



Position paper

The definition of disability and disability related data collection and analyses

Applying the IASC Guidelines in the northwest Syria humanitarian response

Action by humanitarian partners to strengthen inclusion of persons with disabilities in the humanitarian response in an evidence-based manner remains highly needed – this note aims to support that effort by providing background and explanation on the definition of disability as well as on how to interpret and use data related to disability.

The note also provides elaboration on the Syria Protection Cluster (Turkey) recommended disability-related data collection methodology for humanitarian organizations and entities in northwest Syria. Thereby the note aims to stimulate and assist the broader humanitarian community in northwest Syria in adopting the Washington Group Short Set of Questions on Functioning, especially in relation to disability focused data collection and in understanding and utilizing assessment findings, specifically prevalence-rates of disability in northwest Syria.

For more elaborated description of the situation of persons with disability in northwest Syria and practical suggestions for humanitarians on enhancing inclusion of persons with disabilities in programming, this note is to be read in conjunction with the ITWG “Self-reported barriers to activities of daily living of persons with disabilities living in IDP sites in northwest Syria” brief report and recommendations.ⁱ

Moreover, it is encouraged to read this note in conjunction with Chapter 4 (on data and information management) and respective annexes of the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action (2019)ⁱⁱ as well as Chapter 6 (on managing data and information for protection outcomes) of the ICRC Professional Standards for Protection Work Carried Out by Humanitarian and Human Rights Actors in Armed Conflict and Other Situations of Violence (2018).ⁱⁱⁱ Useful considerations are also put forward in: Humanity & Inclusion (2018). Disability Data in Humanitarian Action.^{iv}

The definition of disability

The Inclusion Technical Working Group of the Syria Protection Cluster (Turkey) uses the United Nations Convention on the Rights of Persons with Disabilities (CRPD) definition of disability. In line with the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action the Protection Cluster urges all humanitarian organizations and entities to adopt this definition as well as incorporate the definition in all information management systems. In the CRPD, disability is defined as follows:

'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.^v

- The definition communicates that persons with a disability have the same rights as everyone else in society and that duty bearers have a role to play in upholding these rights.^{vi}
- The definition also explicitly recognizes that disability is an experience of persons who face attitudinal, environmental, and/or institutional barriers to participation in society, accessing services, moving around, etc. Therefore, a person is not defined as 'with disabilities' based on an impairment of a body structure and/or function alone, but due to the interplay between an impairment and barriers (which are the result of unintentional and intentional human actions). Barriers lead to exclusion, making it likely that persons with disabilities will face more or worse threats and vulnerabilities than others affected by a crisis.^{vii}

Data and strengthening inclusion of persons with disability

The IASC Guidance on Inclusion of Persons with Disabilities in Humanitarian Action states that the CRPD should be incorporated in all humanitarian interventions. To do so, the IASC Guidelines state that ‘humanitarian actors should examine and evaluate current practices, processes, and outcomes to ensure that the human rights of persons with disabilities are protected and promoted as required by international law.’

To build a foundation for evidence-based action on disability inclusion it is important for the humanitarian organizations and entities to obtain, analyze, and understand data on persons with disabilities and barriers. A bare minimum in this regard is ensuring disaggregation of data on the affected population by disability – as a matter of principle, data disaggregated by sex and age used within humanitarian organizations as well as the coordination system should also be disaggregated by disability.

Information should also be generated on existing and emerging barriers to access rather than the type of disability itself. Monitoring and evaluation systems, within humanitarian organizations as well as in clusters, should aim to identify barriers to accessing services. These barriers can be internal and external to the humanitarian system, their identification is in line with the Core Humanitarian Standards, the Accountability to Affected Populations principle, etc.^{viii}

This data and information aim to make visible the presence and focus on needs of persons with disabilities, improve the understanding of the different ways in which persons with disabilities experience a crisis, and to monitor their access to assistance. It is the responsibility of all humanitarian organizations to ensure adequate collection and analysis of this data and information.

Towards standardized data collection on disability in northwest Syria

Multiple humanitarian assessment initiatives in northwest Syria, including HNAP, the CCCM Cluster ISIMM+, the Protection Monitoring Task Force, as well as assessments conducted by humanitarian organizations include questions and indicators to measure the prevalence of disability. In some instances, data collection methodologies are not aligned, resulting in complications in comparing data and conducting analyses. The Inclusion TWG calls on all clusters and humanitarian organizations to adopt a standardized data collection methodology in relation to disability.

The data collection framework recommended by the Inclusion TWG is the Washington Group Short Set of Questions on Functioning (WGSS).^{ix} The WGSS is a set of six short questions and is the tool which is most widely used and tested in humanitarian settings. It is easily applied and analyzed while enumerators, information managers, and M&E staff require only a basic training / sensitization to accurately collect the information.

The Washington Group Short Set of Questions on Functioning (WGSS)

Following the CRPD’s and IASC’s definition of disability, the WGSS recognize that disability occurs when a person with an impairment experiences barriers when carrying out one or more core human functions in their environment. Therefore, the WGSS don’t ask ‘do you have an impairment?’ (or, ‘do you have a disability?’).

Rather, the WGSS seek to determine whether the person experiences difficulty at the activity level (e.g., when an individual is carrying out a core and/or daily function such as walking or communicating with others). Thus, in line with the CRPD, in the WGSS the type of impairment or health condition is not the defining factor in determining

disability. The WGSS questions are function-based and seek to capture difficulty across six functional domains in six questions related to:

- Vision
- Hearing
- Mobility
- Cognition (remembering or concentrating)
- Self-care (such as washing and dressing)
- Communication

See annex 1 for the WGSS and links to detailed guidance.

Although a simple set of questions, as noted above, staff designing surveys, enumerators administering surveys, and staff analyzing survey results should receive a basic training on the WGSS in order to reduce errors and ensure reliability of data. The Inclusion TWG can provide guidance on the type of training required based on the type of exercise planned and can provide training to organizations as required.

Use and interpretation of data generated by the WGSS

To facilitate a holistic understanding of the situation of the assessed population (especially the interplay between an impairment and contextual barriers) it is to be advised that the WGSS should be used as follows:

- as part of large data collection exercises to facilitate disaggregation during analysis by comparing between groups of respondents;^x
- in programme monitoring; and
- in conjunction with other assessments and qualitative research using modalities such as Key Informant Interviews and Focus Group Discussions.

It is to be noted that the WGSS measure a risk of limited participation in society only, including in relation to accessing humanitarian assistance and services. The WGSS therefore cannot be used as a replacement for clinical diagnoses or to determine service needs related to impairments or illnesses at the individual level (such as the need for physical rehabilitation or assistive devices).

The use of the WGSS, when used in conjunction with sex and age disaggregation, assists organizations and clusters to understand in more detail how the intersectionality of gender, age and disability impacts on barriers to service access. In program monitoring, through analysis of data and in combination with other (qualitative) information the WGSS and ensuring disaggregation can be used to identify, assess, analyze, and understand access rates of persons with disabilities to humanitarian assistance programmes, thereby informing (corrective) action. Where required, this type of analyses for monitoring and evaluation may rely on baselines established through larger data collection exercises.

For example, the WGSS could facilitate an improved understanding of the inclusiveness of livelihood programmes from a gender-age-disability perspective. Analyzing data disaggregated using the WGSS can provide information on whether women with disabilities are accessing livelihood programs on an equitable basis with women without disabilities and men with and without disabilities. Understanding these dynamics helps staff to identify areas where

programmatic design can be adjusted to ensure barriers are reduced and opportunities equalized for women with disabilities in this regard.

Making sense of disability prevalence percentages

Surveys and assessments across northwest Syria have highlighted a high prevalence of disability in the population, especially when compared with estimated global averages or the 15 per cent rule of thumb as proposed by the IASC guidance in the absence of any data.

When interpreting these high percentages humanitarian staff are encouraged to keep in mind the abovementioned definition used by the CRPD and IASC on disability, as well as the intersectionality between age, gender, and disability (e.g. older people often experience more functional difficulties in activities of daily living and experience further barriers). The CRPD and IASC definition of disability (as well as the WGSS) is based on the human rights model of disability and is proven to be much more relevant than outdated models of disability e.g. the medical model of disability. Percentages of persons reporting disabilities are higher when using the IASC definition of disability rather than the medical model of disability which is due to a focus on difficulties in functioning as a result of impairments and barriers in the former and solely on impairments in the latter.

For humanitarian organizations in all sectors, percentages on disability prevalence using the IASC definition are crucial to be taken into account given the humanitarian imperative of assisting those who are least able to cope with the crisis and in situations of the highest vulnerability. Data on prevalence of disability is an essential component of understanding the specific situations of segments within the affected population and should lead to decisions and adjustments that improve the quality and impact of humanitarian programming for *all* affected by the crisis in northwest Syria.

Conclusion

The definition of disability and its links with the WGSS as well as with the humanitarian principles lie at the basis of the recommendation of the Syria Protection Cluster (Turkey) Inclusion Technical Working Group, in line with the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action (2019), to use the WGSS for the purposes of data collection exercises and analyses by all humanitarian organizations and other entities in northwest Syria. The WGSS are the ideal tool to identify persons who experience functional difficulties and thus are at risk of exclusion from humanitarian services in humanitarian settings and should be integrated across all clusters and organizations.

For further information on the application of the WGSS in your programme, you can contact the Inclusion Technical Working Group of the Syria Protection Cluster (Turkey) by emailing: rehab.dis.specialist@sr.hi.org, zeilstra@unhcr.org, and lamii@unhcr.org.



Annex 1 – Washington Group Short Set of Questions on Functioning

Question	Response options
Preamble to the WG-SS: <i>[Interviewer read:]</i> “The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.”	
VISION VIS_SS [Do/Does] [you/he/she] have difficulty seeing, even if wearing glasses? Would you say... <i>[Read response categories]</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused 9. Don't know
HEARING HEAR_SS [Do/Does] [you/he/she] have difficulty hearing, even if using a hearing aid(s)? Would you say... <i>[Read response categories]</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused 9. Don't know
MOBILITY MOB_SS [Do/Does] [you/he/she] have difficulty walking or climbing steps? Would you say... <i>[Read response categories]</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused 9. Don't know
COGNITION (REMEMBERING) COG_SS [Do/does] [you/he/she] have difficulty remembering or concentrating? Would you say... <i>[Read response categories]</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused 9. Don't know
SELF-CARE SC_SS [Do/does] [you/he/she] have difficulty with self-care, such as washing all over or dressing? Would you say... <i>[Read response categories]</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused 9. Don't know
COMMUNICATION COM_SS Using [your/his/her] usual language, [do/does] [you/he/she] have difficulty communicating, for example understanding or being understood? Would you say... <i>[Read response categories]</i>	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all 7. Refused 9. Don't know

See for further notes and discussion of the WGSS, including guidance for conducting statistical analyses, as well as other sets of questions: <https://www.washingtongroup-disability.com/question-sets/>

Arabic translations of the WGSS questions can be accessed via: <https://www.washingtongroup-disability.com/resources/translations-of-wg-question-sets/>



ⁱ <https://www.humanitarianresponse.info/en/operations/stima/document/self-reported-barriers-activities-daily-living-persons-disabilities-living>

ⁱⁱ <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>

ⁱⁱⁱ <https://www.icrc.org/en/publication/0999-professional-standards-protection-work-carried-out-humanitarian-and-human-rights>

^{iv} <https://humanity-inclusion.org.uk/en/projects/disability-data-in-humanitarian-action>

^v United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006); accessible via:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>; see also:

<https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>

^{vi} The IASC has emphasized the relevance of international law in humanitarian crises, in particular international humanitarian law (IHL), international human rights law (IHRL), and international refugee law. These bodies of law provide a legal framework that grounds humanitarian action in internationally agreed principles and standards and affirms the rights of all individuals affected by crises. This explicitly includes the UNCRPD – practical guidance in this regard is offered in the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action (2019).

^{vii} Barriers are factors in a person's environment that hamper participation and create disability. For persons with disabilities, they limit access to and inclusion in society. Barriers may be attitudinal, environmental or institutional.

- Attitudinal barriers are negative attitudes that may be rooted in cultural or religious beliefs, hatred, unequal distribution of power, discrimination, prejudice, ignorance, stigma and bias, among other reasons. Family members or people in the close network of persons with disabilities may also face 'discrimination by association'. Attitudinal barriers are at the root of discrimination and exclusion.
- Environmental barriers include physical obstacles in the natural or built environment that "prevent access and affect opportunities for participation", and inaccessible communication systems. The latter do not allow persons with disabilities to access information or knowledge and thereby restrict their opportunities to participate. Lack of services or problems with service delivery are also environmental barriers.
- Institutional barriers include laws, policies, strategies or institutionalized practices that discriminate against persons with disabilities or prevent them from participating in society.

Barriers may be classified as a threat if they are put in place intentionally. They are described as a vulnerability if their occurrence is inadvertent. In both cases, barriers lead to exclusion, making it likely that persons with disabilities will face more or worse threats and vulnerabilities than others affected by a crisis.

^{viii} <https://corehumanitarianstandard.org> and <https://interagencystandingcommittee.org/iasc-revised-aap-commitments-2017-including-guidance-note-and-resource-list>

^{ix} The Washington Group on Disability Statistics was established in 2001 under the UN Statistical Commission to support improved identification of persons with disabilities. The Washington Group Questions were developed to generate reliable and comparable data on persons with disabilities during national level data collection exercises. For the Short Set of Questions, see: <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>. See also: Nora Groce, et. al. (2018) "Which one to use? The Washington Group Questions of Model Disability Survey"; Working Paper Series 31, University College London.

^x Through collection of the prevalence of individuals reporting functional difficulties, disaggregated analysis of assessment data can for example serve the following purposes:

- To disaggregate data on needs and risks (for example, the number or proportion of food insecure households that are headed by persons with disabilities).
- To determine the number and location of accessible and inaccessible facilities.
- To monitor access to assistance (for example, establish the number or proportion of participants in livelihood programmes who are persons with disabilities).
- To monitor protection concerns (for example, establish the number of human rights violations, or types of human rights violation, experienced by persons with disabilities).

It is recognized that sample sizes are often too small to arrive at reliable conclusions; however, the indicative information generated in this manner does offer important evidence and pointers for corrective actions. Quantitative data collection using the WGSS allows the identification of individuals with disabilities and calculate the number of persons with disabilities in the affected population (via registration data, household surveys, household estimates, etc.) – this allows for arriving at a baseline understanding to further strengthen abovementioned lines of analysis.