May 2019

Data on Persons with Disabilities in Humanitarian Action

Collecting quantitative data with the Washington Group Questions

Key Findings & Recommendations

UKaid
from the British people

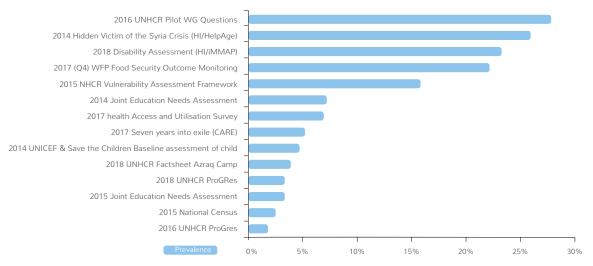handicap international
humanity & inclusion

OVERVIEW

The collection of data on persons with disabilities in humanitarian action contributes to strengthen the inclusion of persons with disabilities in policies and programmes across many sectors and levels. In recent years, there have been considerable efforts to collect, analyse and use data on persons with disabilities catalysed by data collection requirements called for in Article 31 of the **UN Convention on the Rights of Persons with Disabilities (CRPD)**[1]. It resulted, for example, in the inclusion of disability within the **2030 Agenda and Sustainable Development Goals (SDGs)** with the call to 'leave no one behind' and in the **Sendai Framework for Disaster Risk Reduction**[2]. Consequently, disaggregation of data by disability is now a core principle included in many global frameworks. Data from national statistical and data systems are the basis for the compilation of global indicators under these frameworks and it results in many important initiatives to develop new tools and frameworks, including the use of the **Washington Group Questions**[3] **(WGQs)**. These efforts are especially important in identifying those left furthest behind, since data are increasingly disaggregated by income, sex, age, disability and other characteristics.

Calls for more collection of disability data in humanitarian action have also increased in recent years. Donors such as DFID[4] and DFAT[5] are pushing to strengthen internationally comparable disability data collection and analysis on persons with disabilities. The **Global Disability Summit** held in London in July 2018 also led to all national governments and organisations attending making commitments[6] on data disaggregation. As part of DFID Humanitarian Investment Programme, a **Guidance on strengthening disability inclusion in Humanitarian Response Plans**[7] was recently launched to provide support to seven UN entities on how to strengthen inclusion of disability in Humanitarian Response Plans (HRPs) through data collection.

As a result of these initiatives, more and more data on persons with disabilities is emerging in humanitarian action. However, there remains an inconsistent approach to the collection of data on persons with disabilities which results in a lack of comparable and reliable data on persons with disabilities. Without quality data, humanitarian actors are not able to understand whether persons with disabilities are included in humanitarian responses and monitor their interventions.

% of Syrian refugees with disabilities in Jordan

Figure 1 Literature review of available disability data on Syrian Refugees in Jordan

In this context systematic collection, analysis and use of disability disaggregated data using tools such as the WGQs should be promoted to ensure inclusion of persons with disabilities. The **Washington Group on Disability Statistics**[8] was tasked by the UN Statistical Commission to develop a set of questions to collect comparable data on persons with disabilities for national statistical purposes. They identify people who have difficulties in basic, universal activities and are at greater risk than persons without such difficulties of restricted social participation in an unaccommodating environment.

Even though they were not designed to be used in humanitarian action, Humanity & Inclusion's project on Disability Data in Humanitarian Action[9] demonstrated that they could be a useful entry point for inclusive programming although there are elements to consider beforehand. This paper will provide you with the key elements to consider and recommendations.

1   https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
2   https://www.unisdr.org/files/43291_sendaiframeworkfordrren.pdf
3   http://www.washingtongroup-disability.com/washington-group-question-sets/
4   https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/760997/Disability-Inclusion-Strategy.pdf

The Washington Group short set of questions

Six Questions on Short Set

Do you have difficulty seeing, even if wearing glasses?

Do you have difficulty hearing, even if using a hearing aid?

Do you have difficulty walking or climbing steps?

Do you have difficulty remembering or concentrating?

Do you have difficulty (with self-care such as) washing all over or dressing?
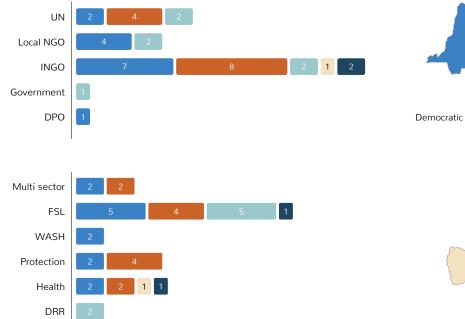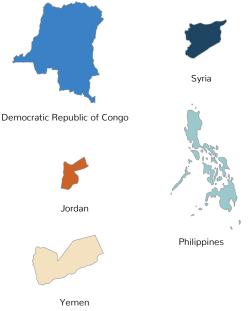
Using your usual language, do you have difficulty communicating, for example understanding or being understood?

Figure 2: Washington Group Short Set of Questions

METHODOLOGY

To tackle the lack of reliable and comparable data in humanitarian action and understand how a validated tool like the WGQs could be used, Humanity & Inclusion has been implementing a project funded by UK Aid on Disability Data in Humanitarian Action to test and assess of the use of the WGQs in humanitarian action. The project supported different types of humanitarian actors working in different sectors and contexts to integrate the questions in their existing practices. It aimed to understand using mixed methods how the questions performed and to determine the necessary process for humanitarian actors to collect useful and quality data using the WG questions:

5   https://dfat.gov.au/about-us/publications/Documents/development-for-all-2015-2020.pdf
6   https://www.gov.uk/government/collections/global-disability-summit-commitments
7   https://reliefweb.int/sites/reliefweb.int/files/resources/Guidance_on_strengthening_disability_inclusion_in_Humanitarian_Response_Plans.pdf
8   http://www.washingtongroup-disability.com/
9   https://humanity-inclusion.org.uk/en/disability-data-in-humanitarian-action

KEY FINDINGS

Identify entry points in the Humanitarian Programme Cycle for collection of disability data:

Approaches to collect data on persons with disabilities can vary depending on the stage of the Humanitarian Programme Cycle (HPC), the context and sector of intervention.

As a result it is fundamental before starting to collect data to reflect on:

Planning for the collection of disability data should not be overlooked. The planning checklist and flowchart developed by HI can guide you in this process.

1. **Whether reliable secondary data is available:** At each stages of the HPC (figure 5), there might be secondary sources of disability disaggregated data relevant for humanitarian staff planning to use the WGQs (CHECK). **If no data is available** you might want to collect primary data on disability and make it available to other (CONTRIBUTE)
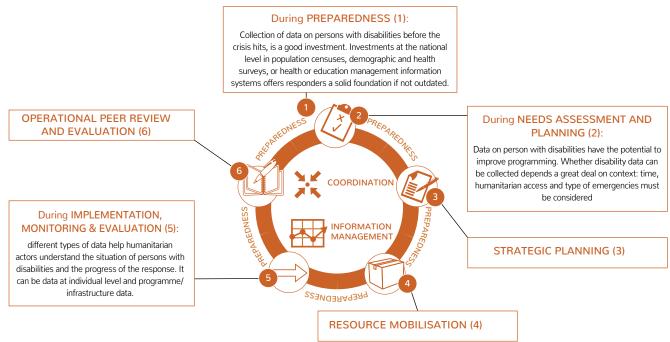
During PREPAREDNESS (1):

Collection of data on persons with disabilities before the crisis hits, is a good investment. Investments at the national level in population censuses, demographic and health surveys, or health or education management information systems offers responders a solid foundation if not outdated.

OPERATIONAL PEER REVIEW AND EVALUATION (6)

During NEEDS ASSESSMENT AND PLANNING (2):

Data on person with disabilities have the potential to improve programming. Whether disability data can be collected depends a great deal on context: time, humanitarian access and type of emergencies must be considered

COORDINATION

INFORMATION MANAGEMENT

During IMPLEMENTATION, MONITORING & EVALUATION (5):

different types of data help humanitarian actors understand the situation of persons with disabilities and the progress of the response. It can be data at individual level and programme/ infrastructure data.

STRATEGIC PLANNING (3)

RESOURCE MOBILISATION (4)

Figure 5: Stages of the Humanitarian Programme Cycle (HPC) and data collection

2. **What context you are operating in:** data collection modalities vary a lot depending on humanitarian contexts. Different types of emergencies play out along very different time-scales. This has very large implications for choosing appropriate modalities for data collection.

   √ In **sudden onset emergencies,** it is hard to collect detailed individual data early in the response and so efforts should be made during emergency preparedness.

   √ During **displacement and refugee emergencies,** data is usually collected at the individual level during registration of refugees.

   √ In **protracted crisis**, data can be collected frequently and used to help monitor the performance of humanitarian programming. Pre-existing context and capacities affect the data available.

3. **What is your sector of intervention and objective for collecting data:** The use of the WGQ in humanitarian contexts was successful to:

   √ Understand the prevalence of persons with disabilities at population level

   √ Understand level of access of persons with disabilities to humanitarian programmes

   √ Disaggregate key programmes indicators by disabilities.

   Different objectives collecting disability data were observed in the food security and/or livelihoods sectors to target vulnerable people (including persons with disabilities), and in the health sector to refer persons with disabilities to health facilities. In these two cases, the use of the WGQs is not recommended.
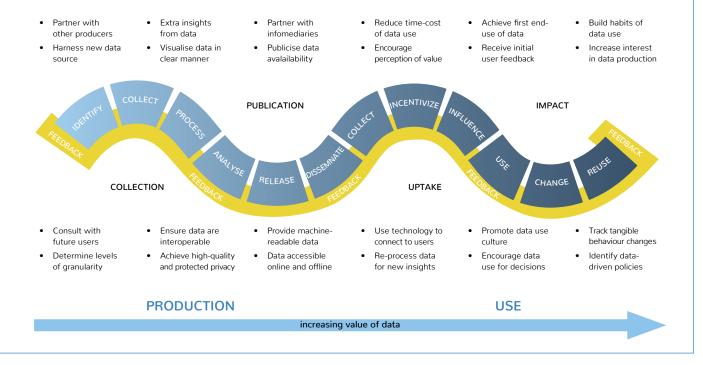
4. **What WGQs is more adapted to your objectives and context:** Short Set, Enhanced Short Set (with focus on anxiety and depression) or Child Functioning Module.
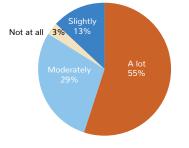
Data Value Chain

USEFUL RESOURCE: DATA VALUE CHAIN

In an effort to improve understanding of the path from data to impact Data2X[10] Open Data Watch created in 2018 the Data Value Chain - a tool that was used during the project to structure the process data undergo from collection to publication to uptake to impact and help frame thinking and discussions around the objective and use of disability data.

- Partner with other producers
- Harness new data source

- Extra insights from data
- Visualise data in clear manner

- Partner with infomediaries
- Publicise data avalailability

- Reduce time-cost of data use
- Encourage perception of value

- Achieve first end-use of data
- Receive initial user feedback

- Build habits of data use
- Increase interest in data production

- Consult with future users
- Determine levels of granularity

- Ensure data are interoperable
- Achieve high-quality and protected privacy

- Provide machine-readable data
- Data accessible online and offline

- Use technology to connect to users
- Re-process data for new insights

- Promote data use culture
- Encourage data use for decisions

- Track tangible behaviour changes
- Identify data-driven policies

PRODUCTION   **USE**

increasing value of data

Training is essential to ensure collection of quality and reliable data

Once the objectives and tools to collect data on persons with disabilities have been identify, it is essential to ensure that programmes staff and enumerators are trained on the WGQ but also on disability. Even though they look short and easy, research findings shows that lack of understanding of disability or training on the questions can result in the collection of poor quality and unreliable data. Research showed that training leads to attitudinal change towards persons with disabilities for 100% of enumerators and successfully builds confidence around applying the WGQs:

Figure 6: Increased understanding of the WGQs after the training

Depending on the time available for training, adapt HI's training pack for enumerators to cover disability and the WGQ and print the do's and don't for enumerator to keep and use during data collection.

USEFUL RESOURCE:

To support these efforts Humanity & Inclusion has been designing a learning toolkit[11] created by as an entry point to address the training needs: understanding, planning for and using the WGQs to identify persons with disabilities in humanitarian action as well as supporting resources for enumerators during the data collection.

10   https://opendatawatch.com/reference/the-data-value-chain-executive-summary/
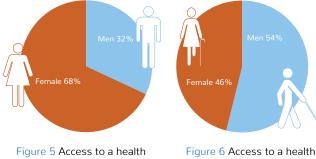
Use the WGQs to inform inclusive programming

Successful planning and training results in the collection of disability data that can be used in decision making to improve disability inclusive programming.

1. **Understanding demographics with prevalence of persons with disabilities:** Using the WGQs in population level survey enables humanitarian actors to understand prevalence of persons with disabilities in a given area. For example, the Syria Humanitarian Needs Overview 2019[12] released by OCHA, identified 11.7 million people in need of humanitarian assistance; 3 million of which are persons with disabilities.

11.7 million
People in need of various forms of humanitarian assistance

3 million
People live with a **disability** in Syria

2. **Measure access to services by persons with disabilities:** Adding the WGQs in case management/registration activities provide information on the number of persons with disabilities accessing programmes or services. Further disaggregation by age, sex, location and other relevant characteristics can highlight humanitarian actors of potential barriers to access for certain groups – such as women with disabilities from Syrian origin in the pie chart below.
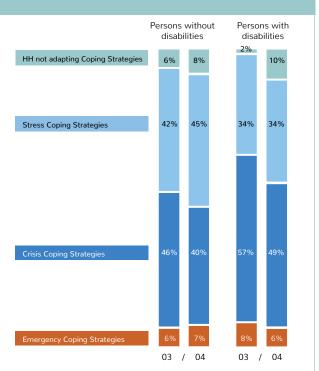
Men 32%

Female 68%

Men 54%

Female 46%

Always disaggregate data by sex, age, disability, geographical location and other relevant factors to understand inclusion of different subgroups.

Figure 5 Access to a health centre for Syrian refugees disaggregated by sex

Figure 6 Access to a health centre for Syrian refugees **with disability** disaggregated by sex

3. **Disaggregation of programmes indicators by disability:** Data broken down by sex, age and disability is an informative way to understand the situation of persons with disabilities and assess effectiveness of humanitarian action.

EXAMPLE OF GOOD PRACTICE:

Survey to assess household level food security using the WGQs World Food Program Food Security Outcome Monitoring (FSOM) survey[13]

By using the WGQs, WFP was able to disaggregate food outcome security indicators by disability and understand whether levels of food security of Syrian refugees' household in Jordan differed when a member of the household has a disability. Analysing data in this way gave WFP an insight into how persons with disabilities are included in WFP's services, in comparison with persons without disabilities, or indeed other vulnerable groups. They identified that household with member with disabilities are resorting to more severe coping mechanisms and hence gathered valuable information for future programming.

	Persons without disabilities		Persons with disabilities	
HH not adapting Coping Strategies	6%	8%	2%	10%
Stress Coping Strategies	42%	45%	34%	34%
Crisis Coping Strategies	46%	40%	57%	49%
Emergency Coping Strategies	6%	7%	8%	6%
	03 / 04		03 / 04	

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11   https://humanity-inclusion.org.uk/en/disability-data-in-humanitarian-action#8

12   https://hno-syria.org/#resources

13   https://docs.wfp.org/api/documents/WFP-0000104593/download/?_ga=2.244088517.1972049402.1557934679-235597009.1556704602

Missing piece: Collecting data on barriers is essential to plan an inclusive response:

Collection of data on persons with disabilities using the WGQ is useful for the purposes highlighted below. However, to be able to plan an inclusive response, it needs to be complemented by question on barriers and enablers can give humanitarian actors a better understanding of barriers faced by persons with disabilities to access services.

Data on barriers and facilitators can be collected using qualitative methodology. A standardised methodology currently doesn't exist.
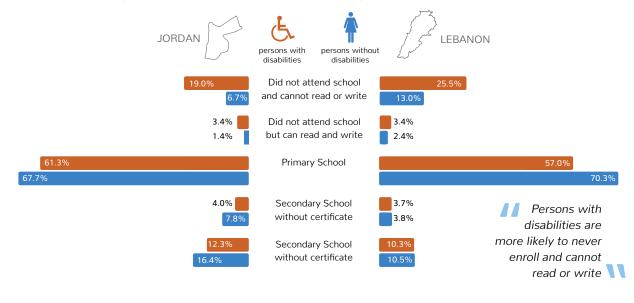
EXAMPLE OF GOOD PRACTICE:

conducting a survey on disability among refugees to barriers to access education: [14]
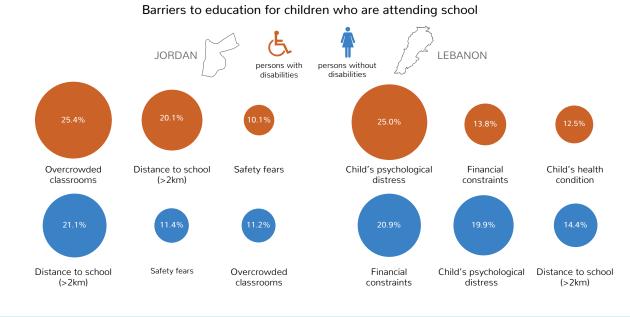
By collecting information on barriers in their study, HI and iMMAP were able to understand what barriers faced by children with disabilities to access education.

Education for Persons Aged 13+

Highest level of education completed among persons 13 years and over

JORDAN   persons with disabilities   persons without disabilities   LEBANON

	JORDAN persons with disabilities	JORDAN persons without disabilities		LEBANON persons with disabilities	LEBANON persons without disabilities
Did not attend school and cannot read or write	19.0%	6.7%		25.5%	13.0%
Did not attend school but can read and write	3.4%	1.4%		3.4%	2.4%
Primary School	61.3%	67.7%		57.0%	70.3%
Secondary School without certificate	4.0%	7.8%		3.7%	3.8%
Secondary School without certificate	12.3%	16.4%		10.3%	10.5%

Persons with disabilities are more likely to never enroll and cannot read or write

Enrolment Status of Children Aged 6-12 years

Barriers to education for children who are attending school

JORDAN   persons with disabilities   persons without disabilities   LEBANON

JORDAN – persons with disabilities:
- Overcrowded classrooms 25.4%
- Distance to school (>2km) 20.1%
- Safety fears 10.1%

LEBANON – persons with disabilities:
- Child's psychological distress 25.0%
- Financial constraints 13.8%
- Child's health condition 12.5%

JORDAN – persons without disabilities:
- Distance to school (>2km) 21.1%
- Safety fears 11.4%
- Overcrowded classrooms 11.2%

LEBANON – persons without disabilities:
- Financial constraints 20.9%
- Child's psychological distress 19.9%
- Distance to school (>2km) 14.4%

SUMMARY

1. **Plan adequately for data collection:**
   Ensure that the objective of the data collection is clear and that data analysis phase is planned and adequately supported. Explore the barriers/needs/possibilities for using qualitative and secondary data more effectively for planning, implementing, monitoring and evaluating impactful interventions. Identify other entry points in humanitarian data collection processes where the use of the WGQs is appropriate.

2. **Training on the Washington Group:**
   Make training available to staff involved in the data collection and analysis and integrate training around disability awareness and inclusion. Ensure that enumerators are trained to ask questions sensitively and manage expectations when asking questions.

3. **Capacity building on inclusive programming:**
   Build the capacity of humanitarian stakeholders to collect, analyse and use data to strengthen inclusion of persons with disabilities in humanitarian action and actions that can be put in place to ensure inclusive programming. Work with other INGOs to share knowledge, data and best practice.

4. **Participation**
   Promote the participation of accountability towards persons with disabilities and organizations of persons with disabilities (DPOs) in efforts related to data collection and decision-making processes