# Strengthening Collection and Use of Data on Persons with Disabilities for Inclusive Humanitarian Action

May 9-10, 2019, The Hague Humanity Hub, The Hague, Netherlands

## SUMMARY

This two-day workshop involving thirty participants from the United Nations (UNICEF, OCHA, WFP, IOM), international NGOs (IFRC, IRC, Save the Children, HI, ALNAP, CBM, Christian Aid, Inclusion International) and Organizations of Persons with Disabilities (IDA, Pacific Disability Forum and Shruti Nepal) met its five objectives according to a post-workshop evaluation:

1. Follow up on the recommendations from the 2017 workshop in New York, 'Collecting Data in Humanitarian Contexts', commitments made at the Global Disability Summit.

2. Build capacity on collection of data on persons with disabilities, data literacy and use of data to inform/guide inclusive programming.

3. Identify entry points in the humanitarian architecture for collection of data on persons with disabilities and relevant tools and processes that need to be adapted.

4. Promote better inter-agency collaboration on disability data.

5. Gather feedback on demand for learning pathways or technical support needed to take data collection and use further towards disability inclusive programming and coordination at global and/or country coordination level.

Participation and workshop evaluation can be found here.

Participants gather at The Hague Humanity Hub to discuss opportunities for more effective, responsible, and inclusive humanitarian action. (Photo: OCHA Centre for Humanitarian Data)

## PROGRESS ON DISABILITY DATA SINCE 2017

Workshop participants were asked to reflect on disability data-related initiatives that took place subsequent to the NY workshop. Small group teams thought through these accomplishments in terms of their significance, the learning that took place and the next steps necessary to leverage the achievement:

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| **Capacity - Building on Washington Group Questions** | Investments have been made by Humanity and Inclusion, UNICEF, IFRC, Save the Children and WFP (amongst others) to improve disability disaggregated data. Training materials and other resources have been developed and tested. More and better targeted materials are required to improve the use of data in decision-making and programming. |
| **OCHA Centre for Humanitarian Data** | OCHA opened the Centre for Humanitarian Data in The Hague in December 2017. The Centre created a platform for finding, using, and sharing humanitarian data called the Humanitarian Data Exchange, or HDX. Currently among the nearly 10,000 datasets on HDX, only about 25 include data on disabilities. In 2019 its Data Fellows Program will focus a fellowship in the area of disability statistics. |
| **Integrating Disability Data into Mainstream Guidance** | In 2018 the Humanitarian inclusion standards for older people and people with disabilities was published. But in addition to stand-alone resources like the HIS, attention has also been paid to integrating disability data into other mainstream guidance such as Sphere, the Core Humanitarian Standard and the Protection Mainstreaming Toolkit. |
| **IASC Guidance Process** | An IASC Task Team was established in July 2016 to develop system-wide humanitarian guidance on the inclusion of persons with disabilities in humanitarian action. Development of this guidance has been as much about the process as the product expected by mid-2019. High levels of participation by a diversity of organizations in a "bottom up" multi-regional process that has embraced differences in humanitarian contexts has created a demand for the guidance from multiple perspectives. The guidance will be rolled out in the last quarter of CY2019. |
| **Inclusive Humanitarian Needs Overview/ Humanitarian Response Plan Guidance** | Specific guidance was developed in 2018 to support disability inclusion in the humanitarian needs overview and humanitarian response planning processes that will take place in 2019. The guidance emphasizes the importance of identifying barriers to inclusion and recognizing intersectional identities (women with disabilities, or religious minorities with disabilities). The on-going rollout of this guidance will require a strong focus on capacity-building of humanitarian actors. |
| **Advancing the CRPD Article 11** | Article 11 of the CRPD is a commitment to the rights of persons with disabilities that should be guaranteed even in conflict, crisis or humanitarian emergency. In 2018 various events reinforced the importance of this including the Global Disability Summit and the Arria-formula meeting focused on the disproportionate impact of conflict on persons with disabilities. The importance of better data, and not just quantitative data were themes highlighted by these initiatives. |

Capacity-building and stronger inter-agency coordination were identified as necessary next steps to better leverage many of these accomplishments. More detailed insights from these presentations can be found at this link.



Participants share learnings from the previous year of disability data-related initiatives. (Photo: OCHA Centre for Humanitarian Data)

### DISABILITY DATA AND THE HUMANITARIAN PROGRAM CYCLE

The 2017 New York workshop looked at disability data from the perspective of different types of humanitarian situations, including rapid onset, complex or protracted, refugee operations, as well as the European migrant crisis that peaked in the summer of 2015.

The May 2019 workshop considered disability data from the perspective of different points along humanitarian program cycle. Small groups were formed based on how individuals self-identified themselves in the introduction: primarily focused on humanitarian action, primarily focused on humanitarian data, or primarily focused on disability inclusion issues.

Each group looked particularly closely at practical challenges or important lessons learned about disability data in humanitarian action, as well as under-used or unexplored disability data entry points.

- Lack of disability data makes it challenging to evaluate, as there is no baseline
- Uses of data for targeting, counting of activities and for donor reporting are common, but uses beyond these are rare
- **Safety audits**
- **Using large scale national systems such as health and education MIS**
- **Need to collect better data to track accessibility of services**
- **Feedback and complaints mechanisms**

- Not enough trained staff to support other actors. Required sustained, not just one-off training
- **Financial tracking systems to track how much is being allocated to disabilities, to whom/by whom and where**

**Disability Data Challenges** *and* **Entry Points**

Implement-ation, Monitoring and Evaluation

Preparedness

Resource mobilization and allocation

Needs Assessment and Analysis

Joint and Coordinated Planning

- Not enough support to implement disability data collection as a preparedness step, either from partners or global level
- Limited OPD capacity to engage in systematic data collection
- **Secondary data use, e.g. national census data, DHS, Education and Health Ministry data, local NGO/DPO data**

- Lots of guidance available related to needs assessment processes, but less shared understanding of its use and applicability
- Primary data collection tends to be limited to household surveys, not individual surveys that might be more useful for understanding the barriers and risks associated with disability
- **3W, 4W and 5W approaches are underused in terms of who is doing what specifically related to disability inclusion**

- Many organizations need to collect the same data from the same people leading to "participation fatigue"
- Host governments and humanitarian actors my have different motives and perspectives on the disability data issue
- **Matching up specialized disability organizations with mainstream INGOs, DPOs and governments to build capacity in using disability data for planning**

The graphic above captures many of the key points made during the discussion regarding disability data challenges and entry points.

Themes that came out strongly in this session included the importance of qualitative data, especially related to barriers and risks, as well as the use of existing secondary data sources. The Washington Group is developing a module (with UNICEF) to assess barriers to access schools, as well as another (with ILO) to assess barriers to access employment.

A similar module could be developed to assess barriers to accessing humanitarian assistance. Accessibility data can be collected can be collected in a number of ways: through accessibility audits, using existing processes such as safety audits performed in GBV, or through feedback mechanisms. A more detailed presentation of the complete group work result in mapping practical challenges, unexplored entry points as well as issues that apply across the HPC and interesting current uses of disability data can be found at this link.

Throughout the workshop, a learning gap on the use of data was repeatedly identified. Humanitarians are beginning to collect improved disability data, but its use to improve program quality remains poor. Some reasons stated for this included "lack of knowledge", but with the growing amount of guidance related to disability data (UNICEF, IASC, HNO/HRP, CHS) the lack of guidance in this area should not be an excuse.

## WASHINGTON GROUP QUESTIONS AND THE DATA LIFECYCLE

Disability data collection, analysis and use was the overall theme of these learning sessions that began with an overview presentation and discussion that can be [downloaded here](#).

Most participants were familiar with the Washington Group questions already. The discussion focused instead on introducing the importance of secondary data, where primary data is collected exploring the importance of planning and clearly defining the purpose of the data. Small groups discussed these issues particularly in relation to different types of humanitarian contexts such as rapid onset disasters, complex or protracted crises, developed country contexts and refugee crises.

A presentation of the "[Building Peaceful Futures Project](#)" in Iraq was a useful grounding to several issues related to the Washington Group Questions, including training and analysis. The experience in Iraq using the WGQs underlined the need for more guidance on:

- How to use the WGQs in household surveys

- How/when to use other WG question sets besides Short Set

- Appropriate questions to learn about barriers and facilitators

- Using disability data once collected, and the ethics of collecting without first knowing use

- What to do about targeting – cash vulnerability assessments or WASH vulnerability assessments

## EXPLORING EXPERIENCES

Four learning sessions were organized to allow participants to explore experiences related to disability data, including the use of the Washington Group questions, the importance of qualitative data and its relative underuse, collecting qualitative data on barriers and facilitators, and the use of HDX (Humanitarian Data Exchange), the humanitarian data platform. To the extent possible, these sessions emphasized participation.

## ACCESS AND USE OF HDX

With the assistance of OCHA Centre for Humanitarian Data, participants were given a hands-on opportunity to explore three different disability datasets currently found on HDX: one complex and relatively comprehensive set (Syrian refugees in Jordan and Lebanon), one disability-focused one, although with limited data (Bangladesh) and a third data set produced by the Government of Kenya. The purpose of the exercise was to raise awareness about the HDX platform, as well as to stimulate a discussion around the use of secondary disability data.

Several conclusions about the use of secondary data emerged from the discussion. With two of the three datasets explored, only limited metadata was available. "Metadata" is data describing the data, such as the study's timeframe, definitions, the questions asked survey participants, and other information about the methodology of the study such as how the data was collected. The group exercise allowed individuals with laptops to query HDX and download data, as well as learn more about how data could be contributed to the platform.



Participants explore existing datasets related to disability currently available on HDX. (Photo: OCHA Centre for Humanitarian Data)

## BARRIERS AND FACILITATORS, QUALITATIVE DATA ON ACCESS

After the group who explored the Bangladesh data through HDX shared their observations, a more detailed presentation was made about the Bangladesh study. One of the issues was clearly the small sample size. Although detailed data was collected from persons with disabilities, because of the limited sample size representative data capturing different types of disabilities was difficult.

More participatory tool design would have also overcome challenges related to language, allowing more precise and relevant questions, and ultimately better buy-in to the conclusions. Where possible, this type of barriers and facilitators study should be integrated into wider multi-sector, multi-agency needs assessment processes in order to inform the broader response community. Finally, the study approach to better understanding barriers and facilitators is particularly applicable to implementation monitoring.



Participants discuss key disability data themes to consider at each stage of the humanitarian program cycle. (Photo: OCHA Centre for Humanitarian Data)

## IMPROVING USE OF QUALITATIVE DATA IN MONITORING (ALNAP)

Qualitative approaches are seldom presented as good for evidence generation or for measurement of results. But quantitative surveys are seldom able to achieve statistically representative sampling due to a combination of limited capacity and constrained access in humanitarian contexts.

Qualitative data can provide explanatory knowledge of how/ why a program is working (or failing to work), or on the complex nature of needs.

Key insights around qualitative datasets include:

| Design & Analysis | • Qualitative research does not have to be more time consuming than quantitative surveys. Purposive sampling can be acceptable. Transcription and coding are not always necessary.<br>• Fundamental Question: What questions need to be answered; what sorts of decisions need to be made based on the qualitative data? |
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| Capacity | • Recognize where external support is required<br>• Think beyond training |
| Utilization | • Build analysis tools based on expected use of data<br>• 'Death to the report'? |





**During breakout sessions, participants address specific issues impacting the community to develop key recommendations.** (Photo: OCHA Centre for Humanitarian Data)

## TEN RECOMMENDATIONS

A working session at the conclusion of the workshop produced ten global recommendations based on inputs and observations of participants aimed at maintaining momentum and recalibrating the disability data agenda.

Recommendations are intended to help agencies prioritize and advance their work on data of disabilities in humanitarian action. They are not intended for any particular agency, and are meant to inform the community as a whole.

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| 1. Strengthen the methods for the collection and use of primary and secondary data on barriers and other qualitative information about the rights of persons with disabilities. | **Progress is being made in the humanitarian community towards improving disability data but greater efforts to "demystify" the process are required.** |
| 2. Build on existing inter-agency coordination mechanisms to set up a learning and sharing platform on qualitative and quantitative data collection, analysis and use. Expand the number of tested tools, guidance and collaborative processes to make humanitarian action more accountable to and inclusive of persons with disabilities, their needs and rights. | **Progress on disability data since the 2017 workshop underlines the importance of working together across agencies and sectors.** |
| 3. Identify the most relevant indicators in humanitarian action to promote the disaggregation by disability in order to monitor the inclusiveness of assistance, using the IASC indicator registry as a basis. Improve indicators used in humanitarian action and develop new ones that better include persons with disabilities, in line with existing best practice. | **HNO/HRP and IASC guidance both identified the need to improve indicators relevant to disability in humanitarian action.** |
| 4. Explore the barriers, needs and possibilities for using qualitative and secondary existing data more effectively for planning, implementing, monitoring and evaluating impactful interventions that benefit persons with disabilities. Build capacities in data literacy so that humanitarian actors can use existing secondary data more effectively. | **Disability data already exists in many forms. More data needs to be made available to humanitarian actors.** |
| 5. Build capacity within the sector including local DPOs, mainstream INGOs, UN agencies and clusters to collect, analyze and use disability disaggregated data. Ensure that new training materials, data tools, guidance and other resources integrate best practice and advice for integrating disability data and are tailored to different staff cadres. | **The importance of continued capacity-building, as well as the production and dissemination of training resources, was frequently raised by participants as a key issue.** |

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| 6. Further strengthen the participation and accountability towards persons with disabilities and Organizations of Persons with Disabilities (DPOs) in efforts related to data collection and decision-making processes. DPOs are often well placed to support humanitarian data collection processes given their understanding of the local context. | **There is over-reliance on INGOs specialized in disability data.** |
| 7. Generate evidence of the financial cost of making mainstream humanitarian programs inclusive of persons with disabilities across all humanitarian sectors. Improve the tools in place to plan and budget inclusive humanitarian action. | **Improved disability data sets the context for programming decisions. This needs to be complemented with improved guidance on planning and budgeting.** |
| 8. Make disability data more widely available by sharing datasets on inter-agency platforms such as the Humanitarian Data Exchange (HDX). Encourage contributors to include data descriptions to assist users in evaluating the quality of the data and the methodologies used to collect it. | **Only a tiny fraction of the existing HDX data pertains to disability issues.** |
| 9. Wherever relevant, ensure that humanitarian data collection processes are aligned with global accountability frameworks including the Charter for Inclusion of Persons with Disabilities in Humanitarian Action, the United Nations Disability Inclusion Strategy and the System-Wide Action Plan, and voluntary national review processes contributing to High Level Political Forums. | **Advancing CRPD Article 11.** |
| 10. Ensure that data is responsibly used in humanitarian action. The collection and use of disability data must not further victimize persons with disabilities or place them at greater risk of harm or exploitation. | **Reference to the OCHA Data Responsibility Guidelines, now in working draft.** |

**PARTICIPANT ORGANIZATIONS**

- Active Learning Network for Accountability and Performance (ALNAP)
- CBM International
- Christian Aid
- Global Education Cluster
- Humanity & Inclusion (Iraq & Bangladesh)
- Inclusion International

- International Disability Alliance
- International Federation of the Red Cross
- International Organization for Migration
- International Rescue Committee
- OCHA Centre for Humanitarian Data
- Pacific Disability Forum
- Save the Children

- SHRUTI
- UN Office for the Coordination of Humanitarian Affairs
- UNICEF
- World Food Programme