Identification of Persons with Disabilities and Washington Group Questions

Humanitarian actors are often unaware of the number of persons with disabilities in a given disaster or crisis.[i] Without persons with disabilities being systematically identified, humanitarian actors are not in a position to implement an appropriate inclusive response that will ensure persons with disabilities (regardless of the type of disabilities and not limited to physical disability) have an equitable access to basic services. These gaps were reflected by the *Charter on Inclusion of Persons with Disabilities in Humanitarian Action*[ii] launched at the World Humanitarian Summit in 2016, which to date has been endorsed by more than 160 stakeholders. A number of substantial challenges exist as regards the collection and use of data on persons with disabilities in different humanitarian settings, including the Syrian refugee context.

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Regularly-used humanitarian assessment tools ask a binary "yes-no" question, such as "do you have a disability?" or "do you have a medical condition?" to capture disability, which reinforces a medical interpretation of disability and leads to underreporting. The stigma attached to the word "disability" has been demonstrated by various research[iii]; some people are reluctant to identify themselves or their relatives as persons with disabilities as they fear discrimination or exclusion from their community. This question is also likely to capture only the most severe cases of disability.

In addition, it implies that the persons know about their medical conditions, although that is not necessarily the case. Even if they do, there is a great variance in functioning among people with same diagnosis. It will also exclude older people who will think their difficulties simply as the consequences of ageing, but will not label them as 'disability.' As a result, this question will not generate data that is sufficiently comparable or reliable to information humanitarian programming.

Humanitarian actors lack information and knowledge about other available or appropriate tools to collect data on persons with disabilities and how to use them. Mainstream humanitarian actors often rely on disability-focused organisations to take ownership over provision of services and rights for persons with disabilities. Yet some, disability-focused organisations usually have limited capacity and have little experience or expertise in humanitarian response. They are therefore not equipped to identify and address the needs of persons with disabilities affected in a given crisis. While an internationally standardised set of questions to assess disability prevalence exists, its use has been limited and unsystematic in humanitarian action.

The Washington Group on Disability Statistics

The Washington Group tools to identify persons with disabilities

The Washington Group (WG) on Disability Statistics[iv] was created as a result of this lack of common definitions, concepts, standards and methodologies in the production of statistics about persons with disabilities. The UN Statistical Commission during an International Seminar on the Measurement of Disability in 2001[v] recognized that definitions and methodologies for data collection have not been consistent among UN Member States, resulting in inability to compare data. Hence, the WG on Disability Statistics was formed in 2001 as a United Nations Statistical Commission City Group.[vi] Its goal is to develop and test tools **to collect accurate and internationally comparable disability statistics, in order to help actors better identify persons with disabilities, to measure how successfully persons with disabilities are reached by current programs and policies, and to inform future initiatives.**

Since its creation, the WG has developed and tested clear and precise survey questions that can adequately and accurately capture the disability. The first priority was the development of a *Short Set of Questions* that could be easily integrated in existing census or survey to disaggregate the population by disability status to ascertain if persons with disabilities are participating equally in all aspects of society. To date, over 60 countries have used these questions in censuses or surveys.

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In addition to the short set, the WG also developed the **Extended Question Set of Functioning** and, in collaboration with UNICEF, a third set developed to focus on children "the **Child Functioning Module"**, in order to capture more extensive information on disability. It is also working to develop other tools on specific areas such as *mental health* and *the environment and participation* (e.g. *inclusive education* and *employment*).
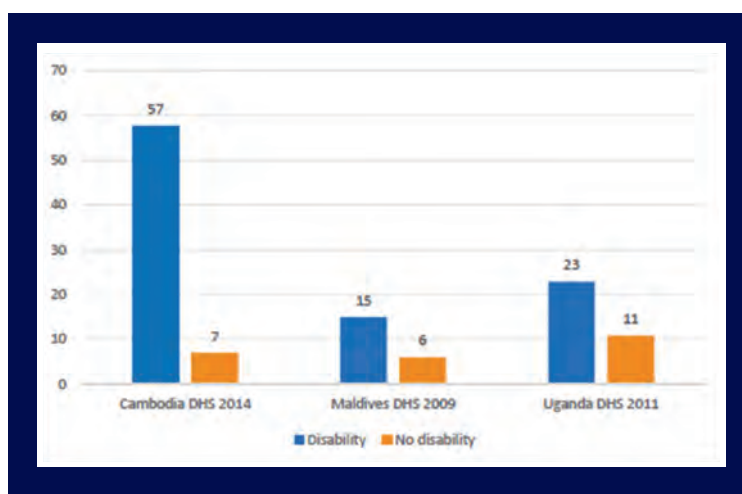
Disaggregation of Data Using the WG Tools

<u>Disaggregation of data using the WG tools</u>
Use of the WG allows stakeholders to **disaggregate collected data by disability** and to look at the difference in outcomes between persons with and without disabilities. For example, the WG questions can be used to calculate the prevalence of disability which can also be disaggregated by other characteristics like gender or age. It also gives you a breakdown by type of disability and information on the range of severity. Patterns in the rates of disability can be identified for different groups.

Example of disaggregated data using the WG questions

Out-of-school rate of children of primary school age, countries using Washington Group questions, by disability status (%)

Source: UIS Fact Sheet No. 40 (UNESCO, 2017)[vii]

WG tools in humanitarian context

While the WG questions were intended for use in national census or survey, they can be used in humanitarian settings, too. The *Vulnerability Assessment Framework paper*[viii] drafted by HI and UNHCR calls on humanitarian agencies providing direct services to refugees in Jordan to use **the WG questions as a tool for screening and flagging disabilities**. It is a quick and efficient way to identify refugees with disabilities that can be introduced in existing data collection tools. It can easily be used by registration staff with no medical knowledge and understood by refugees as it focuses on basic actions. This tool also provides organisations with comparable data across different settings and allows them to identify trends and inform project implementation.

Lack of Comparable Disability Data in Jordan

In Jordan, the disability data is lacking. Recognizing this problem, it is commendable that the Government of Jordan used the WG Short Set of questions used in the 2015 Population and Housing Census. The Census found that 2.7% of people in Jordan (5 years and above) have an *acute or total functional disability* and this goes up to 11% when taking into account *any degree of functional disability (simple to total disability)*[ix] . This percentage is lower than what is expected when using the WG questions with the WG recommended cut-off (i.e. at least one functioning domain is coded as *a lot of difficulty or cannot do it at all*). The methodology used to administered and analyse the census data is unknown so we cannot explain the low prevalence. However, the report refers to simple, acute or total disability which could imply that a different cut-off was used.

With regards to Syrian crisis affected populations, UNHCR registration staff collects and keeps records of registered refugees' information in the UNHCR's global data management and tracing system, called the Profile Global Registration or ProGres. According to ProGres, using the question 'are you disabled? 2.36% of refugees registered in Jordan was found to have a disability (as of October, 2016)[x]. With the on-going refugee crisis, UNHCR has paid increasing attention to the challenges of identifying and meeting the needs of refugees with disabilities[xi]. The Disability Task Force[xii]UNHCR has been leading as the Chair also reached to a consensus to enhance identification of persons with disabilities and gaps of their inclusion. In this context, UNHCR received technical support from HI (see the next section for the project details) and during this process UNHCR piloted the WG questions in 98 registration interviews. Disability prevalence from this pilot was 27.55 % - a 25% increase from the existing data of 2.36 %[xiii]. UNHCR registration staff who involved in this pilot confirmed the benefits of the WG

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questions, mentioning that they help reveal "hidden" disabilities and encourage people disclose their difficulties.

Hidden Victim of the Syrian Crisis: disabled, injured and older refugees research by HI and HelpAge International[xiv] did not use the WG tools to identify persons with disabilities. However, it found that, out of the Syrian refugees surveyed, 30% have specific needs. 22.4% of the surveyed people had some functional limitations in terms of physical, sensory or intellectual ability. Aging is a key factor affecting activities and access to services and in total 77% of older refugees surveyed have specific needs.

Some of data presented above did not use the WG tools but the difference between on one side the data from the Jordan census and ProGres database and on the other hand the UNHCR pilot and the Hidden Victim report show that there is a lack of comparable data on persons with disabilities in Jordan. As such, HI's project Disability Statistics in Humanitarian Action proposes to address this issue by working with humanitarian actors to collect data using the WG questions.

Handicap International Disability Statistics in Humanitarian Action Project

Action-Research in Jordan

As the use of the WG questions was intended for use in national census or survey, it was never tested in humanitarian action. For this reason, HI is piloting the use of the WG questions in three humanitarians contexts selected for their geographical and thematic diversities, including Jordan *(Disability Statistics in Humanitarian Action project).*[xv] This action-research started in March 2017 will last until March 2018. The objective is to assess and understand how the WG questions perform in different humanitarian settings and sectors of inter-

> Steps for humanitarian actors under the project
> ***Disability Statistics in Humanitarian Action***
>
> 1. Advice to adapt humanitarian actors' data collection tools to include the WG questions
> 2. Train partners' enumerators
> 3. Technical Support to data collection and analysis of collected data
> 4. Recommend how actors' can improve inclusive programming for persons with disabilities

vention to identify persons with disabilities as well as the process necessary for humanitarian actors to collect useful and quality data using the WG questions. The research process involves support to humanitarian actors working in different sectors and humanitarian contexts, to integrate the WG questions in their existing practices.

Progress in Jordan so Far

A wide range of organisations have been contacted such as UN agencies, international and local NGOs, disabled peoples' organizations and government agencies, from different sectors, ensuring that the action-research to be representative of various sectors. HI conducted a number of trainings to partners including; UNHCR Registration Staff and VAF Officer, REACH, World Food Programme, International Medical Corps, International Rescue Committee and Danish Refugee Council. Some of them modified their data collection tools to include WG questions, and started the data collection. HI will assist the analysis of data as soon as the collected data are shared.

One of the key actors in this project is UNHCR. It endorsed the WG questions as effective tools to identify persons with disabilities and its registration staff received training on the use of WG questions. There are discussions around the inclusion of the WG Short Set of questions in ProGres. UNHCR also successfully included the WG Short Set of Questions, and some questions from the extended questions set in its Vulnerability Assessment Framework (VAF) which assesses the needs of refugees and establishes the eligibility and priority criteria for refugees' vulnerability at household level in host communities. Currently, VAF quarterly survey is on-going. VAF Baseline (annual), conducted in the beginning of 2017, collected information using WG Short Set as well as the Extended Light set for some parts. The results are expected to reveal various information, disaggregated by disability.

HI delivered a presentation about the WG Questions and HI worked with UNHCR at the NGO-UNHCR conference in Geneva in June 2017. It was a vital opportunity to raise awareness about the WG questions in front of other global actors and show how the questions can be used. The UNHCR NGO Consultation report in 2017 even recommends screening people effectively upon arrival to identify needs and vulnerable individuals and this should include the Washington Group Questions on Disability.[xvi]

Findings from the Action-Research: Data Collecting Experience in Jordan

- **Disability is not always a priority**
  Throughout the thorough discussions, meetings and trainings with different organisations, it became clear that all of the organisations with protection mandate often collect disability data but use different methodology to collect these information, based on their needs for project implementation. Disability questions are either listed under the health sector and assessment or part of the protection assessment. They mainly use one simple and direct question, addressed to beneficiaries, asking about the medical condition of the individual.

  The project also found that some actors do not collect disability data at all – especially when they do not have a protection mandate. In emergency response situations, humanitarian actors will be pouring the optimum level in delivering basic services such as food, non-food items and shelters. Therefore, identifying people based on their vulnerabilities is not one of the priorities for humanitarian actors in this situation.

- **Sensitisation on disability and training**
  Training registration staff on disability is a pre-condition to a successful use of the WG Short Set of questions. The WG questions challenge the way registration staff usually talks about disability. Training is the opportunity to move away from the medical understanding of disability, focusing on impairments such as physical, sensory and intellectual ones. HI delivers training on the WG questions in a way participants understand the questions as well as why they are designed this way. Part of the training is dedicated to the disability definition, the different models of disability and the need for disability data. This helps reflection of participants' own medical understanding about disability and facilitates the introduction of the WG questions.

- **Data sharing agreement**
  In order to make relevant recommendations to support humanitarian actors to use the WG questions, it is helpful for HI to be able to look at the data collected by partners and discuss with them how it can be analysed and used to improve inclusion of persons with disabilities (e.g. the project aims to create learning materials and guidance designed specifically for humanitarian actors). Yet, signing data sharing agreement with the different organisations has been a challenge from the start of the research. The action-research partners have concerns around data protection and use of the data that had to be discussed at different levels of the organisation (from the field to the global level) which take time. The project is holding a number of meetings at different level of the organisations, to address their concerns.

- **Data Management Information System**
  It is not enough to just adapt data collections tools to include the WG questions. It is essential to understand how the data is collected, analysed and used. In Jordan the action research found that the WG questions could be added easily; however, changing the data management system is an issue. Especially, when the data management system is centralized (e.g. ProGres database for UNHCR), it is much more difficult to adapt it as it will have implications for the organisations at large.

- **Use of the data**
  Data on refugees with disabilities will highlight where access and participation issues exist, and can easily be used by actors to adjust service delivery and improve inclusion of refugees with disabilities. However it will not tell actors what the barriers are. This will require more data collection exercises. In Jordan, HI has worked with UNHCR to create a list of indicators disaggregated by disability for VAF that can be extracted from the database and used to improve decision-making.

Conclusion

To ensure refugees with disabilities are not left behind, we recommend organisation to start disaggregating data by at least age, sex and disability - using the WG questions. This will ensure that persons with disabilities are identified in a timely way and will lead to more adequate planning and monitoring of services and support. To support this effort, HI is developing training materials and guidelines on the use of the WG questions in humanitarian action. We will also continue to support UNHCR and other humanitarian stakeholders to ensure that refugees with disabilities are identified during registration efforts as a first step for the full recognition of their rights.

Frequently asked questions and answers on the WG questions (experiences in Jordan)

Q: Do I need specialized staff to use the WG questions?
A: No. It is not necessary to have a medical background to administer the questions, anyone can do it. However, **training is needed**, to understand the questions and how to conduct the interview.

Q: Can we (humanitarian workers) know what services are necessary for identified persons with disabilities, or how we should modify our activities/projects, by using the WG questions?
A: No. The WG questions will identify persons with different functional difficulties and tell you whether they are accessing your services, but it will not tell their needs or barriers in your activities/projects. **Additional barrier analysis and inclusion assessment** are required.

Q: Can I use the Short Set to understand **psychosocial impact of crisis** that leads to functional difficulty?
A. The Short Set does not cover this domain. The **Extended Set of Functioning** covers a wider range of functional domains including anxiety & depression, and fatigue.

More FAQ, such as below, can be found at *http://www.washingtongroup-disability.com/frequently-asked-questions/*

Q: Can the Short Set be used as a diagnostic tool?
A: The WG Short Set does not identify particular health conditions or diagnostic categories.

References

i   See, for example, Avicenna Consulting Pvt Ltd (٢٠١٢) Disability Evaluation Report, Pakistan Alleviation Fund
    http://www.ppaf.org.pk/Sector/evaluation٢٠٤report.pdf
ii   http://humanitariandisabilitycharter.org/
iii   For example, the disability prevalence in Zambia was ٪٢٫٧ in the ٢٠٠٠ Census, when using the question   *Are you disabled in any way ?* The
    ٢٠٠٦ survey using the WG short se t of questions found the prevalence of ٪٨٫٥. S ee http://www.washingtongroup-disability.com/wp-
    content/uploads/٠٥/٢٠١٧ /Session-١-powerpoint.pdf
iv   http://www.washingtongroup-disability.com/
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vi   https://unstats.un.org/unsd/statcom
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ix   http://www.dos.gov.jo/dos_home_e/main/population/census٢٠١٥ /index.htm https://www.unicef.org/jordan/media_١٠٨٩٤ .htm
x   https://www.handicap-international.org.uk/sites/uk/files/documents/files/٢٠١٦ -١١ -disability-universal-indicator-jordan-unhcr.pdf
xi   See, for example, UNHCR Jordan Operational Update March ٢٠١٥:
    http://reporting.unhcr.org/sites/default/files/UNHCR٢٠Jordan٢٠   Operational٢٠Update٢٠March٢٢٠٢٠١٥٪FINAL.pdf
xii   Established in ٢٠١٥ under the Protection and Health Working Groups. Its aim is to ensure the needs of persons with disabiliti es and/or in
    disabling situation (in particular elderly and people with injuries) are thoroughly considered through the humanitarian response. See ٢٠١٧ TOR
    http://data.unhcr.org/syrianrefugees/working_group.php?Page=Country&LocationId=١٠٧&Id=٧٩
xiii   https://www.handicap-international.org.uk/sites/uk/files/documents/files/٢٠١٦ -١١ -disability-universal-indicator-jordan-unhcr.pdf
xiv   http://www.handicap-international.us/hidden_victims_of_syrian_crisis
xv   https://www.handicap-international.org.uk/page/disability-statistics-in-humanitarian-action
xvi   See page ٧ http://www.unhcr.org/events/conferences/٥٩ ad٢٢ da٧٧/final-report-٢٠١٧ -annual-consultations-ngos.html

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