanitarian Data Exchange platform being developed by OCHA is an attempt to share information between agencies. Beyond this, reports from the United Nations Special Rapporteur on Persons with Disabilities and data from human rights monitoring and others could also inform humanitarian data for programming purposes related to persons with disabilities.

- **Raise awareness on the importance of collecting and using data to promote the rights of persons with disabilities in humanitarian contexts in line with the States' obligations under CRPD articles 11 and 31.**

- **Improve the IASC registry of humanitarian indicators by proposing the development of new indicators on persons with disabilities and reviewing existing ones that explicitly reference persons with disabilities and marginalized groups.** The current indicator registry is a compilation of contributions by humanitarian action specialists that represent different technical sectors. Work is needed to further develop, promote and adapt indicators that can capture persons with disabilities and also promote data sharing, focused on the identification of quantitative and qualitative indicators at the activity and output levels.

- **Modify existing data collection mechanisms to include the WG modules to identify persons with disabilities and assess if programmes and interventions are reaching persons with disabilities.** Tools such as UNHCR's proGres database application collects data on disability based on codes in its registration handbook but does not use the WG sets of questions. Therefore, proGres undercounts persons whose disability is unidentified.

- **Consistently use the WG modules to improve the comparability of data collected by different implementing agencies.** Different agencies conducting similar activities may not collect data in similar ways; consistent use of the WG questions will improve the comparability of data.

- **Continue to advocate for improvements in disability-disaggregated data in humanitarian action.**

Endnotes

1. The Joint Intersectoral Analysis Framework aims to establish critical issues to be considered by engaged humanitarian assistance players through the use of a humanitarian needs overview exercise.

2. Resolution adopted by the United Nations General Assembly, 2007.

3. For a rights-based understanding of disability, see: Inter-agency Standing Committee, *Guidelines on Inclusion of Persons with Disabilities*.

4. World Health Organization, *World Report on Disability*, p. 31.

5. Sustainable Development Goals, target 17.18, "By 2020, enhance capacity-building support to developing countries, including for least developed countries and Small Island Developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts".

6. Inter-agency Steering Committee, *Protection in Humanitarian Action*.

7. Washington Group on Disability Statistics, available at: <www.washingtongroup-disability.com>.

8. Madans, 'Mainstreaming Disability'.

9. These include using the Washington Group Short Set of questions in a recent census, survey or pre-testing process, but also other reported activities to collect and use disability data. Golden, 'Summary of Annual Activities Related to Disability Statistics'.

10. Ibid.

11. Humanity & Inclusion, available at: <humanity-inclusion.org.uk/en/disability-statistics-in-humanitarian-action>.

12. United Nations General Assembly, *One Humanity*.

13. Agenda for Humanity.

14. Charter on Inclusion of Persons with Disabilities in Humanitarian Action.

15. Inter-agency Standing Committee, *Guidelines on the Inclusion of Persons with Disabilities*, ch. 5.

16. Global Disability Summit 2018, 'Charter for Change'.

17. Available at: <www.unicef.org/disabilities/files/Guidance_on_strengthening_disability_inclusion_in_Humanitarian_Response_Plans_2019.pdf>.

18. Lord, 'Draft Desk Review'.

19. Sphere, *The Sphere Handbook*.

20. The Humanitarian Standards Partnership is a collaboration between the world's leading standard-setting initiatives. It aims to improve the quality and accountability of humanitarian action through the increased application of humanitarian standards. See: <www.spherestandards.org/humanitarian-standards/standards-partnership>.

21. Developed by the Small Enterprise Education and Promotion Network's Minimum Economic Recovery Standards in 2010. Disability (and all other specific vulnerabilities) is treated as a cross-cutting issue that programmers need to be aware of, although no specific guidance is offered.

22. The Minimum Standards for Education: Preparedness, Response, Recovery, developed by the Inter-agency Network for Education in Emergencies (2010), frequently references the disability inclusion issue and practical steps that need to be taken, although in terms of data its emphasis is on gender and age disaggregation only.

23. The Livestock Emergency Guidelines and Standards (2014), overseen by a steering group including humanitarian agencies such as the International Federation of Red Cross and Red Crescent Societies and the Food and Agriculture Organization, discusses vulnerable groups and data disaggregation primarily in terms of gender, but also considers social vulnerability in terms of age, ethnicity and caste.

24. Age and Disability Consortium, *Humanitarian Inclusion Standards*.

25. The Age and Disability Consortium is a group of seven agencies (CBM, DisasterReady.org, Handicap International, HelpAge International, IFRC, Oxford Brookes University and RedR UK) working together. The Age and Disability Capacity Programme is an initiative of this group funded by UKAID, USAID and the Start Network, as well as NGOs.

26. Age and Disability Consortium, *Humanitarian Inclusion Standards*.

27. Actions related to sex-, age- and disability-disaggregated data are referenced 12 times in the draft guidance tool, three times under separate key inclusion standards, and under each sector-specific standard.

28. Lord, *Disaster, Disability, & Difference*, p. 37. One OPD focal point in Nepal reported how his/her advice to disaggregate data by disability in terms of mortality statistics was ignored by the humanitarian protection cluster coordinators.

29. The main purpose of a basic 3W (who does what, where) is to show the operational presence by sector and location within an emergency. At this basic level, the 3W Operational Presence (3W:OP) can enable organizations to help identify potential partners, quickly give a very rough understanding of an ongoing response, and superficially identify potential overlaps or gaps in response. See: <www.humanitarianresponse.info/es/applications/tools/toolbox-item/3-w-process-guidance-graphic>.

30. New Era Consulting/National Planning Commission, *A Situation Analysis*.

31. Lord, *Disaster, Disability, & Difference*, p. 35.

32. Ibid., p. 38.

33. United Nations Office for Disaster Risk Reduction, *Sendai Framework*.

34. The INFORM Index for Risk Management database is a tool used by humanitarian decision makers to analyse risk potential. See: <www.inform-index.org/InDepth>.

35. Inter-agency Standing Committee and UN Working Group on Transitions, 'Humanitarian-Development-Peace Nexus Workshop'.

36. Rohwerder, *Disability in Somalia*, p. 6.

37. Ibid., p. 7.

38. United Nations Population Fund/Federal Republic of Somalia, *Population Estimation Survey 2014*.

39. Ibid.

40. United Nations High Commissioner for Refugees, *Internal Displacement Profiling*.

41. "Does [NAME] have any of the following conditions/situations? Physical disability (yes/no); mental disability (yes/no)."

42. Mont, *Measuring Disability Prevalence*.

43. Inter-cluster coordination is a cooperative effort among sectors/clusters and the HCT to assure coherence in achieving common objectives, avoiding duplication and ensuring areas of need are prioritized. See: <www.humanitarianresponse.info/en/how-to/do-inter-cluster-coordination>.

44. Stoddard, *Cluster Approach Evaluation*, p. 40.

45. As of 2016, there were 579,483 Somali refugees residing in neighbouring Kenya, Ethiopia and Djibouti.

46. Devictor and Do, 'How many years do refugees stay in exile?'.

47. United Nations High Commissioner for Refugees, *Statistical Yearbook*.

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49. United Nations High Commissioner for Refugees, *Handbook for Registration*, p. 43.

50. International Office for Migration, *Humanitarian Response Plan*, p. 10.

51. Arbeiter-Samariter-Bund, *Age and Disability Rapid Assessment Report*.

52. European Union Agency for Fundamental Rights, *Thematic Focus*.

53. CRPD defines reasonable accommodation as the necessary and appropriate modification and adjustments, when needed in a particular case, that do not impose a disproportionate or undue burden and ensure that persons with disabilities enjoy or exercise all human rights and fundamental freedoms on an equal basis with others. The denial of reasonable accommodation constitutes discrimination. See: <www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#2>.

54. European Union Agency for Fundamental Rights, *Thematic Focus*.

55. United Nations Children's Fund, *Lessons Learned*.

56. United Nations High Commissioner for Refugees, *Regional Refugee and Migrant Response Plan for Europe*, p. 7.

57. United Nations High Commissioner for Refugees, *Internal Displacement Profiling*.

58. European Union Agency for Fundamental Rights, *Thematic Focus*.

59. The Grand Bargain is an agreement between more than 30 of the biggest donors and aid providers that aims to get more means into the hands of people in need. Two of the initiative's goals that would benefit from improved data collection are (1) improving joint and impartial needs assessments and (2) promoting a participation revolution to include people receiving aid in making the decisions that affect their lives. See: <www.agendaforhumanity.org/initiatives/3861>.

60. See: <centre.humdata.org/#>.

61. Inter-agency Standing Committee, *IASC Transformative Agenda*.

62. Inter-agency Standing Committee, *Guidelines on the Inclusion of Persons with Disabilities*, ch. 5.

63. United Nations High Commissioner for Refugees, UNHCR Operations Management Cycle, available at: <emergency.unhcr.org/entry/125456/unhcr-operations-management-cycle>.

64. Inter-agency Standing Committee, *Reference Module*.

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66. UNHCR's standardized needs codes (see: <cms.emergency.unhcr.org/documents/11982/52542/Standardized+Specific+Needs+Codes+June+2009/906f8591-264c-4943-949c-3cea1ba40dc5>) are in the process of being revised to better align with the Washington Group guidance.

67. Inter-agency Standing Committee, *Humanitarian Needs Overview*.

68. See: <training.unicef.org/disability/emergencies>.

69. See: <reliefweb.int/sites/reliefweb.int/files/resources/Humanitarian_inclusion_standards_for_older_people_and_people_with_disabi....pdf>.

70. Figure 2 combines implementation and monitoring with evaluation, which are considered separate stages in the HPC (see: <www.humanitarianresponse.info/en/programme-cycle/space>). It is combined here given the similar data tools used in both. For example, an evaluation of a humanitarian action will draw extensively on implementing partner plans and their programme monitoring data.

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73. World Food Programme, *Emergency Food Security Assessment Handbook: Part II*.

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77. Inter-agency Standing Committee, Humanitarian Indicator Registry.

78. Ibid., Camp Coordination and Management, CM-23.

79. Humanity & Inclusion, *South Sudan Project*.

80. Ibid.

81. Inter-agency Standing Committee, *Indicator Registry*.

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83. Nepal Planning Commission Secretariat, *National Population and Housing Census*.

84. Crock and Smith-Khan, 'Swift and Systematic?', pp. 305–318.

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