

## JOINT GUIDANCE NOTE FOR CLUSTER PARTNERS ON COLLECTING DATA ON PEOPLE WITH DISABILITIES IN THE CONTEXT OF THE HUMANITARIAN PROGRAMME CYCLE (HPC)

### ●●●● BACKGROUND

**Persons with Disabilities (PwD) are recognized as having specific needs. “Disability” is not an attribute of the person:** if a person lives in an inclusive and comprehensively accessible environment, his or her impairment might not lead to a disability. As such, PwD require additional services to improve their societal integration.

This joint guidance note provides harmonized guidance on how humanitarian actors can collect data on PwD in the process of assessments and studies and encourages all Clusters to develop specific guidance on data on disability partners should collect in the process of monitoring and reporting activities.

It is important to collect data on the number of PwD and the various types of disabilities, so that humanitarian and development organisations can have a better understanding of the number of people with specific needs and the nature of such needs. This, in turn, should help promote **targeted and disability-inclusive humanitarian assistance**<sup>1</sup> and help development actors to plan accordingly longer-term projects, in support of the authorities. Collection of data on PwD also allows agencies to facilitate the process of inter-agency referrals that ensures PwD are supported in safely accessing additional needed services.

Although a dedicated procedure exists in Ukraine to define the conditions and criteria<sup>2</sup> for establishing disability<sup>3</sup>, many people living in areas affected by the conflict in eastern Ukraine struggle to establish or renew their disability status as a result of lengthy and often expensive procedures, which is further complicated by limited access to social and health services. As a result, **not all IDPs and conflict-affected People with Disabilities (PwD) have an official disability certificate**. This limits their access to specific social benefit and services they would otherwise be entitled to, and may also limit their access to humanitarian assistance. In 2018, a needs’ assessment showed that out of the 4,595 older people surveyed, 17.2% were bedridden or immobile, of whom only 17.1% held a disability certificate.<sup>4</sup> In addition, the classification of disability in three groups refers to the severity and not to the domain of disability, which results in **limited opportunities for humanitarian actors to tailor their responses to the needs of PwD**.

### ●●●● DEFINITION

The UN [2006 Convention on the Rights of Persons with Disabilities](#) defines disability as the **result of “the interaction between persons with impairments and attitudinal and environmental barriers** that hinders their full and effective participation in society on an equal basis with others”.

Article 1 of the Convention further qualifies impairments as being “long-term physical, mental, intellectual or sensory impairments”. The Ukraine legal definitions<sup>5</sup> of disability and PwD refer to the Convention and are very similar in content.

In humanitarian contexts, **barriers are external factors in the environment in which people live** that hinder PwD to fully access and participate in humanitarian assistance on an equal basis with others (e.g. discrimination or lack of access to facilities). A barrier free environment should be promoted and advocated for by all actors.

#### GUIDANCE #1 – Enhanced HPC

- Data needs to be collected and disaggregated at a minimum by age, sex and disability
- When reliable data on disability is not available, the [HNO global guidance](#) (p.26) recommends to apply the planning assumption that **PwD make up 15% of the population** (19.2% of women and 12% of men). As [UNDESA](#) (p.9) estimates that **PwD make up 46% of people aged over 60 years old**, this planning assumption should be used when relevant.
- When elaborating the HRP, partners may use the dedicated [Guidance on Strengthening Disability Inclusion](#)

<sup>1</sup> See also the Age and Disability Consortium [Humanitarian inclusion standards for older people and people with disabilities](#), 2018.

<sup>2</sup> [Resolution](#) of the Cabinet of Ministers of Ukraine of December 3, 2009 No. 1317.

<sup>3</sup> 2.7 million people were granted disability status as of 2014, State Statistics Service in Ukraine. Amongst registered IDPs, 50,000 hold a disability certificate, MoSP – August 2019.

<sup>4</sup> Help Age, Emergency protection-based support to conflict affected older women and men in the GCAs location of Luhansk and Donetsk oblasts, [baseline report](#), July 2018.

<sup>5</sup> [Law](#) of Ukraine on the Basis of Social Protection of the Persons with Disability in Ukraine. 2018.

# COLLECTING DATA ON PEOPLE WITH DISABILITIES: NEEDS ASSESSMENTS

## GUIDANCE #2 - Needs assessments

### AT A MINIMUM, SYSTEMATICALLY INCLUDE:

- A question on whether or not the person has a disability
- If yes, whether or not the person holds a disability certificate

### ALTERNATIVELY, CONSIDER INCLUDING:

- The Washington Group Short Set of questions designed to identify persons with impairments
- Specify the affected domain(s) of functioning

In Ukraine, the official proof of disability issued by national social protection authorities is the **primary source of information on disability** but it is not sufficient for assessing the prevalence of disability amongst IDPs and conflict-affected people.

The [Washington Group Short Set of Questions](#) is the most relevant tool for collecting data on the prevalence of disability in humanitarian contexts and should not be understood as a diagnostic tool. It seeks to **obtain information on difficulties a person may have in undertaking basic activities** that, in a non-accommodating environment, are associated with a higher risk of participation restrictions.<sup>6</sup>

DOMAINS	QUESTIONS	Answer by one of the following options:
VISION	1. Do you have difficulty seeing, even if wearing glasses?	<input type="checkbox"/> No – no difficulty <input type="checkbox"/> Yes – some difficulty <input type="checkbox"/> Yes – a lot of difficulty <input type="checkbox"/> Cannot do at all  The <b>recommended cut-off point</b> is as follows: If any individual answers : ‘Yes - a lot of difficulty’ or ‘Cannot do it at all’  <b>to at least one of the six questions</b> , they should be considered a person with a disability for data disaggregation purposes.
HEARING	2. Do you have difficulty hearing, even if using a hearing aid?	
MOBILITY	3. Do you have difficulty walking or climbing steps?	
COGNITION	4. Do you have difficulty remembering or concentrating?	
SELF-CARE	5. Do you have difficulty (with self-care such as) washing all over or dressing?	
COMMUNICATION	6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	

- It is recommended to include the six questions in needs assessment and surveys to identify disability prevalence. This strongly decreases the underestimation of the number of PwD in a humanitarian context.<sup>7</sup>
- It is recognized that **the short set of questions is not always the adequate tool to use, in particular regarding mental health and psychosocial related domains, as well as for children.**<sup>8</sup> These questions may be supplemented by the extended sets on functioning developed by the Washington Group that function similarly as the short set of questions<sup>9</sup>. It is recommended to **use the sets as designed**.

WHAT TOOL?	The <a href="#">Washington Group extended sets on functioning</a> (include between 12 to <a href="#">39 questions</a> )	The <a href="#">WG/UNICEF child functioning module</a>
FOR WHICH USE?	<b>To assess additional domains: upper-body, anxiety, depression, pain and fatigue</b> and further investigates the six initial domains The extended sets are intended for: <ul style="list-style-type: none"> <li>- Population-based household survey</li> <li>- Larger disability survey</li> <li>- Multi-sectoral assessment</li> </ul>	<b>To identify children<sup>10</sup> with disabilities</b> It comprises two sub-modules: <ol style="list-style-type: none"> <li>1. For children 2-4 years old</li> <li>2. For children 5-17 years old</li> </ol> To be administered to the child’s parent or his or her primary caregiver

- Since activities differ considerably among the partners, **data collection needs may also differ. Organisations may therefore want to use WHO tools as an alternative to the WG ones.**

The main tool is the [Model Disability Survey](#) of which a [brief version](#) has been developed in 2017. Interested partners may **approach the Health Cluster for further guidance on the use of these tools.**

<sup>6</sup> [Washington Group on Disability Statistics](#). The Data Collection Tools Developed by the Washington Group on Disability Statistics and their Recommended Use, 2017.

<sup>7</sup> A pilot study conducted in 2016 by UNHCR using the WG-SS on 98 refugee households in Jordan found that 27.55% of refugees had a disability as opposed to the 2016 estimate of 2.36% in their registration system Profile Global Registration (ProGres).

<sup>8</sup> Disability Data Collection: a [summary review](#) of the use of the WGQ by humanitarian and development actors, 2018.

<sup>9</sup> For the domains Anxiety, Depression, Pain and Fatigue, the person is considered a PwD if the highest level of difficulty on a four-point scale is coded to at least one question of the said domain.

<sup>10</sup> For more information, see also UNICEF Guidelines on [Including Children with Disabilities in Humanitarian Action](#), 2017.

## ●●●● COLLECTING DATA ON PEOPLE WITH DISABILITIES: MONITORING AND REPORTING

For monitoring and reporting purposes, it is the **responsibility of each sector to decide on a tailored methodology to collect data on disability**. All clusters are encouraged to discuss and agree on **common requirements that are contextualized to their sector**.

The following aspects must be considered:

- **Sectors and types of activities:** disaggregation by disability might not be relevant for all activities.  
*What data is relevant and useful for adequate planning and delivery of the humanitarian response?*
- **Partners' resources and capacities:** collecting this data requires partners to update their internal systems, collect disaggregated data on a regular basis and report on it.  
*What data do partners already collect? What data can they collect in a sustainable manner? With which tool? Is specific support and/or training needed?*
- **Data collection tools:** depending on the sectors certain sets of questions might be more adapted than other because of either the length of the sets of questions or the type of disability (this applies in particular to MHPSS) or the target population (children in particular).  
*What tools would both meet sectoral needs and match with available resources and capacities?*

It is recommended that the new approach to collecting data is introduced from early 2020 onwards, so that partners have enough time to either update or rebuild their systems.

**The Protection Cluster has reflected on the above and is sharing its guidance** on collecting data on disability for monitoring and reporting purposes, in particular through the 5W process.

### GUIDANCE #3 – Monitoring & reporting

Each cluster discuss and agree on a common methodology tailored to:

- The sector and types of activities
- The capacities and resources of partners

Monitoring and reporting data on disability imply for each cluster to identify:

- The activities
- The level of disaggregation

## PROTECTION

ACTIVITIES	LEVEL OF DISAGGREGATION	RATIONALE
Legal assistance	Disability: YES/ NO → If yes, disability certificate: YES/ NO	IDPs and conflict-affected people benefiting from legal assistance might struggle to establish or renew their disability certificate and therefore be in need of tailored legal support.
Individual psychosocial support	Disability: YES/ NO → If yes, disability certificate: YES/ NO OR <u>Preferably</u> , Domain(s) of impairment according to the Washington Group short set of questions	People in need of individual psychosocial support are may have disabilities or impairments. PSS activities have to be tailored to specific needs. The level of disaggregation by domain of impairment may improve referrals and programming and inform at a larger level the type of services and capacities needed.
Individual protection assistance (cash/ non-cash)	Disability: YES/ NO → If yes, disability certificate: YES/ NO OR <u>Preferably</u> , Domain(s) of impairment according to the Washington Group short set of questions	IPA is delivered on a need basis. Disabilities and impairments impact the nature of such needs. The domain(s) of impairment is particularly useful to tailor the humanitarian response. Types of assistance may include e.g. the provision of specific assistance devices for PwD.
Mine victims assistance	Disability: YES/ NO → If yes, disability certificate: YES/ NO OR <u>Preferably</u> , Domain(s) of impairment according to the Washington Group short set of questions	Mine victims are more likely to have disabilities or impairments due to the nature of injuries resulting from mine-related incidents. Assistance provided must be tailored to the needs of the victims, therefore emphasizing the relevance of disaggregating data on disability by domain(s) of impairment.
Provision of shelter to GBV survivors and community spaces to older people and PwD	Disability: YES/ NO → If yes, disability certificate: YES/ NO OR <u>Preferably</u> , Domain(s) of impairment according to the Washington Group short set of questions	The shelter and community spaces as well as on-spot services might need to be adapted so that identified impairments do not prevent affected people to access humanitarian assistance. It might also facilitate further referrals for support.