



## Collecting Data on Persons with Disabilities in Humanitarian Contexts

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Labouisse Hall, UNICEF  
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A **technical workshop** considering issues related to collecting data on persons with disabilities in humanitarian contexts was organized jointly by [UNICEF](#), [Handicap International](#)<sup>1</sup>, the [International Disability Alliance](#), the [Washington Group on Disability Statistics](#) and [UNHCR](#) was held in **New York on 11-12 December 2017**. It brought over forty specialists in humanitarian action together with statisticians with expertise in collecting data on persons with disability, representatives from organizations of persons with disabilities (or DPOs) and United Nations agencies.

Figure 1 Meeting Flow



This was the first meeting of its kind that sought to build bridges between the different communities who share a common interest to improve humanitarian action for persons with disabilities, but who bring very different skill sets and perspectives into the conversation. Figure 1 illustrates the steps in the two-day meeting that this report will follow.

The meeting began, first, by creating a common foundation with the dissemination of a background paper describing the broad diversity of humanitarian contexts and entry points for data on persons with disabilities prior to the meeting. Beginning presentations were reminders of the why collecting data on persons with disabilities is so important, that a significant (and growing) political commitment to disability statistics exists globally through such mechanisms as the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) and as supported by processes such as the Sustainable Development Goals. Significant political buy-in exists, but the international community now needs to determine how to move forward together. Data collection in humanitarian contexts was discussed, as well as the progress being made by the Washington Group on Disability Statistics.

Second, the group heard about experiences from the field where disability statistics have been used in different humanitarian contexts.

The third session considered four different humanitarian action scenarios from the perspective of disability data, and small groups attempted to unpack where and how these data could be used, and their importance for improved programming in those settings, as well as the anticipated barriers.

Fourth, the group looked at the use of disability data along the timeline of an emergency, diving in for a deeper look at where disability data fits into particular points along the [humanitarian program cycle](#) as well as in different contexts to propose possible entry points for disability disaggregated data, and how it could be used to improve programming and promote inclusion.

<sup>1</sup> Handicap International was renamed “Humanity and Inclusion” on January 24, 2018. ([www.humanity-inclusion.org.uk](http://www.humanity-inclusion.org.uk))

Finally, in step five the meeting concluded with a discussion of priority recommendations and possible next steps needed to move the process forward.

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### Priority Recommendations

1. Emphasize the importance of incorporating the Washington Group data tools in survey processes such as Demographic Health Surveys, Multiple Indicator Cluster Surveys as well as national censuses in high humanitarian risk countries, as well as identifying other entry points in humanitarian data collection processes where the use of this methodology is appropriate
2. Modify standard data collection tools and databases used in humanitarian action to include Washington Group data tools to identify people with disabilities, as well as how programs and interventions are reaching out to persons with disabilities
3. Develop guidance on strengthening data collection to enhance inclusion of persons with disabilities in humanitarian action
4. Strengthen the demand for data on persons with disabilities in humanitarian action through donor reporting requirements
5. Build the capacity of humanitarian stakeholders to collect data to strengthen inclusion of persons with disabilities in humanitarian action
6. Improve the IASC registry of humanitarian indicators by proposing the development of new indicators on inclusion of persons with disabilities and reviewing/promoting ones that are sensitive to the inclusion of persons with disabilities
7. Strengthen collection of information on services inclusive of, and targeted to persons with disabilities in humanitarian contexts by modifying operational mapping tools such as the standard 5W:OP data analysis process
8. Promote the participation of and accountability towards persons with disabilities and organizations of persons with disabilities (DPOs) in efforts related to data collection and decision-making processes
9. Raise awareness on the importance of collecting and using data to promote and strengthen the rights of persons with disabilities in humanitarian contexts in line with the State obligations under the CRPD Articles 11 and 31
10. According to the [Humanitarian-Development Nexus](#), integrate information on persons with disabilities from other sources including development, human rights reporting and peace building into humanitarian action processes
11. Continue to advocate for improvements in disability disaggregated data in humanitarian action

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## Acronyms

5W:OP	Who does What, Where? Operational presence analysis including the “when” and “for whom” dimensions
CRPD	UN Convention on the Rights of People with Disabilities
DHS	Demographic and Health Survey
DPO	Organizations of persons with disabilities
EMIS	Education Management Information Systems
HMIS	Health Management Information Systems
IASC	Inter-Agency Steering Committee, mechanism for inter-agency coordination of humanitarian assistance
INGO	International Non-Governmental Organization
L3	Level 3 Emergency, a system-wide designation for the most complex and challenging emergency situations
MARA	Monitoring, Analysis, and Reporting Arrangements on Conflict-Related Sexual Violence
MICS	Multiple Indicator Cluster Survey
MIS	Management Information Systems
MRM	Monitoring and Reporting Mechanisms on grave violations
OCHA	Office of the Coordinator of Humanitarian Affairs
OHCHR	Office of the High Commissioner for Human Rights
ProGres	Profile Global Registration System, the UNHCR database application for refugee registration data
UNDESA	United Nations Department for Economic and Social Affairs
UNDP	United Nations Development Program
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children’s Fund

## 1. Background -- Data in Humanitarian Action and the Washington Group's Work

The World Health Organization estimates that than one billion people—approximately 15% of the global population—are persons with disabilities, 80% of whom live in poverty<sup>2</sup>. Article 11 of the Convention on the Rights of Persons with Disabilities (UN CRPD, 2006) obliges States to protect and ensure the safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters. In Article 31 of the CRPD, States commit to collecting appropriate information to enable them to formulate and implement policies in a form that is disaggregated as appropriate to identify and address barriers faced by persons with disabilities in exercising their rights.

A representative<sup>3</sup> from the **African Disability Forum**, in making the case for why collecting data on persons with disabilities is important, emphasized the growing political commitment that exists in the international community to drive towards greater inclusivity through initiatives like the Sustainable Development Goals. In order to complement this better data on persons with disabilities is required in humanitarian action, but the question remains: how to do this? Strong political commitment needs to be complemented by better tools and processes.

A humanitarian data specialist<sup>4</sup> from **UNICEF Office of Emergency Programs** described in broad strokes some of the challenges generally associated with data collection and data use in humanitarian contexts: What data do you need? When do you need it? And what decisions are you making based on the data you collect? Emergency and disaster situations are highly diverse, but in cases where the crisis unfolds quickly, the data collection process must move towards actual response planning very fast given the lives at stake. Much depends therefore on the quality of pre-crisis data that is available to responders because at the early stages of a response little time is available to organize large-scale data collection processes involving large samples and complex questionnaires. Better pre-existing quantitative data is invaluable to humanitarian actors to understand the scope of the problem.

The focus of initial rapid needs assessments that the humanitarian community undertakes is an attempt to produce a situational overview answering questions such as the scale and scope of the problem, profiling the affected population, the capacities on the ground to respond, and the state of humanitarian

### Meeting Objectives

- Discuss the technical aspects and feasibility of data collection on persons with disabilities in humanitarian action
- Identify challenges, solutions, and best practices for collection of data on persons with disabilities in humanitarian action

<sup>2</sup> World Health Organization and the World Bank, [World Report on Disability](http://www.who.int/disabilities/world_report/2011/report.pdf) (2011)

[http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf) Controversy exists about how accurate this estimate is given the methodology used to produce it. As this paper will indicate, weaknesses with disability statistics led to the international efforts by the Washington Group to improve the comparability and accuracy of data including estimates such as this one.

<sup>3</sup> Berhanu Tefera

<sup>4</sup> Kate Alley

access, i.e. the access responders have to the population considering issues like security, but also, the access the affected population has to services. More can be done at this stage to more systematically involve affected populations in the data collection process, although this will generally involve more qualitative methods (as compared to sample surveys) to gain insight into the key issues facing people with disabilities.

The number and diversity of actors involved in different or overlapping spaces, the number of activities they undertake and the short timeframes necessary to respond all challenge program performance monitoring and evaluation in humanitarian settings. Double counting and comparable counting (where different agencies record the same thing in the same way) is a risk even with simple activity and output indicators. To overcome these challenges, investments are being made to establish common data platforms and shared “eTools” that can be used by partners in the field to rapidly and more consistently collect data.

Despite the challenges, there is reason for considerable optimism. The diversity of data sources that have applicability to humanitarian action is quite wide, and there is scope for improvement all along the results hierarchy, both to improve national systems (such as Education or Health MIS) as well as better service point data that humanitarian responders collect. Increasing pressure exists for greater rigor in program evaluations of humanitarian action, a trend that will also push agencies towards more quantitative methods. As well there is increased attention to the importance of participation and engagement by affected populations in monitoring and evaluation processes. With the broad scope for improvement that exists, when the resources are available, and with the political momentum energizing the process, improving data collection relevant to people with disabilities in humanitarian contexts is entirely feasible and is a shared goal.

Representatives<sup>5</sup> from the **Washington Group on Disability Statistics** presented their different tools that have been developed and tested to improve the disaggregation involving disabilities: the Short Set, the Short Set Enhanced, Extended Set and Child Functioning Module. Since these tools were designed for use in national censuses and household surveys, their application in humanitarian action contexts must be further explored given the constraints and different needs. Introducing them in this meeting, and discussing their applicability will move this effort forward.

The Short Set was designed for census use. It is very short, only six questions long, easy to administer, and has been successfully used in non-survey settings including high humanitarian risk environments. Analysis shows that only an additional minute is required in a survey to ask these additional questions. The data disaggregation possible when the Short Set is used allows an analysis of functional limitations amongst individuals in the population.

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<sup>5</sup> Jennifer Madans and Dan Mont representing the Washington Group, and Claudia Cappa sharing UNICEF’s contributions to this process through the development of the Child Functioning Modules.

Disability status is a continuum, and you must categorize that continuum. The Washington Group's efforts have been focused on developing tools that capture this complexity.

### Reaction

These three perspectives provided the group with an excellent starting point for discussion and analysis of the issues at stake. It was clear that there is considerable political interest and support from many sides that support develop better data collection processes to help identify and address barriers faced by persons with disabilities in humanitarian situations. At the same time, the state of the art in humanitarian needs assessment, planning, performance monitoring and evaluation generally (even without considering disability disaggregated data) is not yet at the level the international community desires. Advances by the Washington Group are encouraging, but during the discussion some participants were skeptical about where tools like the Short Set are most appropriately used in humanitarian action. Many participants stressed that "good enough" data was the goal; to acquire useful information upon which decisions and actions can be taken are the priority, even if the results of these exercises do not measure up to "scientific" standards.

The group could conclude from this starting point that an ideal would be to know more about patterns of disability before the crisis: what was the prevalence of disabilities? In a crisis, humanitarian responders need to know how this has changed. Meeting participants, including the data specialists and the disability inclusion advocates with less experience in humanitarian action, could recognize the particular challenges of collecting data in disaster zones, but as well could recognize its importance to promote inclusion for people with disabilities.

## 2. Experiences with Disability Data in Humanitarian Action

In order to ground the analysis in field realities, a panel<sup>6</sup> highlighted real world experiences with disability disaggregated data questions. Insights from academia, the INGO sector, DPOs, a donor agency, as well as an operational UN agency provided different perspectives and contexts establishing a useful foundation for analysis. Important observations included:

- A lesson learned from collecting data in the Pacific Islands following a disaster was the importance of cultural and language dimensions, about how individuals understand and interpret disability in themselves and others. This understanding varied quite a lot. Functional disability categories outsiders considered meaningful were not interpreted in the same way suggesting that the issue of translation was critical.
- Use of the Washington Group tools in refugee contexts produces different estimates of disability prevalence than conventional tools considering data on Syrian refugees in Jordan, or Rohingya

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<sup>6</sup> **Frances Wood**, Data and Evidence Lead, Disability Inclusion Team, Department for International Development, UK; **Aliya Souhaid**, International Medical Corps; **Amalina Abdul Majit**, United Nations High Commissioner for Refugees; **Duaa Shaalan**, Handicap International, Jordan; **Wes Pryor**, Nossal Institute, University of Melbourne; **Simione Bula**, Pacific Disability Forum

refugees in Bangladesh. However, the capacity and time to use the Washington Group tools by humanitarian teams was an issue

- Poor alignment of data collected by different agencies creates difficulties. Different agencies may define disability indicators in different ways, with different boundaries, which creates challenges to integrate data from different sources.
- Concerns by agencies about how the data that is collected will be used may be a barrier for sharing data. Data confidentiality issues are real concerns, particularly in refugee situations where protection issues remain.
- Competing priorities of responders may create a disincentive for agencies to take the extra time required to collect disability data. In addition humanitarian responders have very different capacities to collect data, process it, store it and subsequently analyze it meaningfully.

Opportunities that may support or promote improved data collection processes:

- Increased attention and demand for disability disaggregated data, especially by donors and their constituencies.
- Methodologies for the collection of service point data, such as those used by UNHCR, allow a “layering” and revision of data based on subsequent contacts with persons of interest and later follow-up
- Commitments by humanitarian actors to disaggregate data by sex, age and disability

Acquiring better data is one dimension of the challenge, but the use of the data to improve operational response was equally important. Collecting data on persons with disabilities is not an end in itself; humanitarian actors need to think carefully how this will impact different services and if these services are even available. Where no services exist, the data is useful to advocate for additional funding to provide those services to people in need. Humanitarian actors must translate pockets of good experience to influence system-wide change.

### 3. Challenges and Opportunities

*What* data are needed *when*, and *how* will it be used varies according to the context of the humanitarian event. Four humanitarian scenarios were used as a starting point for conversations in the meeting. They were chosen primarily to provide diversity in the discussions:

Humanitarian Context	Characteristics
Rapid onset emergencies (often natural disasters such as earthquakes, floods or storms)	<ul style="list-style-type: none"> <li>• Massive disruption, poor understanding of the scenario especially at the outset</li> <li>• Validity of existing data may be questioned; but demands for quick answers and rapid action</li> <li>• Damage or loss of assistive devices, separation from caregivers</li> </ul>
Protracted and complex	<ul style="list-style-type: none"> <li>• Access to affected population may be limited; many service</li> </ul>

<b>(often involving displacement, conflict or other complicating factors such as food insecurity or health emergencies)</b>	<p>providers with varying commitments, priorities and technical competence</p> <ul style="list-style-type: none"> <li>• Serious data coordination issues, the humanitarian cluster system “silos” technical sectors making cross-cutting issues like disability harder to integrate</li> <li>• People with new impairments that may lead to disability as a result of the crisis</li> </ul>
<b>Refugee response operations</b>	<ul style="list-style-type: none"> <li>• Range of possible settings, with long-term displacement common in many cases (since 1991 between 5-7 million people had spent more than five years in exile<sup>7</sup>)</li> <li>• Initial registration, then follow-up (opportunities for service point individual data collection)</li> <li>• Access to services through the reduction of barriers in camp settings</li> </ul>
<b>Developed country settings (European migrant crisis)</b>	<ul style="list-style-type: none"> <li>• Mobile populations who may desire anonymity as they move from their point of origin towards their destination; Migrants concerned that sharing personal data would put their status at risk</li> <li>• Where is the data? Who owns it?</li> <li>• Linking migrants with disabilities to appropriate services; knowing what kinds of services are required, where, and for how many</li> </ul>

### Exploring data issues in different humanitarian contexts

There was wide acknowledgement that there is a data gap regarding persons with disabilities in humanitarian action. The humanitarian program cycle is complex, and different contexts and situations introduce an array of issues making it challenging to know at what stage data on persons with disabilities can be collected, and the level of detail required. Collecting data before problems occur in high humanitarian risk settings at the preparedness stage was highlighted as an obvious entry point, as there is more time at this point to set appropriate sample frames to collect meaningful data.

In an ideal world, we would push to use disability disaggregation methodologies in surveys undertaken in every high-risk country where we can be fairly certain in the next ten years there will be some type of disaster. ☑Were these data in place, it would provide very useful insight into pre-crisis disability patterns so that it was readily available at the initial assessment point to aid first responders. But undertaking large-scale surveys is not something that humanitarian actors can do in the midst of responding to a natural disaster.

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<sup>7</sup> Xavier Devictor, “How many years do refugees stay in exile?”, World Bank Blogs, September 2016 (<http://blogs.worldbank.org/dev4peace/how-many-years-do-refugees-stay-exile>)

In fast evolving conflict situations, accurate data is hard to obtain. Whatever situation may have existed *pre-crisis* will have changed as a result of the conflict. Even if very accurate data had been collected, as affected people move and seek safety, statistical profiles of communities become inaccurate.

Camps housing refugees or the internally displaced offer more stable possibilities for data collection. In contrast in chronic or protracted crisis settings, that often involve a variety of humanitarian risk factors, is where major data challenges exist. In these settings, there might be security issues that limit access to humanitarian actors, as well as large displaced populations who are hard to count accurately because of their mobility. Despite large-scale humanitarian action in several protracted crisis settings that have been ongoing for years or even decades, the international system needs to develop its capacity to collect better data, and more inclusive data.

Protection and access to assistance should be the main focus when collecting data on persons with disabilities. However, an important barrier affecting appropriate and effective humanitarian action, no matter the context, is the lack of awareness of disability and its implications, especially how it intersects with programming. A need was identified to build a common understanding across the humanitarian sector – irrespective of the type of emergency – about how disability is defined and understood. For external actors involved in data collection the local socio-cultural understanding and implications of disability may not be understood, or respondents may be reluctant to share information that may have an associated social stigma.

An issue that cuts across the use of disability data in humanitarian situations relates to the capacity of actors responsible for collecting, analyzing and using it. Current data collection tools in the humanitarian system tend to be over-simplified binary indicators, identifying an individual as “disabled or not”, rather than capturing the multi-dimensional and continuous nature of disability. One remedy is rather than focusing on the medical perspective, which is more related to an impairment, to use instead activity limitations (difficulties in functioning) in identifying individuals with disabilities. This is the approach taken by the Washington Group and it has yielded more accurate approaches to estimate the prevalence of persons with disability in the population, and the type and extent of functional difficulties faced. Information management and knowledge management in humanitarian situations is challenging already, and adding the requirement to disaggregate data by disability could potentially overwhelm the system if capacity is not developed in parallel. Investments in capacity building to improve monitoring, evaluation and learning skills from a disabilities perspective were identified as being urgently needed.

In disaster situations that begin with little warning and rapidly evolve, existing data may no longer be relevant making it complicated to know the extent of the situation particularly for people with disabilities. Following an earthquake, for example, demographic data of a neighborhood that may have included disability disaggregation may be of limited use if the former residents have been evacuated. During the European migrant crisis, one data constraint had to do with understanding which Government (or agency within a particular Government) was responsible to collect these data as the migrants passed from one country to the next. These migrant populations were also actively avoiding border controls. In cases where data were collected in one country, neither was there a mechanism in

place at the peak of the crisis to transfer data from one jurisdiction to the next, nor was there a protocol for identifying individuals.

Key ideas to take forward:

- Importance of a rights-based definition of disability in data collection processes during humanitarian action that allows the analysis of interactions between persons with long-term activity limitations and attitudinal and environmental barriers. More nuanced data about the types of functional difficulties may be useful in program design, implementation and evaluation. Better-designed humanitarian action should aim to promote access and removal of barriers.
- Invest in the capacity of humanitarian actors to collect and effectively use disability-disaggregated data. Raising the awareness of humanitarian actors about the implications of the barriers to participation and accessing services, as well as the risks they cause for persons with disabilities, will reduce the chance that people are left behind or passed over. Before collecting any disability data, humanitarian actors can do a lot to make the services they provide more accessible.

## 4. Disability Data and the Humanitarian Program Cycle

### Preparedness and relevant pre-crisis data

Lack of existing or reliable secondary data on persons with disabilities was identified as being a general challenge. Where such data does exist prior to the emergency it is enormously helpful in rapidly assessing needs.

Investments at the national level in population censuses, demographic and health surveys, or health or education management information systems pay off following a humanitarian crisis by offering responders a solid foundation on which to assess the scenario as well as the likely impacts on affected populations.

Pre-crisis data is not relevant in every situation. Pre-conflict data might be outdated. In some scenarios sharing of data may be limited due to the lack of political will, accountability, or the fact that the government may be a party to the conflict itself. Also, how data is shared in these situations could have important protection issues for affected persons.

Important ideas at the preparedness stage:

- Collection of data on persons with disabilities in “peace time”, before the crisis hits, is a good investment
- Especially in conflict settings pre-crisis data can be contentious and protection issues exist

### Needs Assessment and Planning

Data on people with disabilities have the potential to improve programming. How much disability data to collect during the needs assessment and planning stage depends a great deal on context. What data

collection modalities are justifiable – or even possible – in different humanitarian contexts varies a lot depending on circumstances. In situations where life saving is the immediate need, the time available to collect data before taking action is limited. While time for data collection is a big factor to consider in a sudden onset crisis response, in many *protracted* humanitarian situations that drag on for years, humanitarian actors have plenty of opportunity for more careful data collection processes that does allow for disaggregation.

Given the urgency to respond to life-threatening situations, and therefore the limited time available to collect specific data on disabilities, even the earliest actions following a crisis must be designed from the outset in an accessible manner so as to not to create a barrier for persons with disabilities. Providing more efficient relief on the basis of need alone and without discrimination is the central idea behind the humanitarian aid's impartiality principle.

The safety and security of the data collectors is another constraint. Given limited humanitarian access, it is important to be realistic and flexible in considering how data on persons with disabilities can best be collected, and the kind of approaches that make the most sense. Security issues put constraints on methods used by both local actors as well as external humanitarian actors including the size of survey samples and the length of questionnaires. In some humanitarian contexts, feasible sample sizes may be too small to allow meaningful disaggregation. In these cases, qualitative methods might produce better insight.

Aside from the feasibility of collecting the data, determining when disability disaggregated data is the most relevant or useful to help improve humanitarian action is important. Rapid onset versus slow onset emergencies, acute crises versus prolonged ones: although data about disabilities is always useful at the planning stage, the level of detail needed at the assessment and planning stage relates to the need to prioritize fundamental needs – i.e. *how much and what kind of data is good enough?* The data needed by responders in the first few days following a major natural disaster is much different than what can be effectively integrated by planners years into addressing a protracted refugee situation for example. In principle disability data needs to be placed on a level of demographics, with sex and age data: that is, when sex and age data on individuals is collected during a humanitarian action, at that point it is also appropriate to collect data regarding disability.

Key take-aways:

- Time is a factor. In some humanitarian contexts it would be irresponsible to undertake a major data collection exercise prior to taking action when lives were at risk. To mitigate this limitation the earliest humanitarian interventions following a crisis must be accessible.
- Where humanitarian access is limited because of security or other factors, qualitative methods might produce better results than a small quantitative sample.
- Different types of emergencies play out along very different time-scales. This has very large implications for choosing appropriate modalities for data collection.

## Types of program Implementation, monitoring and evaluation data

Different types of data help humanitarian actors understand the situation of people living with disabilities and the progress of the response.

1. Data at the **individual level** that identifies disability, needs, and barriers individuals may face as well as the capacities they may have. Individual data allows the population to be differentiated, providing an insight into size of the population of persons with disabilities that allows meaningful planning targets to be set and evaluations to occur. Individual data can be obtained in two ways:
  - Data that **extrapolates for the whole population** such as a national census or large-scale sample survey helps determine prevalence, and is useful to shape programmatic interventions. This type of individual data is better gathered in advance of the crisis, and where it exists this type of data provides an excellent baseline against which to assess the response during an evaluation.
  - **Administrative processes** where data from individuals is collected during the course of a humanitarian response can also be used effectively to understand how people with disabilities are being reached. Data such as collected by UNHCR when a refugee is registered that is entered into the “ProGres” database can be used by the humanitarian community to understand the prevalence of persons with disabilities. Administrative data of this type has limitations if it was improperly captured, if individuals were “unregistered”, or their disabilities were “unidentified”.
2. **Service level data** on the availability of inclusive services (or barriers to be addressed) does not track individuals, but the proportion of services, facilities or activities in terms of accessibility to persons with disabilities. Data of this type can be used for program planning, setting targets, measuring progress and evaluations. During a humanitarian action, this kind of data may be easier to obtain. This kind of data looks at the proportion of WASH facilities are accessible, for example, or what proportion of protection staff had received adequate disability awareness training etc. This type of information can be captured very early in a humanitarian action as needs are assessed by the different humanitarian Cluster teams<sup>8</sup>.
3. A third type of disability-related data can record **activities and outputs**, and these are actually the most common type of data in humanitarian situations. In a project, several activities might be specifically targeted at persons with disabilities. Data of this type are used for performance monitoring, tracking achievements against targets, such as the number of assistive devices that were distributed compared to the plan, or the number of shelters that were modified to be made more accessible.

During the implementation of a humanitarian action it is feasible that data related to administrative processes, service levels and activities and outputs can be collected in a disability inclusive manner.

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<sup>8</sup> The Protection Mainstreaming Toolkit recommends the approach to proactively look for needed services or services being provided by humanitarian actors that are not accessible.  
[http://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) See questions about access, p. 46.

Especially with disability-aware administrative processes, more work piloting and action research is required to align tools like the Washington Group Short Set of questions into existing systems.

## 5. Prioritizing Recommendations

Considering the different humanitarian contexts and disability data use at different phases of the humanitarian response a number of recommendations emerged, with some actions already planned or underway:

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### Recommendations

<b>1. Emphasize the importance of incorporating the Washington Group data tools in survey processes such as Demographic Health Surveys, Multiple Indicator Cluster Surveys as well as national censuses in high humanitarian risk countries, as well as identifying other entry points in humanitarian data collection processes where the use of this methodology is appropriate</b>	<p>This is a critical preparedness step especially in high humanitarian risk settings. Work is already underway, for example with <a href="#">humanitarian MICS applications</a>.</p> <p>Washington Group tools might also be incorporated in humanitarian action at points where data collection from individuals takes place, such as in <a href="#">registration</a> of individuals by UNHCR using the ProGres database, following mine action incidents where common <a href="#">information management tools</a> are used, or when other sample surveys are used<sup>9</sup>.</p>
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<sup>9</sup> The use of sample surveys in humanitarian action is becoming more common both to improve accountability to affected populations as well as to improve program planning, monitoring and evaluation especially during the course of protracted crises, for example through profiling exercises for internally displaced populations.

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**2. Modify standard data collection tools and databases used in humanitarian action to include Washington Group data tools to identify people with disabilities, as well as how programs and interventions are reaching out to persons with disabilities**

As the UNHCR rightly observes, “registration saves lives, especially in an emergency”<sup>10</sup> Standard tools such as UNHCR’s ProGres database application collects data on disability based on codes in its [Registration Handbook](#), but not using the Washington Group approach, and therefore under-counts persons whose disability is unidentified<sup>11</sup>.

Humanity & Inclusion (formally Handicap International) is producing evidence-based training materials and guidance for use of the Washington Group short set in humanitarian action that complement other resources for collecting data on disability (more information [here](#)).

Where targeting criteria for social protection and cash transfer programming includes disability as a criteria, the Washington Group approach to data disaggregation is a more objective benchmark.

Standard questions related to inclusive humanitarian action should to be added as a standard feature of the terms of reference for all L3 evaluations.

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<sup>10</sup> Dirk Hebecker, UNHCR’s senior registration officer. “The sooner we know how many refugees there are in which location, including children and people with special needs, the faster we can distribute aid to everybody...” (<http://www.unhcr.org/news/latest/2004/12/41d42e904/registration-project-improves-profile-refugees-mozambique.html>)

<sup>11</sup> Laura Smith-Khan, et. al. “To ‘Promote, Protect and Ensure’: Overcoming Obstacles to Identifying Disability in Forced Migration”, [Journal of Refugee Studies](#), Volume 28, Issue 1, 1 March 2015

<p><b>3. Develop guidance on strengthening data collection to enhance inclusion of persons with disabilities in humanitarian action</b></p>	<p>The development of the IASC guidelines on inclusion of persons with disabilities will cover collection of data on persons with disabilities.</p> <p>Effective identification is the key inclusion standard 1 in the <a href="#">Humanitarian Inclusion Standards for older people and people with disabilities</a>, as well as the first key action in each of the other inclusion standards.</p> <p>Ensure that the development of Standard Operating Procedures related to disabilities in humanitarian contexts is aligned with OCHA led processes to review and improve the humanitarian program cycle.</p> <p>Identify at what points in the humanitarian program cycle tools like the Washington Group short set of questions can be used.</p>
<p><b>4. Strengthen the demand for data on persons with disabilities in humanitarian action through donor reporting requirements</b></p>	<p>Donors have enormous leverage. Support the development of a “disability marker” similar to the IASC “<a href="#">gender marker</a>” to make financial flows supporting disabilities in humanitarian action more visible</p>
<p><b>5. Build the capacity of humanitarian stakeholders to collect data to strengthen inclusion of persons with disabilities in humanitarian action</b></p>	<p>Disability disaggregation will generate far more data than is currently collected and processed in humanitarian action. Investments in building the capacity of humanitarian actors to collect and utilize it are required, or the system itself could be overwhelmed.</p> <p>Raising awareness about disability, and the implications of barriers to people with disabilities, is an important form of capacity building.</p>

<p><b>6. Improve the IASC registry of humanitarian indicators by proposing the development of new indicators on inclusion of persons with disabilities and reviewing/promoting ones that are sensitive to the inclusion of persons with disabilities</b></p>	<p>Technical sector specialists in humanitarian action have contributed to an <a href="#">indicator registry</a> to encourage agencies to harmonize and align their monitoring, reporting and evaluation approaches.</p> <p>Work needs to be done to further develop, promote and adapt indicators sensitive to persons with disabilities, focused on the need to create standard codes for information management system and data sharing.</p>
<p><b>7. Strengthen collection of information on services inclusive of, and targeted to persons with disabilities in humanitarian contexts by modifying operational mapping tools such as the standard 5W:OP data analysis process</b></p>	<p>The standard 3W:OP exercise led by OCHA to determine operational presence during an emergency (by collecting information on “who, what and where”) could be made more inclusive by augmenting data on when services are being provided, and for whom.</p>
<p><b>8. Promote the participation of and accountability towards people with disabilities and organizations of persons with disabilities (DPOs) in efforts related to data collection and decision-making processes</b></p>	<p>Several of the “Grand Bargain” work streams, particularly those looking at localisation, reforms to the needs assessment process, multi-year planning, and accountability to affected persons should take on issues of inclusion.</p> <p>To improve effectiveness, partnerships between humanitarian actors and DPOs or other agencies with experience in working with persons with disabilities</p>
<p><b>9. Raise awareness on the importance of collecting and using data to promote and strengthen the rights of persons with disabilities in humanitarian contexts in line with the State obligations under CRPD Articles 11 and 31</b></p>	<p>Build capacity of humanitarian actors to improve collection of data on persons with disabilities</p> <p>Map learning needs in different contexts and levels of the humanitarian system including local partners, implementing agencies, humanitarian cluster coordinators and the Humanitarian Country Team</p>

<p><b>10. According to the <a href="#">Humanitarian-Development Nexus</a>, integrate information on persons with disabilities from other sources including development, human rights reporting and peace building into humanitarian action processes</b></p>	<p>OHCHR reporting on human rights, reports from the UN Special Rapporteur on Persons with Disabilities, and data from <a href="#">Monitoring and Reporting Mechanisms on grave violations</a> (MRM) and <a href="#">Monitoring, Analysis, and Reporting Arrangements on Conflict-Related Sexual Violence</a> (MARA), could also inform humanitarian data for programming purposes.</p>
<p><b>11. Continue to advocate for improvements in disability disaggregated data in humanitarian action</b></p>	<p>Redraft the workshop background document to incorporate inputs such as these recommendations.</p> <p>Strong engagement in key events, such as the annual <a href="#">Humanitarian Networks and Partnership Week</a> and the <a href="#">Global Action on Disability (GLAD) Network</a>, as well as the upcoming Global Disability Summit in July 2018.</p>

### Conclusions and Next Steps

The process that brought these different communities together for the first time was a critical first step. Much better understanding resulted about the wide range of humanitarian contexts, but also of the great potential for better disability disaggregated data to improve humanitarian action and make it more inclusive for the population with disabilities who face barriers and heightened risks in humanitarian contexts. The list of prioritized recommendations that the group developed can be seen as an “agenda for action” to improve the current situation.

There is much work already underway. The [IASC Task Team](#) on inclusion of persons with disabilities in humanitarian action will produce guidelines in 2018. A data work stream has been added to the work of this Task Team to involve people with experience or interest in collecting data on persons with disabilities, so that this can be incorporated into the development of the guidelines. This report will be shared so that its recommendations can be taken into account while the IASC guidelines are developed. Humanity and Inclusion’s<sup>12</sup> action research on the collection of data on persons with disabilities using the Washington Group questions in humanitarian action will conclude and be evaluated in 2018. This will generate important learning for the community, and will provide evidence of how this tool can be used across the humanitarian project cycle. HI expects to create guidance and learning materials based on its action research concerning how the Washington Group questions can be used effectively in humanitarian action. UNICEF has produced sector-specific guidance for including children with disabilities in humanitarian action. Rolling out this material to its partners will be a priority in the coming year.

<sup>12</sup> Formally Handicap International

In addition to these on-going processes, a lot more needs to be done to move the humanitarian community forward towards making its action more inclusive. The group emphasized the need for more political will, so as to open the door for higher-level decision-making and prioritization. The group concluded that the conversation needed to continue, with new learning as it is developed shared widely with participants. Opportunities for this included the upcoming Humanitarian Networks and Partnerships Week in Geneva (February 2018), Global Action on Disability Network meeting in Helsinki (February 2018) and the Global Disability Summit in London (July 2018). The group concluded that while the meeting's objectives to look at the feasibility of data collection on persons with disabilities in humanitarian action and to identify challenges, solutions and best practices had been met, the process was just at the beginning.

## Meeting Participants

<b>Names</b>	<b>Organizations</b>
Berhanu Tefera	African Disability Forum
Abraham Abdallah	Arab Organization of Persons with Disability (AOPD)
Alberto Gomez	Arbeiter-Samariter-Bund (ASB)
Gordon Rattray	CBM
Dan Mont	Center for Inclusive Policy
Steve Perry	Consultant
Paula Iwanowska	Delegation of the European Union to the United Nations
Frances Wood	UK Department for International Development
Zoe Ayong	Government of Vanuatu's National Disaster Management Office
Pierre Gallien	Handicap International
Pauline Thivillier	Handicap International
Kate Aykroyd	Handicap International
Ricardo Pla Cordero	Handicap International
Duaa Shaalan	Handicap International Jordan
Nuhad Al-Alfi	IASC Secretariat
Georgia Dominik	International Disability Alliance
Ruth Warick	International Federation of Hard of Hearing People
Aliya Souhaid	International Medical Corps
Anna Reichenberg	International Organization for Migration
Alice Hawkes	International Rescue Committee
Nora Groce	Leonard Cheshire Disability & Inclusive Development Centre
Wes Pryor	Nossal Institute – University of Melbourne
Patrick Rooney	Office of the United Nations High Commissioner for Human Rights
Simione Bula	Pacific Disability Forum
Priscila Gonzalez	International Federation of the Red Cross
Mei Lin Leon	International Federation of the Red Cross
David Coffey	UN Women
Maria De Freitas Martinho	UN Department for Economic and Social Affairs (UNDESA)
Xing Lu	UN DESA
Stefanie Afonso	United Nations Development Programme (UNDP)
Amalina Abdul Majit	United Nations High Commissioner for Refugees (UNHCR)
Kristin Lange	UNHCR
Ehsan Ul Haq	United Nations Children's Fund (UNICEF)
Asma Maladwala	UNICEF
Gopal Mitra	UNICEF
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Hellen Nyangoya	UNICEF
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<b>Jennifer Madans</b>	Washington Group on Disability Statistics
<b>Romina Woldemariam</b>	World Food Programme
<b>Penny Hartin</b>	World Blind Union
<b>Emma Pearce</b>	Women Refugee Commission

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