

# Guidance: Identification of Persons with Disabilities at Registration and other data collection efforts

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## Introduction

## Purpose of this document

This guidance recognizes that registration is an important entry point for working with persons of concern to UNHCR, and the numerous challenges currently exist to identification of persons with disabilities. This document aims to improve identification of persons with disabilities as an entry point to strengthened access to protection, assistance and solutions.

The primary purpose of identifying persons with disabilities is to flag individuals who may be at heightened protection risk and/or who may need specific support in order to have equal access to protection, assistance and solutions. The purpose of identifying persons with disabilities at registration is not to make a medical diagnosis, to classify individuals by impairment type, or to make determination of eligibility for specific assistance. However, registration is an important entry point for identifying individuals for further assessment in order to inform appropriate protection, assistance and solutions interventions. Identifying persons with disabilities may also enable the collection of data to be used for planning, monitoring and reporting.

This guidance applies to all stages of registration, whether initial, continuous or emergency registration. However, and acknowledging the reduced time available to collect comprehensive data during initial and emergency registrations, it is expected that the identification of persons with disabilities will progressively improve in the context of continuous registration. This guidance may also be useful in the context of surveys and other data collection or identification efforts, including protection monitoring, case management, and community outreach. It should be read in conjunction with community outreach and protection monitoring strategies and tools.

This guidance is intended for staff and partners conducting registration activities, including where registration is conducted in collaboration with or solely by state authorities. In contexts where registration is conducted by state authorities, it also serves as a practical advocacy tool towards these state authorities to enhance their identification processes.

This document presents an approach to registration interviews using revised Specific Needs Codes (SNCs), to be rolled out progressively. This guidance can be used as a basis for developing Standard Operating Procedures (SOPs) for registration at country level. In addition, the guidance may also inform other individual or household-level data collection processes, in order to ensure that processes

<sup>&</sup>lt;sup>1</sup> Continuous registration refers to the continuous updating and verifying of records that takes place as part of day-to-day registration and case management activities over time (UNHCR Guidance, Module 8).



for identification of persons with disabilities are consistent across UNHCR's various data collection processes.

This document has been developed jointly by the Division of International Protection (DIP) and Division of Resilience and Solutions (DRS) and the Global Data Service<sup>2</sup> reflecting the cross-cutting nature of work on disability inclusion. It should be read in conjunction with UNHCR's Guidance on the Protection of Personal Data of Persons of Concern to UNHCR (in particular, section 3.8); and UNHCR's Guidance on Registration and Identity Management, specifically the proGres v4 Registration baseline SOPs;4 it should be as well read in conjunction with relevant regional and country context guidance and procedures.

This document will be also complemented by additional learning modules and guidance on the steps to be taken following identification of someone as having a disability, including assessment and referral, in order to promote equal access to protection, assistance and solutions.<sup>5</sup>

### Background

Through the Conclusion on refugees with disabilities and other persons with disabilities protected and assisted by UNHCR.6 UNHCR adopted the concept of disability contained in the UN Convention on the Rights of Persons with Disabilities (UNCRPD):

"Persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments, which in interaction with various attitudinal and environmental barriers hinder their full participation in society on an equal basis with others"

Persons with disabilities make up an estimated 15% of any population. In situations of forced displacement, the incidence of disability is expected to be even

higher owing to an increased number of persons with injuries, lack of access to quality medical services and the creation of new barriers in the environment. However, despite agreement internationally on the above concept of disability, there is a lack of consistency in how persons with disabilities are identified in data collection processes, reflected in incomparability and wide disparities in reported national disability prevalence rates as well as in assessment and other data collection processes in displacement contexts.

For UNHCR currently, a systematic and consistent approach to identification of persons with disabilities at registration, for recording in proGres, is required, and this may be also the case in situations where state authorities conduct the registration. Prior to the application of the changes reflected in this guidance, identification of persons with disabilities at registration was based largely on visual cues, self- reporting, reporting by family or other household members and medical reports. Further, community- based identification of persons with disabilities were often not systematically updated in proGres; and enabling environments were not in place in many locations to facilitate selfreporting of disabilities. Practical tools and guidance were therefore needed to operationalize the concept of disability contained in the UNCRPD for data collection purposes and to inform adequate response to needs.

<sup>4</sup> Available internally.

<sup>&</sup>lt;sup>2</sup> UNHCR is also grateful for technical advice received from the Washington Group on Disability Statistics, Humanity and Inclusion, Oxfam UK and UNICEF.

<sup>&</sup>lt;sup>3</sup> Available at https://www.unhcr.org/registration-guidance/.

<sup>&</sup>lt;sup>5</sup> Module 5 on Collecting, analysing and using data for the inclusion of persons with disabilities can be found within the UNHCR - Training Package: Strengthening Protection of Persons with Disabilities in Forced Displacement.

<sup>&</sup>lt;sup>6</sup> Conclusion on refugees with disabilities and other persons with disabilities protected and assisted by UNHCR No. 110 (LXI) - 2010.

<sup>&</sup>lt;sup>7</sup> World Bank and WHO (2011) World Report on Disability.



UNHCR has committed in its 2018 Policy on Age, Gender and Diversity to ensure at a minimum, that all data collected by UNHCR will be disaggregated by age and sex and by other diversity considerations, where contextually appropriate and possible, for purposes of analysis and programming.<sup>8</sup> At implementation, this requires disaggregation of all data, at a minimum, by sex, age and disability, as also reflected for Core Indicators in UNHCR results-based management system COMPASS. In addition, UNHCR also committed in the Global Disability Summit in 2018, to improve the identification and recording of persons with disabilities during continuous registration.<sup>9</sup> These commitments also require UNHCR offices to advocate for the disaggregation of data collected by state authorities conducting registration, when this is the case. Further, these commitments can be as well shared in other humanitarian settings and interagency coordination structures.

## The Washington Group short set of disability questions

WHO has adopted the International Classification of Functioning, Disability and Health (ICF) as a framework for measuring health and disability. In the ICF people are classified according to a detailed description of their functioning within various domains- body structure and function; activities; and participation, as well as how a person's environment affects their ability to function. The WHO ICF has been used as a conceptual model for a set of questions to be used as an internationally comparable disability measure, developed by the Washington Group on Disability Statistics and widely tested and endorsed. The Washington Group short set of disability questions identify people at greater risk than the general population for participation restrictions due to the presence of difficulties in six core functional domains. This question set is:

#### Because of a health problem:

- 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 (customary) language, do you have difficulty communicating, for example understanding or being understood?

For each of the above questions, the following responses are possible: 13

- No- no difficulty
- Yes some difficulty
- Yes a lot of difficulty
- Cannot do at all

This guidance sets out how the Washington Group question sets can be adapted and integrated into UNHCR Registration processes as well as other data collection or identification efforts; and presents

<sup>&</sup>lt;sup>8</sup> Core Action 1, https://www.unhcr.org/5aa13c0c7.pdf.

<sup>&</sup>lt;sup>9</sup> See <a href="https://www.gov.uk/government/publications/multilaterals-global-disability-summit-commitments/united-nations-high-commissioner-for-refugees">https://www.gov.uk/government/publications/multilaterals-global-disability-summit-commitments/united-nations-high-commissioner-for-refugees</a>.

<sup>10</sup> www.who.int/classifications/icf/en/

<sup>&</sup>lt;sup>11</sup> 'The Washington Group' was formed in 2001 with the authorization of the United Nations Statistical Division to address the need for statistical and methodological work on an international level in order to facilitate the comparison of data on disability cross- nationally. See <a href="http://www.washingtongroup-disability.com/">http://www.washingtongroup-disability.com/</a>.

<sup>&</sup>lt;sup>12</sup> See overview of the short set of questions at: <a href="http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/">http://www.washingtongroup-disability.com/washington-group-question-group-question-sets/short-set-of-disability-questions/</a>.

<sup>&</sup>lt;sup>13</sup> For the purpose of Registration, only the two answers recommended by the Washington Group Secretariat as recommended cut-off for the identification of persons with disabilities will be displayed in proGres: *a lot of difficulty* and *cannot do at all*.



revised Specific Needs Codes for disability. This process has been initiated in order to improve access to protection, assistance and solutions for all persons of concern to UNHCR. Previous approaches to identifying persons with disabilities at registration, with a stronger focus on medical diagnosis, are no longer in line with international good practice, do not ensure comparable data and miss the majority of persons with disabilities, resulting in significant protection gaps. These previous approaches relied largely on the perceptions of individual registration staff, rather than on a global understanding of disability aligned with the Convention on the Rights of Persons with Disabilities.

The revised approach to identification presented in this guidance, with question sets designed to flag individuals at risk of participation restrictions and exclusion from protection, assistance and solutions, is not aligned with the SNCs in place in 2019. The SNCs have therefore also been revised in order to simplify the recording of SNCs in proGres and to facilitate a consistent approach to identification of persons with disabilities in line with international practices. For example, the binary categories of 'moderate' and 'severe' have been removed in recognition of the nature of disability as existing along a continuum and that the lived experience of having a disability is not solely defined by the nature of an individual's impairment but by the obstacles they face to access and participation.

Example of application of Washington Group Question Set in the field: Using Washington Group questions in the <u>Vulnerability Assessment Framework</u>, Jordan

In Jordan, UNHCR integrated the Washington Group short set of disability questions into the Vulnerability Assessment Framework (VAF) questionnaire. The VAF is a harmonized definition and management tool for vulnerability, and the questionnaire is used during household visits to identify needs and vulnerabilities of Syrian refugees. The Washington Group questions were used to develop a 'Disability Universal Indicator', based on scoring of responses to the six questions. The Disability Universal Indicator was used to inform strategic and programme planning, identification, targeting and response, including to flag individuals for prioritization in terms of further needs assessment and specific interventions. The use of the Washington Group questions was considered to be useful for identifying individuals with 'hidden' disabilities and to overcome challenges associated with stigma surrounding the term 'disability'.

# Interviewing Guide<sup>14</sup>

- Support identification of disabilities. To improve identification of persons with disabilities at registration, the questions proposed in this guidance should be asked to all persons registered in proGres v4 or engaged in individual data collection efforts (e.g. surveys). Continuous registration can provide opportunities for identification of person with disabilities.
- Ask questions and select response categories based on answers. In regular circumstances, it will take between one and three minutes to ask all questions set out below to identify persons with disabilities. Additional time may be needed where individuals require communication supports.
- **Provide support if required**. For individuals who have difficulties communicating (understanding or being understood), it is important to first ask how they prefer to communicate (e.g. in writing, using a sign language interpreter, or with assistance from a support person).
- Collect individual data whenever possible. The questions set out below are to be asked in individual registration and should where possible, be asked of all members of the household. Where operational exigencies do not allow, the questions should be posed to the focal point

<sup>14</sup> The printable short version of the Interview Guide with the current questions in proGres v4 is available at <u>UNHCR - UNHCR Specific Needs Codes – Disability Interview Guide</u>.



of the registration group or the adult members of the family (e.g. head of the household, primary applicant, or a trusted adult), on behalf of the individuals within the family/ registration group.

- **Do not use the word disability**. It is important that no prior screening questions are asked (e.g. 'do you have a disability?') before asking the questions set out below. This is because disability is understood differently in different contexts and often carries stigma. Further, asking questions about disability may create expectations for assistance that cannot be met.
- Avoid making assumptions, including based on visual observations. For example, if an individual is using a wheelchair or other mobility aid, do not assume that they are not able to walk. Instead, ask all the questions and collect answers.
- Emergency registration: In emergency settings with clear time and capacity constraints, a simplified version of the codes may be used. In this case, only for the emergency registration purpose, use the following question to identify persons with disabilities: 'Does anyone in the family/group have a lot of difficulty with walking, seeing, hearing, or remembering? Would you say... [Yes]'. As soon as possible, check sub-categories and use the guiding questions in SNC-DS entity.
- Use information for disability inclusion. The questions do not provide proof of disability but will support identifying persons who may face barriers in accessing services, heightened risks of abuse or discrimination, or additional needs such as assistive devices. These actions may require additional assessment and referrals, including to disability certification processes in country if these are available for refugees with disabilities.

## **Consent procedures**

• Like any other individual, persons with disabilities should provide informed consent (or assent, in case of youth under 18 years-old) before their data is collected and shared.<sup>15</sup>

• Information about the registration process and how personal data will be used should be provided in accessible formats, including written, verbal and easy-to-understand formats.<sup>16</sup>

Usual processes for obtaining and recording informed consent may need to be adapted to an
individual's needs and preferences.<sup>17</sup> For example, some individuals may need additional time
to make decisions about sharing of their personal data or may request assistance from a
trusted support person.

<sup>&</sup>lt;sup>15</sup> See UNHCR Registration Guidance (Module 5)- Consent should be informed and freely given. *Informed* means that the individual is provided information and able to understand the circumstances, purpose, risks and benefits of sharing personal information. Information should cover *all of the envisaged data processing activities* to be carried out, in particular which data elements will be shared with host government, implementing partners or other third parties. *Freely given* means that the individual has a genuine choice and is able to refuse or withdraw without adverse consequences.

<sup>&</sup>lt;sup>16</sup> See UNHCR Registration Guidance (Module 5)- Factors such as age, level of education, mental health or disability may affect an individual's ability to understand the implications of data processing. UNHCR staff should adapt their counselling to ensure that all persons of concern are able to understand and exercise their rights to the fullest possible extent.

<sup>3.1.1</sup> All refugees and asylum-seekers are informed in a language and manner they understand and have access to, about the specific purpose(s), intended outcomes and their rights and obligations with regard to registration, identity management and related processes. The provision of such information should be both available and accessible to persons of concern.

<sup>3.1.2</sup> All adults within the family or group provide their free and informed consent for the collection and/or transfer of personal data for the specified purposes of protection and durable solution, and signed statements or declarations of this consent should be duly recorded where possible. In the case of children, consent should generally be obtained from the child's parent or guardian, as well as consent or assent from the child according to the child's age and maturity. Individuals should be appropriately counselled on the implications, if any, of refusing to provide their registration data and/or of refusing to share their data with a third party.

17 Refer to paragraph 3.8 of the Operational Guidelines on Data Protection for further guidance on Seeking consent from individuals with mental health conditions and intellectual disabilities.



- In very specific circumstances, where individuals are not able to provide informed consent as
  required supports are not available, personal data should only be collected if it is in the
  individual's vital and best interest.
- In the case of children, consent should be, in most cases, obtained from the child's accompanying parent, family member with parental responsibility, or legal or customary caregiver.<sup>18</sup>
- For further guidance, see UNHCR Guidelines on the Protection of Personal Data of Persons of Concern to UNHCR (sections 3.3. and 3.8), UNHCR Registration Guidance (Module 5) and the draft UNHCR Policy on Registration.

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<sup>&</sup>lt;sup>18</sup> Refer to paragraph <u>3.7 of the Operational Guidelines on Data Protection</u> for further guidance on seeking assent/consent in the case of children.



## Question set and revised Specific Needs Codes

The questions highlighted in bold in the below table should be routinely asked in data collection efforts and at registration interviews, following the guidance provided in this document. The first column on the left reflects the codes used up to 2021 in proGres v3 and v4. This legacy data was transferred to the revised codes for disability (second column) following the procedures outlined in the Annex Update of the 'Disability' subcategories and inclusion of the Washington Group Questions in PRIMES (available <a href="here">here</a>).

Note on translating the questions: The following revised codes and questions are available in all languages supported by PRIMES (English, French, Spanish and Arabic). Additional translations of the Washington Group Questions are available on the official website of the Washington Group on Disability Statistics,<sup>19</sup> as well as translation guidelines<sup>20</sup> (if your requested language is not available). Colleagues undertaking translations of the questions below are encouraged to contact the Community-Based Protection team in DIP for support and potential access to existing translations.

Mapping of old SNCs		Question set for adult individuals	Question set for children <sup>21</sup>
	(proGres)		

<sup>19</sup> https://www.washingtongroup-disability.com/resources/translations-of-wg-question-sets/

<sup>&</sup>lt;sup>20</sup> https://www.washingtongroup-disability.com/implementation/translation-guidelines/

<sup>&</sup>lt;sup>21</sup> Adapted from UNICEF and Washington Group (2017) module on Child Functioning <a href="http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/">http://www.washingtongroup-disability.com/washington-group-question-group-question-group-disability/</a>



DS- physical disability- moderate Person who has a physical impairment from birth or resulting from illness, infection, injury or old age, which does not significantly limit the ability to function independently. This category may include mine victims and persons who lost fingers or limbs, which may be corrected with a prosthetic device  DS-PH physical disability- severe	Lower Body Mobility (DS-LBM)  Person who has a limitation or difficulty in moving around on foot. <sup>22</sup>	Do you have difficulty walking or climbing steps? <sup>23</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all' <sup>24</sup>	Compared with children of the same age, does (name) have difficulty walking? <sup>25</sup> Would you say  - No difficulty  - Some difficulty  - A lot of difficulty  - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'
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<sup>&</sup>lt;sup>22</sup> Difficulties walking can include those related to impairments in balance, endurance, or other non-muscoskeletal systems, for example, blind people having difficulty walking in an unfamiliar place or deaf people having difficulty climbing stairs when there is no lighting. Adapted from the Washington Group on Disability Statistics (2017) *The Washington Group Short Set on Functioning: Question Specifications* 

<sup>&</sup>lt;sup>23</sup> Washington Group Question – Short Set MOB\_SS

<sup>&</sup>lt;sup>24</sup> For the purpose of Registration, only the two answers recommended by the Washington Group Secretariat as recommended cut-off for the identification of persons with disabilities will be displayed in proGres: *a lot of difficulty* and *cannot do at all.* This applies to all questions in this form

<sup>&</sup>lt;sup>25</sup> Adapted from the Washington Group – UNICEF Child Functioning Questionnaire – Questions CF10 (Age 2-4) and CF12 (Age 5-17)



Person who has a physical impairment from birth or resulting from illness, infection, injury or old age, which severely restricts movement, significantly limits the ability to function independently or pursue an occupation, and/or requires assistance from a caregiver	Upper Body Mobility (DS-UBM)  Person who has a limitation lifting or carrying objects and	using your hands and fingers? <sup>27</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty	Compared with children of the same age, does (name) have difficulty picking up small objects with his/ her hand? <sup>28</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty
	carrying objects and	<ul><li>A lot of difficulty</li><li>Cannot do at all</li></ul>	<ul><li>Some difficulty</li><li>A lot of difficulty</li><li>Cannot do at all</li></ul>

Adapted from the Washington Group Questions – Extended Set UB\_1 and UB\_2
 Washington Group – UNICEF Child Functioning Questionnaire (Age 2-4) – Question CF 11



	using their arms and/ or hands. <sup>26</sup>	Threshold: 'a lot of difficulty' or 'cannot do at all'	Threshold: 'a lot of difficulty' or 'cannot do at all'
DS-BD visual impairment (including blindness) Person who has a visual limitation from birth or resulting from illness, infection, injury or old age, which impacts daily life, may restrict independent movement, or require ongoing treatment, special education or regular monitoring	Vision (DS-V)  Person who has vision difficulties, including seeing things close up or far away. <sup>29</sup>	Do you have difficulty seeing? <sup>30</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'	Does (name) have difficulty seeing?³¹Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'

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<sup>&</sup>lt;sup>26</sup> Adapted from the Washington Group Extended Set on Functioning: Question Specifications.

<sup>&</sup>lt;sup>29</sup> Seeing out of one eye or seeing directly in front but not to the sides. Adapted from the Washington Group on Disability Statistics (2017) <u>The Washington Group Short Set on Functioning: Question Specifications</u>

<sup>&</sup>lt;sup>30</sup> Adapted from the Washington Group Question – Short Set VIS\_SS. The mention to the use of glasses included in the original question has been omitted, based on the assumption that the use of glasses may not be common, and/or that this device may have been lost, in contexts where UNHCR may ask this question. For more information on situations when the clause can be ommitted, please consult the Frequently Aksed Questions at: <a href="Short Set - The Washington Group">Short Set - The Washington Group (washingtongroup-disability.com)</a>

<sup>&</sup>lt;sup>31</sup> Washington Group – UNICEF Child Functioning Questionnaire (Ages 2-4 and 5-17) – Question CF3. The Washington Group – UNICEF Child Functioning Module includes additional questions on wearing glasses and using hearing aids. These questions have been omitted here based on the assumption that the use of glasses and hearing aids may not be common, and/or that these devices may have been lost, in contexts where UNHCR may ask these questions. For more information on situations when the clause can be ommitted, please consult the Frequently Aksed Questions at: <a href="Short Set - The Washington Group">Short Set - The Washington Group</a> (washingtongroup-disability.com)



DS-DF hearing impairment (including deafness) Person who has a hearing limitation from birth or resulting from illness, infection, injury or old age, which impacts daily life, and may require regular treatment, special education, monitoring or maintenance of artificial hearing device. The person may be able to communicate through sign language	Hearing (DS-H)  Person who has hearing limitations or difficulties of any kind with their hearing. 32	Do you have difficulty hearing? <sup>33</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'	Does (name) have difficulty hearing sounds like people's voices and music? <sup>34</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'
DS-SD speech impairment/ disability	Communication (DS-C)	Using your usual (customary) language, do you have difficulty communicating, for	(Children 5 years and older) When (name) speaks, does he/ she have difficulty being understood or understanding others? <sup>37</sup> Would you say

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<sup>&</sup>lt;sup>32</sup> Included are problems: hearing in a noisy or a quiet environment; distinguishing sounds from different sources; and hearing in one ear or both ears. Adapted from the Washington Group on Disability Statistics (2017) <u>The Washington Group Short Set on Functioning: Question Specifications</u>

<sup>&</sup>lt;sup>33</sup> Adapted from the Washington Group Question – Short Set HEAR\_SS. The mention to the use of a hearing aid included in the original question has been omitted, based on the assumption that the use of hearing aids may not be common, and/or that this device may have been lost, in contexts where UNHCR may ask this question. For more information on situations when the clause can be ommitted, please consult the Frequently Aksed Questions at: <a href="Short Set">Short Set</a>- The Washington Group (washingtongroup-disability.com)

<sup>&</sup>lt;sup>34</sup> Washington Group – UNICEF Child Functioning Questionnaire (Ages 2-4 and 5-17) – Question CF6. See footnote 32 regarding the use of hearing aids.

<sup>&</sup>lt;sup>37</sup> Adapted from Washington Group – UNICEF Child Functioning Questionnaire (Age 5-17) – Questions CF15 and CF16



	Person who has difficulty with talking, listening or understanding speech such that it contributes to difficulty in making themselves understood to others or understanding others. <sup>35</sup>	example understanding or being understood by others? <sup>36</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'	- No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'
DS-MM mental disability- moderate Person who has mental or intellectual impairment from birth, or resulting from illness, injury, trauma or old age, which does not significantly limit the ability to function independently and	Emotions and behavior (DS- EB)  Person who has difficulties in controlling emotions, as indication of mental health issues or psychosocial disabilities.	Do you have difficulty controlling your emotions? Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'	(Children 5 years and older) Compared with children of the same age, does (name) have difficulty controlling his/her behaviour? <sup>38</sup> Would you say  - No difficulty  - Some difficulty  - A lot of difficulty  - Cannot do at all  Threshold: 'a lot of difficulty' or 'cannot do at all'

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<sup>&</sup>lt;sup>35</sup> It may involve mechanical problems such as hearing impairment or speech impairment, or it may be related to the ability of the mind to interpret the sounds that the auditory system is gathering and to recognize the words that are being used or an inability of the mind to compose a sentence or say a word even when the person knows the word and sentence. Included is the use of the voice for the exchange or using signs (including sign language) or writing the information to be conveyed. Included are problems making oneself understood, or problems understanding other people when they speak or try to communicate in other ways. NOTE: Difficulty understanding or being understood due to non-native or unfamiliar language is NOT included. Adapted from the Washington Group on Disability Statistics (2017) *The Washington Group Short Set on Functioning: Question Specifications* 

<sup>&</sup>lt;sup>36</sup> Washington Group Question – Short Set COM\_SS

<sup>&</sup>lt;sup>38</sup> Washington Group – UNICEF Child Functioning Questionnaire (Age 5-17) – Question CF21



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interact, but may			
require special			
education, some			
monitoring and			
modest medication.			
DS-MS mental			
disability- severe			
Person who has			
mental or intellectual			
impairment from birth,			
or resulting from			
illness, injury, trauma			
or old age, which			
significantly limits the			
ability to function			
independently or to			
pusue an occupation.			
It requires assistance			
from a caregiver, and			
may require			
medication and/ or			
medical treatment.			



Remembering and concentrating (DS-RC) Person who has difficulties with recalling incidents or events, accomplishing tasks such as reading, calculating numbers, and learning something. <sup>39</sup>	Do you have difficulty remembering or concentrating? <sup>40</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'	(Children 5 years and older) Does (name) have difficulty concentrating on an activity that he/she enjoys doing? <sup>41</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'
Self-Care (DS-SC)  Person who has difficulties with the processes of cleaning one's entire body, and putting clothing on	Do you have difficulty with self-care such as washing all over or dressing? <sup>43</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'	(Children 5 years and older) <b>Does (name)</b> have difficulty with self-care such as

Adapted from the Washington Group on Disability Statistics (2017) <u>The Washington Group Short Set on Functioning: Question Specifications</u>
 Washington Group Question – Short Set COG\_SS
 Washington Group – UNICEF Child Functioning Questionnaire (Age 5-17) – Question CF19
 Washington Group Question – Short Set SC\_SS



the upper and lower body. 42	feeding or dressing him/herself? <sup>44</sup> Would you say  - No difficulty - Some difficulty - A lot of difficulty - Cannot do at all Threshold: 'a lot of difficulty' or 'cannot do at all'
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# **Emergency Registration**

Acknowledging that the full use of the Specific Needs Codes for Disability may not be feasible in emergency registration, a simplified version of the codes may be used. In this case, and for the purpose of **emergency registration only**, use the following question to identify persons with disabilities:

• 'Does anyone in the family/group have a lot of difficulty with walking, seeing, hearing, or remembering? Would you say... [Yes]' Check sub-categories and use guiding questions in SNC-DS entity as soon as possible.

<sup>&</sup>lt;sup>42</sup> Adapted from the Washington Group on Disability Statistics (2017) <u>The Washington Group Short Set on Functioning: Question Specifications</u>

<sup>&</sup>lt;sup>44</sup> Washington Group – UNICEF Child Functioning Questionnaire (Age 5-17) – Question CF14



## Practical examples- application of the Washington Group questions

- Ali was injured when fleeing his country 9 months ago and has not been able to access health care that he needs. Because of his injury, he can only walk about 100 meters without assistance and is not able to work in manual labour, his source of income before being injured. Ali answered 'a lot of difficulty' to the question, 'do you have difficulty walking or climbing steps' and is allocated a DS-LBM code.
- Greta is 90 years old and has been gradually losing her sight since she was 75. She can still navigate in her home if wearing glasses, but finds it difficult to walk around in unfamiliar places and gets lost easily. She recently fled her home and has been living in a new city for the past 1 month, but is not able to leave her home alone. Greta answers 'a lot of difficulty' to the question, 'do you have difficulty seeing', and is allocated a DS-V code.
- Amina is 20 years old and has an intellectual disability that affects the way she learns new things. Amina was born in the refugee camp where she still lives with her family and has never accessed education because the local school is not inclusive. Amina is only able to understand very basic sentences and most people outside the family do not understand her when she speaks due to the way she pronounces words. Amina's mother answered 'a lot of difficulty' to the question 'does Amina have difficulty communicating, for example understanding and being understood by others?'. Amina is allocated a DS-C code.
- Leisha is 14 years old and was injured by a bullet when fleeing from conflict. Because of her injury, she uses a wheelchair and has very little mobility in her arms and hands. She can use an adapted spoon and pencils to eat and do her homework, but she requires support to get dressed. Leisha answered "cannot do at all" to the DS-LBM code, "a lot of difficulties" to the DS-UBM code and "a lot of difficulties" to the DS-SC code, which were recorded in proGres.
- Due to an illness when he was an infant, Jorge has difficulty hearing and is only able to hear loud sounds. He has learned to lip read so he is able to communicate with others, but is not able to hear announcements made in the camp. Jorge answered 'cannot do at all' to the question, 'do you have difficulty hearing' and is allocated a DS-H code
- George has difficulty working outside the home as he frequently becomes very agitated and behaves in a way that frightens other people. He reports that he sometimes feels overwhelmed by the memories of his experiences in his country of origin and at these times finds it difficult to control his behavior. George answers 'a lot of difficulty' to the question 'do you have difficulty controlling your emotions' and is allocated a DS-EB code.
- Grace is 65 years old and is increasingly finding it difficult to remember things. Recently, she
  has been finding it more difficult to find her way home when she goes out, so she no longer
  leaves her shelter alone. As a result, she is becoming socially isolated and is sometimes not
  able to access the latrines when she needs to. Grace answers 'a lot of difficulty' to the
  question 'do you have difficulty remembering, concentrating or learning new things' and is
  allocated a DS-RC code.



# Considerations- recording Specific Needs Codes

- More than one disability- related SNC can be used for the same individual. For example, someone who has difficulty communicating (DS-C) may have an underlying hearing impairment (DS-H), which affects their ability to communicate verbally. In this case, both codes can be recorded in proGres.
- A disability- related SNC can be allocated in addition to a Serious Medical Condition code. Disability relates to difficulties in activity functioning and participation restrictions, which may or may not be linked to an underlying medical condition -which in many cases may not have been diagnosed yet. Similarly, individuals with medical conditions may or may not experience disability (i.e. functional difficulties and participation restrictions) as a result. For example, one individual with a chronic illness (SM-CI) based on a medical diagnosis, may also be allocated a SNC for disability due to the functional difficulties arising out of their chronic illness; while a second individual with the same medical diagnosis may not experience disability. Finally, an injury or disease may lead to temporarily experiencing difficulties in activities and impacting participation, which may or not lead to a long-term impairment. In this case, both codes could be recorded -if the individual answers the questions as suggested in the guidance above- to identify persons at higher risk of participation restrictions and to support prioritizing access to medical interventions, with the recommendation of updating the record in case the medical condition improves or disappears, but not the difficulties (in which case a only DS code would be kept) or inactivating both codes if both the medical condition and the difficulty recede. For temporary injuries, the end date field in the Specific Needs form can be used to invalidate the SNC after a certain period (e.g. when a cast used for a fracture will be removed).
- Disability is an evolving concept, resulting from the interaction between an individual's impairment and the environment. Disability is experienced as restrictions to equal participation, and the Washington Group questions assess difficulties performing basic activities, as a proxy to identifying individuals who are at heightened risk of participation restrictions due to functional difficulties and barriers in the environment. Therefore, medical diagnosis is not required for recording of a SNC for disability in proGres. Rather, allocation of a SNC for disability relies on self- reporting of an individual's experience. More detailed assessment by protection and other partners may therefore result in revision of SNCs allocated, due to having a more detailed understanding of participation restrictions experienced by an individual.
- It is not expected that all persons with disabilities will be identified at initial registration; it may as well happen that some persons may acquire a disability after their initial registration. Therefore, processes should be put in place to continue updating SNCs in proGres as persons with disabilities are identified during verification exercises and regular protection and assistance programming. This process need not be completed only by registration officers, proGres should be updated by other UNHCR staff (depending on SOPs in place for each office). Implications of this include that partners and others who are identifying persons with disabilities should use these guidelines consistently and ensure that they record the unique identifier of each person, in order to enable this to be fed into proGres<sup>45</sup>.
- ProGres v4 contains a 'review' field, for input by protection staff. This field provides a space for protection staff and partner agencies to record qualifying information regarding participation restrictions faced by an individual and supports to be put in place to enable access to protection, assistance and solutions.
- Where partners have a role in identifying persons with disabilities, a coordinated approach is
  essential to avoid persons with disabilities having to provide the same information on a number
  of different occasions.

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<sup>&</sup>lt;sup>45</sup> Note that depending on procedures in place for each office, partners can be provided access to proGres to make these changes themselves, or a designated UNHCR Protection Officer can update on their behalf.



- Refugees, internally displaced persons, stateless persons, returnees and host communities
  associations/ committees of persons with disabilities and local organizations of persons with
  disabilities can have a valuable role in supporting identification of persons with disabilities,
  especially those who are more isolated. These groups should be supported to implement an
  identification process consistent with that outlined above, including in regards to principles of
  confidentiality and informed consent.
- It is also important to note that identifying persons with disabilities for statistic, planning and monitoring purposes is different from disability assessment and determination systems.
- Accessing these processes and programmes is usually regulated by national laws,<sup>46</sup> and can allow accessing certain entitlements, such as transportation and accessibility allowances, access to assistive devices, etc.
- Identity cards are often provided as proof of entitlements. UNHCR should work to promote
  equal access to refugees with disabilities to these disability certification process, on an equal
  footing with nationals.
- Additional datasets and data collection efforts may be needed to identify needs on accessing assistive devices<sup>47</sup> and identifying barriers faced by persons with disabilities.<sup>48</sup>

<sup>&</sup>lt;sup>46</sup> See, for example, <u>Disability Assessment and Determination in the Arab Region: An Overview - ESCWA</u> (unescwa.org)

<sup>&</sup>lt;sup>47</sup> See, for example, the rapid Assistive Technology Assessment tool (rATA) (who.int)

<sup>&</sup>lt;sup>48</sup> See, for example, the <u>Inclusive Client Responsiveness - Toolbox | IASC Accountability and Inclusion Resources Portal (alnap.org)</u>, and the <u>DTM MSLA for Disability Inclusion | Displacement (iom.int)</u>