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

Background:

The inter-census data 2019 shows that the disability prevalence rate in Myanmar is 12.8% with the most common type being difficulties in seeing (6.3%), followed by walking/climbing steps (5.4%), remembering/concentrating (4.4%), hearing (2.4%) and communication (1.6%).[1] Persons with disabilities and those with mobility challenges face additional risks to their lives because they may not be able to protect themselves or find disability-friendly infrastructure, and access to protection or other essential services may be compromised. It becomes particularly difficult in times of conflict when they cannot quickly access safe places or leave an area under siege. In addition to difficulties when accessing services due to infrastructure, people with disabilities also often face attitudinal and institutional barriers, resulting in difficulties for their daily living and access to humanitarian assistance and protection. Furthermore, persons with disabilities may experience targeted violence and abuse because of their disability. Targeted violence against persons with disabilities may include physical attacks, killings, denial of food and medicine, harassment, emotional abuse, sexual abuse, profound neglect, shackling, and confinement.

People with disabilities are likely to face specific risk and barriers and humanitarian settings. In addition to protection and assistance, they also require access to services response to their requirement, such as rehabilitation care, assistive devices, or nutrition support among others. The Convention on the Rights of Persons with Disabilities (CRPD) recognizes persons with disabilities as *"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"* (Article 1).

"Disability" is a dynamic concept and not an attribute of the person: if a person with impairments in need access barrier-free and inclusive assistance and environment, his or her impairment might not lead to discrimination or exclusion. As such, people with disabilities require needs-based and inclusive services and necessary reasonable accommodations. This joint guidance note provides harmonized guidance on how humanitarian actors can promote

> **GUIDANCE #1 – Enhanced HPC**
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> - *Data needs to be collected and disaggregated at a minimum by age, sex, and disability. If and where possible, it should be disaggregated by type of disability (vision, hearing, mobility, cognition, self-care, communication).*
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> - *When reliable data on disability is not available, the HNO global guidance (p.26) recommends applying the planning assumption that people with disabilities make up 15% of the population (19.2% of women and 12% of men). As UNDESA (p.9) estimates that people with disabilities make up 46% of people aged over 60 years old, this planning assumption should be used when relevant.*
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> - *When elaborating the HRP, partners may use the dedicated*

inclusive humanitarian strategies and programs by enhancing the collecting use and analysis of quality disability data in the process of assessments and encourages all clusters to develop specific guidance on quality disaggregated disability data partners should collect in the process of monitoring and reporting activities.

This, in turn, should help promote targeted assistance and/or mainstream disability in the humanitarian responses[2] and help non-humanitarian actors to plan a sustained/integrated interventions as appropriate. Collection of data on people with disabilities also allows partners to facilitate the process of inter-agency work to promote inclusion and inclusive referrals that ensures people with disabilities are supported in safely accessing needed services.

Protection Mainstreaming principles

Collecting data on risks, needs, priorities and capacities of persons with disabilities among affected communities is extremely important for inclusive planning, budgeting, response, and monitoring. In order to better identify and respond

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[1] Myanmar inter-census survey 2019: https://www.dop.gov.mm/en/publication-category/2019-inter-censal-survey
[2] See also the Age and Disability Consortium Humanitarian inclusion standards for older people and people with disabilities, 2018.

to the needs of persons with disabilities in affected communities, it is necessary to include question related to the risks, stigma, the barriers they might face while accessing assistance, or the gaps in program or service design. In the same way, this process or exercise are also what constitutes an effective way of supporting an accountable humanitarian system. Accountability refers to the responsible use of power, combined with effective and quality programming that recognizes the community's dignity, capacity, and ability for self-determination.

Additional data on specific barrier help to identify gaps within the strategy, services, at the level of communities, households, or the individual. Combining data on barriers with information on needs, access, and participation rates in crucial at every stage of the project to promote inclusion.

To identify and respond to persons with disabilities needs, humanitarian actors need to use different inclusive or accessible methods and tools. Data disaggregation by disability helps for example to identify the number of persons with disabilities, their needs, access rates, yet does not give information on particular risks, stigma, the barriers they might face while accessing assistance or the gaps in program or service design. Strengthening inclusion within an accountable humanitarian action requires the need as well for strong community engagement that encourages and facilitates access to lifesaving information and two-way communication (giving account to), feedback and complaints (being held to account), and meaningful participation (taking account of PWDs with different disabilities).

In order to better identify and respond to the needs of persons with disabilities among affected communities and design inclusive programs' **questions related to the risks, barriers and enablers persons with disabilities might face need to be incorporated.**

The purpose of this guidance note is to support humanitarian actors in collecting and using quality disability data for inclusive programming **IN THE CONTEXT OF THE HUMANITARIAN PROGRAMME CYCLE (HPC). The collection and analysis of quality data allows humanitarian actors to:**

- Have stronger estimate of persons with disabilities in areas of intervention, including their socio-demographic characteristics, to support prioritization and targeting of assistance
- Have stronger data on specific risks and barriers faced by persons with disabilities to access assistance and protection (information about rights, entitlements, and services) or capacities and resources they have
- To support monitoring how humanitarian aid reaches persons with disabilities in need, and reduces their humanitarian risks, or strengthens their capacities.

Protection Mainstreaming

Protection of persons with disabilities is a core aspect of humanitarian programming. This guide provides a brief description on how the four pillars of protection mainstreaming should be considered.

Safety and Dignity; in all assessments, design of programs and delivery of services, the safety and dignity of persons with disabilities should be respected by putting in place measures to ensure and promote equal participation for all. For instance, distribution and or other program sites need to be safe for persons with disabilities to access in a dignified manner. Processes, standards and staff must uphold the dignity of people with disabilities, with training provided for staff to ensure this is achieved.

Meaningful Access: all barriers to access sites, services and information need to be removed so that people with disabilities are enabled to easily access. When sharing information there is need to use multiple approaches for persons with disabilities e.g. using audio means for those with visual difficulties. Agencies should put in place means for inclusion to facilitate access of persons with disabilities e.g. transportation, accessible buildings and rooms, interpretation – where possible. Most of these need to be considered in the budget.

Participation and Empowerment; all participation should be voluntary, safe and meaningful. All persons with disabilities, like other community members, should have equal opportunities to participate and engage in

empowerment programs. Where possible, affirmative action[3] should be considered, as well as existing resources and capacities of the communities. Persons with disabilities should be encouraged to participate in consultations and encouraged to actively participate.

Accountability; AAP mechanisms should be accessible and user friendly for all persons with disabilities. Extra measures should be put in place to enable persons with disabilities to give and receive feedback. Feedback and complaint mechanisms must be available for people with disabilities, including physical access to sites, understandable language, and staff must be trained to receive feedback from people with disabilities.

Definition

The UN 2006 Convention on the Rights of Persons with Disabilities[4] 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 2015 Law[5] of Myanmar defines a 'person with disabilities' as a person who has one or more long-term physical, visual, speech, hearing, psychosocial, intellectual, or sensory impairments, whether innate or not. However, his definition is not aligned with CRPD and rights-based understanding (including the interaction with barriers). In humanitarian contexts, barriers are external factors in the environment in which people live that hinder people with disabilities to fully access and participate in humanitarian response on an equal basis (e.g., discrimination or lack of access to facilities). A barrier free environment should be promoted, supported, and advocated for by all actors.

> **GUIDANCE #2 - Needs assessments and community engagement/consultation**
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> **AT A MINIMUM, SYSTEMATICALLY INCLUDE:**
> - Disaggregate individual level data by disability, by using or adapting the WGQ
> - Whenever possible disaggregate household level data by disability (#of HH with persons with disabilities)
> - Add questions on barriers and enabler persons with disabilities face
> - The process or methodology and even the choice of platform in asking the question should be accessible to persons of disabilities

The Washington Group Short Set of Questions (WGQs)[6] is the most relevant tool for collecting data on the prevalence of disability in humanitarian contexts, nonetheless it 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 higher risk of participation restrictions.

Domains	Question	Answer by one of the following options:
Vision	Do you have difficulty seeing, even if wearing glasses?	- No – no difficulty - Yes – some difficulty - Yes – a lot of difficulty - Cannot do at all
Hearing	Do you have difficulty hearing, even if using a hearing aid?	
Mobility	Do you have difficulty walking or climbing steps?	
Cognition	Do you have difficulty remembering or concentrating?	The recommended cut-off point is a follows: If any individual answers:
Self-care	Do you have difficulty (with self-care such as) washing all over or dressing?	**'Yes - a lot of difficulty'** or
Communication	Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	**'Cannot do it at all'** **to at least one of the six questions**, they should be considered a person with a disability for data disaggregation purposes.

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[3] PWDs can be allowed more chances to access opportunities e.g. setting a quota of the number of PWDs should attend a training.

[4] The Republic of the Union of Myanmar ratified the Convention on the Rights of Persons with Disabilities on 7 December 2011.

[5] https://myanmar-law-library.org/law-library/laws-and-regulations/laws/myanmar-laws-1988-until-now/union-solidarity-and-development-party-laws-2012-2016/myanmar-laws-2015/pyidaungsu-hluttaw-law-no-30-2015-law-on-the-rights-of-persons-with.html

[6] Follow the link - https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/

- It is recommended to include the six questions in needs assessment and surveys in order to disaggregate relevant indicators by disability. The WGQs can be integrated into Multi-sectoral Need Assessment in order to analyze the proportion and types of needs of persons with disabilities. They allow disaggregation of the survey data by disability. This strongly decreases the underestimation of the number of people with disabilities in a humanitarian context.
- Multi-sectoral Needs Assessment mostly commonly use the Washington Group Short Set on Functioning (WG_SS). However, it is recognized that the WGQs is not always the adequate tool to use, in particular regarding mental health and psychosocial related domains, as well as for children.[7] These questions may be supplemented by the extended sets on functioning developed by the Washington Group (WG) that can be used similarly as the WGQs[8]. It is recommended to use the sets as designed.
- Additional questions and response options should reflect the specific risks and barriers persons with disabilities face, and the enablers that enhance their resilience or access to assistance.

WHAT TOOL?	The WG extended sets on functioning[9]	The WG/UNICEF child functioning module[10]
FOR WHICH USE?	To assess additional domains: upper-body, anxiety, depression, pain, and fatigue and further investigates the six initial domains The extended sets are intended for: • Population-based household survey • Larger disability survey • Multi-sectoral assessment	To identify children[11] with disabilities It comprises two sub-modules: • For children 2-4 years old • For children 5-17 years old To be administered to the child's parent or his or her primary caregiver

Monitoring and reporting

For monitoring and reporting purposes, it is the responsibility of each cluster 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 humanitarian response activities. 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?*

> **GUIDANCE #3 – Monitoring & reporting**
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> Each cluster discuss and agree on a common methodology tailored to:
> - The sector/cluster and types of activities
> - The capacities and resources of partners
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> Monitoring and reporting data on disability imply for each cluster to identify:
> - The activities
> - The level of engagement and participation
> - The type of feedback received, reviewed, and addressed.
> - The level of disaggregation

Disability inclusion can only be reached by identifying and directly engaging persons with disabilities (representative of affected communities) among affected communities and while monitoring programmatic outcomes towards

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[7] Disability Data Collection: a summary review of the use of the WGQs by humanitarian and development actors, 2018.
[8] For the domains Anxiety, Depression, Pain and Fatigue, the person is considered a people with disabilities if the highest level of difficulty on a four-point scale is coded to at least one question of the said domain.
[9] Follow the link - https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/
[10] Follow the link - https://www.washingtongroup-disability.com/question-sets/wgunicef-child-functioning-module-cfm/
[11] For more information, see also UNICEF Guidelines on Including Children with Disabilities in Humanitarian Action, 2017.

persons with disabilities. In order to monitor disability –inclusion it is important to understand the socio-demographic situation in areas of intervention (number of persons with disabilities); analyze trends of access/participation in comparison with persons without disabilities (by triangulation of data) and adapt identification and mobilization strategies to reach out to and engage with persons with disabilities.

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 reporting tools and development of the Rapid Information, Communication, and Accountability Assessment (RICAA) tool[12].

Steps for supporting the planning phase and data collection

1) Identify methods and tools used for need assessment and integrate the WGQ in socio-demographic section, so to identify heightened risk of households with one or multiple members with disabilities
2) Include additional questions to assess additional expenses due to disability related needs and risks
3) Include additional questions to ask barriers and enablers faced by persons with disabilities across the different sectors
4) Adapt the data system and analyses matrix to allow disability data analysis
5) Ensure method of assessment is inclusive and accessible, adapted to reach out to households with persons with disabilities and engage with persons with disabilities.

The main question sets, and their use, are outlined below, with more detailed descriptions (including a downloadable version of the full question sets) at- Question Sets - The Washington Group on Disability Statistics (washingtongroup-disability.com).

Question set	Number of questions	Use
Washington Group Short Set on Functioning (WG-SS) https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/	6	Used in surveys to identify the majority of people (aged 5 and over) most likely to face participation restrictions. Designed for population wide surveys where the focus is not disability. Information is collected on six functional domains[13]. Note that some children with disabilities (especially those with intellectual/developmental/psychosocial disabilities) will likely be missed as this question set does not cover all domains relevant to children. This question set should therefore be used for children only when the Child Functioning Module (see below) is not feasible
Washington Group Short Set on Functioning- Enhanced (WG-SS Enhanced) https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-%e2%80%93-enhanced-wg-ss-enhanced/	12	Building on the WG-SS (information is collected on eight functional domains[14]) - can be used in surveys where more extensive information is collected from adults (including general population or disability-specific surveys)

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[12] The Rapid Information, Communication, and Accountability Assessment (RICAA) tool developed by the Protection Cluster integrated core WAQs as part of the engaging at-risk communities or affected population in terms of their information needs, preferred communication channels, and participation in closing the feedback loop process. The integration of the WAQs was part of the PC's commitment to mainstream inclusive AAP in humanitarian action.

[13] Seeing, hearing, walking or climbing stairs, remembering or concentrating, self-care, and communication (expressive and receptive).

[14] Domains from the Short Set, plus upper body activities, and affect (depression and anxiety).

Washington Group Extended Set on Functioning (WG-ES) https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/	34	Building on the WG-SS (information is collected on 10 functional domains[15] and functioning when using mobility assistive devices) - can be used in surveys where extensive information is collected from adults.
Washington Group/UNICEF Child Functioning Module https://www.washingtongroup-disability.com/question-sets/wgunicef-child-functioning-module-cfm/	Age 2-4 years old - 16 Age 5-17 years old - 24	Designed to better identify all children with disabilities. Both are designed for administration to mothers or primary caregivers

Content and structure of questionnaires

Placement of the Washington Group questions will depend upon which question set is being administered. Key recommendations for implementation of Washington Group questions include:

- When using the WG-SS six questions, the recommendation is to add these at the beginning of the questionnaire, **in an upfront section, such as the demographic roster**.
- If not included in the demographic section, they should be included immediately after the demographic section and before any health-related questions, regardless of whether using the WG-SS or longer WG question sets. **The questions should never be included with or immediately following other health-related questions as this may introduce reporting biases**.
- Questionnaires should also include details on the respondent, including whether they are a proxy or direct respondent, their age and sex. If a proxy was interviewed, a response on why a proxy was used.
- Questionnaires should ideally also include an option for enumerators to add their sex, for evaluation purposes.

Where feasible, there is value in adding a section in questionnaires for enumerators to indicate where the interview was carried out, whether the respondent was familiar with the concepts in the questions and if they had any difficulty answering questions (and which questions). This will allow for future evaluation of the WG questions within that context.

Recommendations for using WGQs in household surveys

The following are best practice recommendations for implementing Washington Group questions in household surveys, and apply for both telephone and face-to-face modalities:

Recommendation 1: When integrating the WGQs into household surveys, these questions must be asked at individual level to the extent possible and realistic (i.e., to each individual in the household). These questions are meant to capture an individual's experience, not that of a 'household' or a 'community'.

Recommendation 2: Questions should be directed to the individual about themselves (except when using the Child Functioning Module, in which case questions are asked to the mother or primary caregiver about the child or each child in the household). This may require consideration of communication accessibility (see below). Where it is absolutely not possible to communicate directly with the individual themselves, consider the following steps in order:

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[15] Domains from the Enhanced Set, plus pain, fatigue and additional questions on mobility and use of equipment.

1. Can an interpreter be used? E.g., where the individual communicates using sign language.
2. Can the individual themselves identify a support person to assist with their communication?
3. A proxy should only be nominated by the household head or enumerator if the above 2 steps are not feasible. The proxy should be someone with close daily interaction with the individual who the questions are asked about (e.g., a family member or caregiver)

If none of the above can respond, then the head of household or another respondent can be asked the full question set for household member. I.e., 'does (name) have difficulty seeing….'. However, note that this approach is likely to result in underestimation when questions are asked about children, as mothers and primary caregivers (as opposed to other household respondents or the household head) are known to provide more accurate responses about their children.

Recommendation 3: Do not use any screening or filter question, particularly including any filter that uses the word 'disability' (e.g., "Does anyone in the household have a disability?"). Each of the WGQs are to be asked of every member of the household (see below) in full.

Recommendation 4: Recommendations 1-3 should apply regardless of modality, for both telephone and face to face interviews. However, there may be a greater need for additional accessibility considerations or proxies for respondents with hearing difficulties with telephone surveys.

Recommendation 5: Do not change the order of or skip questions.

Recommendation 6: Read the questions exactly as they are written, including the response options. It is important that survey tools include the wording of the questions without adaptations (see links above).

Recommendation 7: Do not use examples. Repeat the question if needed and move on to the next question if the person does not understand.

Recommendation 8: A transition or introductory statement may be used where the WGQs are not asked as part of the demographic roster or where the WGQs follow other questions that appear to be very unrelated. As above, do not use the word 'disability' in the introductory language such as 'The following questions are for any household member who has a disability'. If an introductory statement is needed to be used, you can state… *'The next questions ask about difficulties you may have in doing certain activities.'*

Recommendation 9: Data should not be recorded based on observations or assumptions. However, data collectors can be sensitive to the situation. It may be necessary to acknowledge what you observe. For example, *"I can see you are in a wheelchair, but can you tell me to what extent you have difficulty walking?"*; *"I can see you use a wheelchair, however I am required to ask all questions as they appear in the survey."*; or *"Can you tell me, in your own words, Do you have difficulty….?"* (Followed up with the response categories).

Recommendation 10: Use official translations whenever possible (see below).

Translations

Recognising the impact that differences in language can have in a successful application to the questions, it is recommended to translate and test to the question in every context.

Questions must never be translated 'on the spot', even if enumerators have strong language skills. Enumerators must always be familiar with the question set, in the language in which it will be administered, before conducting interviews. If you see that data collection will involve a local language or dialect, please ensure you are including adequate time during enumerator training to include the module for group translation of the questions.

Minimum Training and Quality Control Standards

- ✓ Question inserted as part of demographic rosters.
- ✓ Training session for all enumerators on Washington Group questions (English language training material can be found [here](#)) being used, with minimum topics covered including the rationale and exact wording to be used, accessibility considerations, and respectful interviewing techniques.
- ✓ Essential data quality checks, including but not limited to assessing demographic profiles of respondents and survey subjects, irregular reporting patterns in disability by functional domain or by enumerator, potential skipping, or shortcutting of questions.
- ✓ Use only standard translations, if not cognitively tested and back-translated checks. If not possible, then ensure inclusion of an optional training session on local language translations of the Washington Group questions and key concepts.
- ✓ Particularly for children, training should incorporate child safeguarding and child protection and clear instructions on when and how children should be engaged with when implementing WGQ in households.