



Nossal Institute for Global Health

Humanitarian Disability Needs Estimation and Screening Tool (HD-NEST)

Rapid review of disability data collection tools



Humanitarian
innovation fund

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Life Haven
Center for Independent Living



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The Nossal Institute acknowledges the Traditional Owners of the unceded land on which we work, learn and live: the Wurundjeri Woi-wurrung. We pay respect to Elders past, present and future, and acknowledge the importance of Indigenous knowledge in the Academy.

Abbreviations

ADL	Activities of Daily Living
CFM	Child Functioning Module
CRPD	Convention on the Rights of Persons with Disabilities
DRR	Disaster Risk Reduction
EU	European Union
GALI	Global Activity Limitation Indicator
IASC	Inter-Agency Standing Committee
ICF	International Classification of Functioning, Disability and Health
ILO	International Labour Organization
MDS	Model Disability Survey
MICS	Multiple Indicator Cluster Surveys
OECD	Organization for Economic Cooperation and Development
OPD	Organisation of Persons with Disabilities
UN	United Nations
UNICEF	United Nations Children's Fund
RAD	Rapid Assessment of Disability
SHARE	Survey of Health, Ageing and Retirement in Europe
SDG	Sustainable Development Goal
WG	Washington Group
WG-ES	Washington Group Extended Set of Questions
WG-SS	Washington Group Short Set of Questions
WHODAS	WHO Disability Assessment Schedule

1. Introduction

This document summarises findings from a rapid literature review to identify disability data collection tools. The review is part of an Elrha Humanitarian Innovation Fund (HIF) project implemented by the Nossal Institute, University of Melbourne, Arbeiter-Samariter-Bund's Office for Indonesia and the Philippines, Yogyakarta, and Life Haven Center for Independent Living, Manila.

The Humanitarian Disability Needs Estimation and Screening Tool (HD-NEST) project responds to the concern that a lack of disability data is an obstacle to ensuring disability inclusive humanitarian response.¹ Also, that guidance on disability data in humanitarian response has, in the main, been narrowly focused on the question sets developed by the Washington Group on Disability Statistics.^{2,3} We maintain the Washington Group questions should be part of any humanitarian professional's data collection toolkit; however, uptake of the questions has been limited and the questions can be challenging to apply in the early stages of a response.⁴ Barriers to adoption can be exacerbated in time-stressed and resource poor humanitarian response settings.

The Washington Group questions were developed to identify people with disability in national censuses and surveys in more stable settings. The questions allow datasets to be disaggregated by disability and differences in opportunities between people with and people without disability to be measured. The importance of collecting qualitative disability data is also noted in recent humanitarian guidance.^{3,5,6} However, qualitative data can also be difficult to collect and apply in the immediate acute stage of a response.

The HD-NEST project is exploring the development of disability data collection tools for use in the immediate response stage. These would be complimentary to existing and more comprehensive tools, such as the Washington Group questions, and would be best applied as part of an ongoing data collection process during a humanitarian response.

2. A brief history

The Washington Group was established in 2001 and developed question sets based on activity limitations, such as difficulties walking or with self-care, as a standardised and comparable measure of disability. For many humanitarian professionals, the Washington Group questions may be their first exposure to disability data and measurement. However, the work of the Washington Group's work builds on earlier efforts to develop practical and standardised measures of disability.

The term Activities of Daily Living (ADL) was coined in the 1950s by Sidney Katz to describe the basic skills an individual needs for independent self-care.⁷ During the 1960s and 1970s tools to capture activity limitations, including the Index of Independence in Activities of Daily Living (ADL) and measures of independent living, were developed.^{8,9} By the early 1980s, the Organization for Economic Cooperation and Development (OECD) had developed its Long-term Disability

¹ Robinson A, Manjula M, Logam L. 2020. Gap Analysis: The Inclusion of People with Disability and Older People in Humanitarian Response. Key findings from academic and grey literature reviews. Elrha. <https://www.elrha.org/researchdatabase/gap-analysis-humanitarian-inclusion-disabilities-older-people-literature-review/>

² Washington Group on Disability Statistics. <https://www.washingtongroup-disability.com/>

³ Inter-Agency Standing Committee. 2019. Guidelines. Inclusion of Person with Disabilities in Humanitarian Action. https://interagencystandingcommittee.org/system/files/2020-11/IASC%20Guidelines%20on%20the%20Inclusion%20of%20Persons%20with%20Disabilities%20in%20Humanitarian%20Action%20%202019_0.pdf

⁴ Robinson A, Nguyen L, Smith F. 2022. Use of the Washington Group Questions in Non-Government Programming. Int. J. Environ. Res. 18, 11143. <https://doi.org/10.3390/ijerph182111143>

⁵ UN. 2019. United Nations Disability Inclusion Strategy. https://www.un.org/en/content/disabilitystrategy/assets/documentation/UN_Disability_Inclusion_Strategy_english.pdf

⁶ Collinson S. 2020. Addressing the disability data gap in humanitarian action. Network Paper No. 83. Humanitarian Practice Network, London. <https://odihpn.org/publication/addressing-the-disability-data-gap-in-humanitarian-action/>

⁷ Edemokong P F, Bomgaars D L, Sukumaram S, Schoo C. 2022. Activities of Daily Living. Stat Pearls Publishing. <https://www.ncbi.nlm.nih.gov/books/NBK470404/>

⁸ Nagi S.D. 1976. An epidemiology among adults in the United States. Health and Society, Vol 54 No 4. Pp 439-467.

⁹ UN Statistical Division, UNICEF & CDC. 2001. An inventory of health and disability related surveys in OECD countries. International Seminar on the Measurement of Disability. New York June 2001.

Questionnaire for assessing physical disability.¹⁰ At around the same time, the Lambeth Disability Questionnaire was used to identify functioning limitations and activity restrictions in the borough of Lambeth, London resulting in a disability prevalence rate of 15.4%.¹¹ Further examples include the development of the United Nations Children's Fund (UNICEF) Ten Questions screening tool in 1984 for use with children aged 2 to 9 years old and the comprehensive, but lengthy, International Classification of Functioning, Disability and Health (ICF) checklist, 2001.^{12,13} The development of the Washington Group questions is a progression and refinement of earlier and concurrent work on disability data.¹⁴

More recently, data from the World Health Survey informed the 15% global disability prevalence figure reported in the World Report on Disability 2011 and the updated 2022 estimate of 16%.^{15,16} Relevant questions in the World Health Survey drew on the ICF concept of functioning (Figure 1 below) and asked about difficulties over the preceding 30 days in mobility, self-care, pain and discomfort, cognition, interpersonal activities, vision, sleep and energy, and affect.¹⁷

3. Approach

As an initial step in the HD-NEST tool development process a rapid literature review identified existing disability data collection tools. The review was based on a time-limited search of the EBSCO Connect database (University of Melbourne) and Google search. This was supplemented by snowballing from identified literature as well as based on the HD-NEST team's prior knowledge. Simple search strings were used including the following terms, disab*, data, measure*, tool, activity limit*, function*.

In line with the objectives of the HD-NEST project the following exclusion criteria were applied:

- Assessment and diagnostic tools for use by a medical expert or professional.
- Tools that measure satisfaction with life (or equivalent) only.
- Tools that focus on mental health.
- Tools that predate the establishment of the Washington Group in 2001.

Further considerations were:

- Tools should be able to be understood and used by someone who is neither a medical expert nor a disability expert.
- Simple analysis of the data collected is possible. Ideally, basic analysis from simple counts of data should be possible 'in the field'.
- Due to ethical considerations and the focus of HD-NEST the search focused on tools for adults.

As noted, there has been a history of using activity limitations as a proxy for identifying and measuring disability. Activity limitations fall under the umbrella term of functioning. In the ICF framework, functioning includes, body structures and functions, activity limitations, and

¹⁰ The OECD questions are archived and available from: <https://scales.arabpsychology.com/s/oecd-long-term-disability-questionnaire/>

¹¹ Patrick D L. Darby S C. Green S. Horton G. Locker D. & Wiggins R D. 1981. Screening for Disability in the Inner City. Journal of Epidemiology and Community Health (1979-), 35(1), 65–70. <http://www.jstor.org/stable/25566229>

¹² WHO. 2001. International Classification of Functioning, Disability and Health. <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>

¹³ Durkin, Maureen S., Leslie L. Davidson, Patricia Desai, Z. Meher Hasan, Naila Khan, Patrick E. Shrout, Marigold J. Thorburn, Wei Wang, and Sultana S. Zaman. 1994. Validity of the ten questions screen for childhood disability: results from population-based studies in Bangladesh, Jamaica, and Pakistan. Epidemiology 283-289.

¹⁴ Goujon N, Devine A, Baker S M, Sprunt B, Edmonds T, Booth J K and Keeffe J E. 2011. A comparative review of measurement instruments to inform and evaluate effectiveness of disability inclusive development. Disability and Rehabilitation 36:10, 804-812. DOI:10.3109/09638288.2013.821178

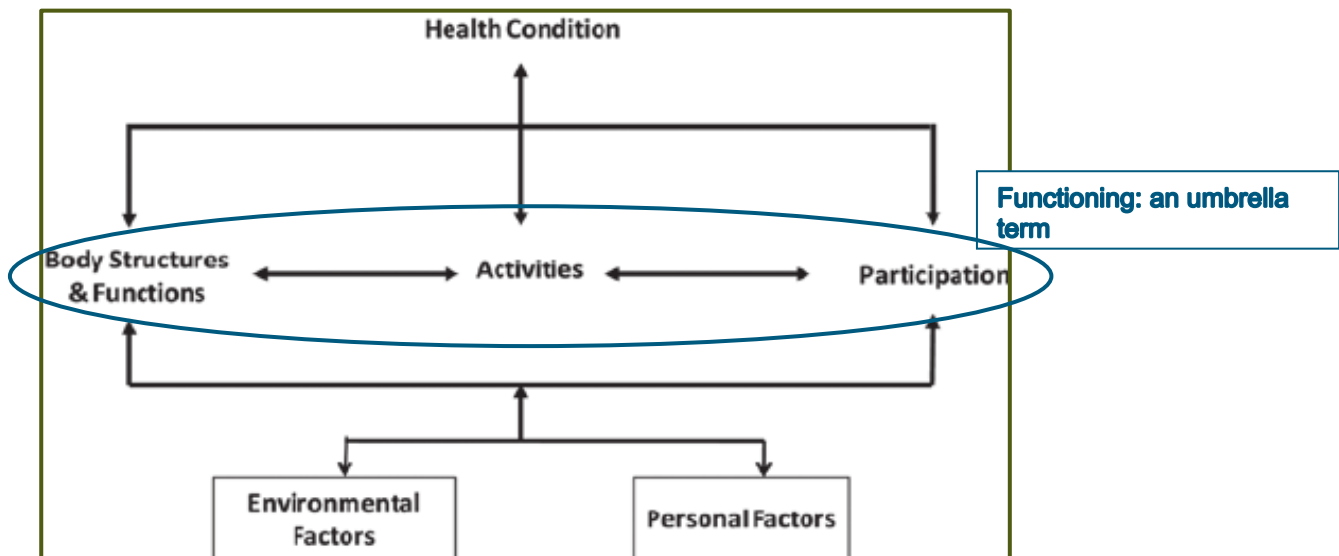
¹⁵ WHO. 2011. World Report on Disability. <https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability>

¹⁶ WHO. 2022. Global report on health equity for persons with disabilities. <https://www.who.int/publications/i/item/9789240063600>

¹⁷ WHO. 2011. World Report on Disability. Technical appendix C. Design and implementation of the World Health Survey. <https://www.ncbi.nlm.nih.gov/books/NBK304080/>

participation restrictions (Figure 1).¹⁸ These interact with health conditions and environmental barriers as well as personal factors. Personal factors include gender, age, and socio-economic status, which are not directly measured in the ICF. The tools identified below reflect this concept of functioning and are organised accordingly.

Figure 1. The ICF framework



While not claiming to be exhaustive, the identified tools are summarised below for reference. Notes relevant to the HD-NEST project are maintained in case they are of interest to readers from a humanitarian response background. Examples of questions from the data collection tools are provided in Appendix 1.

¹⁸ WHO. 2001. International Classification of Functioning, Disability and Health.
<https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>

4. Summary of tools

a. Single item questions

1. Direct question			
Design	Purpose	Issues	Notes
Direct question such as: Do you have a disability? Does anyone in your household have a disability?	Simplest question.	Can result in underreporting due to, for example, stigma associated with disability. May only identify most severe cases of disability. May not identify many of the most marginalised. ¹⁹	Generally, not recommended. May be justifiable in certain situations e.g. with OPD members. Or if identification of severe cases of disability is warranted. Use of a direct question needs careful consideration and justification. ⁷
For early examples of questions used in surveys see: https://unstats.un.org/unsd/disability/pdfs/ac.81-b10.pdf			

2. Global Activity Limitation Indicator (GALI)			
Design	Purpose	Issues	Notes
The GALI question is a single question on general activity limitations.	Standard instrument to measure activity limitations in (social) surveys. Has been widely used in EU. ²⁰	A tested instrument. However, including multiple concepts in one question may be problematic. 'Usual activities' may be understood differently by different people.	Not widely used outside of EU. Not aware of use in development of humanitarian programming.
https://circabc.europa.eu/sd/a/8eec189a-3389-47d3-999e-c12afc4a0f7d/DSS-2015-Sep-04.3%20GALI%20as%20a%20core%20variable.pdf			

b. Functioning- activity limitations

1. Washington Group short set on functioning (WG-SS)			
Design	Purpose	Issues	Notes
6 questions based on activity limitations across the following domains: vision, hearing, mobility, cognition, self-care, communication.	Identify persons with disabilities in censuses and surveys to allow disaggregation by disability.	When used in censuses or surveys does not provide information to identify individuals, such as address or location, that may be used for targeting. Not recommended but may be used with children above 5 years (see CFM).	Increasingly adopted by non-government actors in a wide range of programming contexts. Recommended for disaggregating data by disability for SDG reporting and, widely, for use in humanitarian action. ²¹
https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/			

2. Washington Group short set on functioning- Enhanced (WG-SS Enhanced)			
Design	Purpose	Issues	Notes
As the WGSS with an additional 6 questions. Total of 12 questions	See WGSS. For use in population based health	Longer and more time intensive to use than the WG-SS.	

¹⁹ Trinity College Dublin. 2022. Disability data: An evidence-informed approach to the use of data for disaggregation in WFP programming. https://www.tcd.ie/slsr/research/assets/images/Disability_Data_Finding%20note_20MAY22.pdf

²⁰ Van Oyen H, Bogaert P, Yokota R T C, et al. 2018. Measuring disability: a systematic review of the validity and reliability of the Global Activity Limitations Indicator (GALI). Arch Public Health 76, 25. <https://doi.org/10.1186/s13690-018-0270-8>

²¹ Joint Statement by the Disability Sector: Disability Data Disaggregation. 2017. <https://www.internationaldisabilityalliance.org/data-joint-statement-march2017>

with additional questions on: upper body (including use of hands/fingers), anxiety (2 questions) and depression (2 questions)	surveys and disability focused surveys.		
https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Washington_Group_Questionnaire_3_-_WG_Short_Set_on_Functioning_-_Enhanced_October_2022_.pdf			

3. Washington Group extended set on functioning- Extended (WG-ES)			
Design	Purpose	Issues	Notes
Domains are as the WGSS enhanced with the addition of 2 domains addressing pain and fatigue. Total of 35 questions. Supplementary questions are provided under each domain.	See WGSS. Can be used as a special module for more detailed analysis of disability.	Longer and less appropriate for use in surveys and rapid assessments than the WG-SS.	Additional questions from WG-ES can be drawn on to provide clarity if WG-SS questions not fully understood.
https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/			

4. Disability Screening Questions- Canada			
Design	Purpose	Issues	Notes
Developed as earlier census questions missed some people with (non-physical) disability and overestimated disability overall. Based on the ICF framework and aims to cover 10 'disability types'.	For inclusion in the Canadian Survey on Disability, 2012 and other population surveys. The screening questions were developed to take around 2 minutes to administer.	Question modules that take 3 to 4 minutes were considered too long for population based surveys. So, the short module that takes around 2 minutes to complete was developed.	Covers sensory, physical, cognitive, and mental health. Does not include communication as questions found to be ineffective in testing. Partly attributed to changing communications patterns and use of technology and social media.
https://www150.statcan.gc.ca/n1/en/pub/89-654-x/89-654-x2016003-eng.pdf?st=ALHx0oNj			

5. Census of Population and Housing- Australia			
Design	Purpose	Issues	Notes
Includes 4 questions on 'core activity need for assistance'. Does (Person 1) ever need someone to help with, or be with them for, self-care activities / body movement activities / communication activities? What are the reasons for the need for assistance or supervision (shown in questions [...])?	Since 2006 has been used to indicate disability status in the population.	Not limited to disability. Response options are: Short / long term health condition (6 months), disability (over 6 months), old or young age, difficulty with English, other.	No information on use outside of Australian census.
https://www.abs.gov.au/census/guide-census-data/census-dictionary/2021/variables-topic/disability-and-carers/core-activity-need-assistance-assnp			

c. Functioning- activity limitations and participation restrictions

1. Washington Group UNICEF child functioning modules, 2 to 4 years and 5 to 17 years (CFM)			
Design	Purpose	Issues	Notes
Finalised in 2016. Designed to capture children with developmental disabilities, including those under 5 years, that the WG-SS may miss. There are 2 versions. One for children aged 2 to 4 years (16 questions) and one for children aged 5-17 years (24 questions). Questions are asked to the parent (usually mother) or primary carer.	For use in household surveys. Has been incorporated into the Multiple Indicator Cluster Surveys (MICS) by UNICEF.	Questions asking the carer to compare their child with other children can be difficult for some parents/carers.	Includes some questions on participation restrictions, such as 'making friends' in CFM 5 to 17 years. Note: Although HD-NEST focuses on adults we have included the CFM and the IEM below for reference.
https://www.washingtongroup-disability.com/question-sets/wg-unicef-child-functioning-module-cfm/			

2. The Washington Group ILO Labor Force Survey disability module (LFS-DM)			
Design	Purpose	Issues	Notes
Endorsed by the WG in 2019. Five sections including the WG-SS for identification, barriers to employment, accommodations required, attitudes of employers and workers, and social protection. 17 questions in total.	For use in Labour Force Surveys or other surveys collecting data on employment.	Relatively new and untested. Specific and targeted application.	Extends WG questions clearly beyond activity limitations.
https://www.washingtongroup-disability.com/question-sets/wg-ilo-labor-force-survey-disability-module-lfs-dm/			

3. Washington Group UNICEF Inclusive Education Module (IEM)			
Design	Purpose	Issues	Notes
Under development since 2012. Not yet finalised. Will include section for children outside of school.	To be used with CFM to identify barriers and enablers to participation in school.	None known (not yet completed).	Although not finalised at the time of the review, completed sections may be used if coordinated through the WG Secretariat.
https://www.washingtongroup-disability.com/question-sets/wg-ilo-labor-force-survey-disability-module-lfs-dm/			

4. Model disability survey (MDS)			
Design	Purpose	Issues	Notes
Developed by WHO and World Bank based on the ICF. A complete and standalone survey tool. Includes information on household characteristics, employment/education, barriers to participation,	To provide comprehensive information on disability in a population.	Takes 90 minutes to 120 minute to complete. ²² Analysis (psychometric) of the data collected is complex. As the MDS collects data across a continuum (0= no disability, 100 = extreme disability), it	Recommended by WHO to collect disability/functioning data. Incorporates WG-SS.

²² MDS survey manual 2017 <https://apps.who.int/iris/bitstream/handle/10665/258513/9789241512862-eng.pdf;jsessionid=331A19E050157A545B0B346EB239A7D4?sequence=1>

assistive products, support, activity limitations, health, and quality of life.		can result in high prevalence figures. ²³	
https://www.who.int/news-room/questions-and-answers/item/model-disability-survey			

5. Model disability survey (MDS)- brief			
Design	Purpose	Issues	Notes
Shortened version of the MDS with 3 modules: environmental factors (9 questions), functioning (12 questions), and capacity and health conditions (12 questions).	Shorter version that can be integrated into health and other surveys.	Remains long for integration in humanitarian needs or damage and loss assessments.	Not a standalone survey tool (see MDS). The questions on health conditions may be omitted in a health survey.
https://cdn.who.int/media/docs/default-source/documents/disability/disabilities-mds-implementation-guide-en.pdf?sfvrsn=c85872db_1			

6. WHO Disability Assessment Schedule 2.0 (WHODAS 2.0)			
Design	Purpose	Issues	Notes
Addresses activity and participation. Includes 6 domains: cognition, mobility, self-care, getting along (with other people), life activities (home, leisure, work, school), and participation (community).	To assess disability and health in a standardised way. Designed to be used as a standalone tool.	The complex scoring method (item response theory) gives the most accurate measurement; however, this requires software, or syntax for use in SPSS, from WHO. A simple scoring system based on counts can be used for individual cases. ¹⁷	Available in 36 item and 12 item versions. The former takes around 20 minutes to administer and the latter 5 minutes. The 12 item version captures 81% of the variance of the 36 item version. ²⁴
https://apps.who.int/iris/rest/bitstreams/52276/retrieve			

7. Rapid Assessment of Disability (RAD)			
Design	Purpose	Issues	Notes
A modular toolkit that includes questions activity limitations, well-being, access to services, and participation.	For use as a standalone tool or adaptation for integration into surveys. Developed to inform disability inclusive programming.	As a modular tool its strength is adaptability. It is not an 'off-the-shelf' solution for immediate application in response settings	In the RAD, activity limitations are measured using the WG-SS.
https://mispgh.unimelb.edu.au/research-groups/nossal-institute-for-global-health/inclusive-health-and-development/the-rapid-assessment-of-disability-rad			

8. Survey of Health, Ageing and Retirement in Europe (SHARE)			
Design	Purpose	Issues	Notes
Includes two sets of questions on functioning (10 questions and 15 questions). These relate to showcards which are used as prompts. ²⁵	Questions on activity limitations and participation restrictions included in EU's largest social science panel study.	Multiple questions suggest it is too complex for use in acute phase of humanitarian settings.	Targets older people but includes items of potential interest for disability data measurement.
https://share-eric.eu/data/data-documentation/questionnaires/wave-8			

²³ PSA, 2019. Disability Spares No One: A New Perspective <https://psa.gov.ph/ndps/disability-survey-id/138567>

²⁴WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/who-disability-assessment-schedule>

²⁵ SHARE. (2019) Showcards. Wave 8. https://share-eric.eu/fileadmin/user_upload/Questionnaires/Q-Wave_8/Showcards_W8_generic_en.pdf

d. Humanitarian specific tools

1. Communication, maintaining health, independence, services, support and self-determination, and transportation (CMIST)			
Design	Purpose	Issues	Notes
Developed in US by Red Cross to identify access and functioning needs in general population evacuation shelters. Aims to directly identify needs and follow up actions.	Screening tool for identifying individual needs (cot-to-cot) in evacuation shelters.	Only used in limited number of high income settings. Checklist format that may not always be self-evident to the non-specialist.	Tested in Hurricane Sandy 2012. 70% of needs identified under 'maintaining health'.
https://pubmed.ncbi.nlm.nih.gov/27863579/			

2. Individual rehabilitation assessment form			
Design	Purpose	Issues	Notes
For screening in health facilities post-disaster. Based on ICF.	Tested in the Typhoon Haiyan response, Philippines, 2013- 2014.	The screening form is likely too long for general application in immediate response.	Although for use in health facilities, includes basic activity limitation questions.
https://ojs.wpro.who.int/ojs/index.php/wpsar/article/view/357			

Note: Tools have been developed by individual organisations for use in humanitarian response that are centred on the Washington Group question sets. These are often community-based survey tools that supplement the WG-SS with additional questions. For example, on whether the respondent identifies as a person with disability and/or uses assistive technology. We did not include these Washington Group Plus tools or approaches in this review as they face the same challenges for wider adoption in the immediate humanitarian response face as the WG-SS.

Appendix 1.

Question examples

a. Global Activity Limitation Indicator (GALI)

1. For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do?

Would you say you have been: severely limited, limited but not severely, or not limited at all.

b. Washington Group Short Set (WGSS)

1. [Do/Does] [you/he/she] have difficulty seeing, even if wearing glasses?
2. [Do/Does] [you/he/she] have difficulty hearing, even if using a hearing aid(s)?
3. [Do/Does] [you/he/she] have difficulty walking or climbing steps?
4. [Do/does] [you/he/she] have difficulty remembering or concentrating?
5. [Do/does] [you/he/she] have difficulty with self-care, such as washing all over or dressing?
6. Using [your/his/her] usual language, [do/does] [you/he/she] have difficulty communicating, for example understanding or being understood?

[After each question] Would you say 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all.

c. Washington Group Short Set- Enhanced

WG-SS plus the following:

1. [Do/Does] [you/he/she] have difficulty raising a 2 liter bottle of water or soda from waist to eye level?
2. [Do/Does] [you/he/she] have difficulty using [your/his/her] hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?

[After each question] Would you say 1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all.

3. How often [do/does] [you/he/she] feel worried, nervous or anxious?
Would you say 1. Daily 2. Weekly 3. Monthly 4. A few times a year 5. Never,
4. Thinking about the last time [you/he/she] felt worried, nervous or anxious, how would [you/he/she] describe the level of these feelings?
Would [you/he/she] say 1. A little 2. A lot 3. Somewhere in between a little and a lot 7. Don't know,
5. How often [do/does] [you/he/she] feel depressed?
Would [you/he/she] say 1. Daily 2. Weekly 3. Monthly 4. A few times a year 5. Never 7. Refused 9. Don't know DEP_2
6. Thinking about the last time [you/he/she] felt depressed, how depressed did [you/he/she] feel?
Would you say 1. A little 2. A lot 3. Somewhere in between a little and a lot 7. Don't know.

d. Washington Group Short Set- Extended

WG-SS Enhanced plus supplementary questions for each of the WG-SS/Enhanced domains. Plus, the following additional questions:

1. In the past 3 months, how often did [you/he/she] have pain?
Would you say 1. Never. 2. Some days 3. Most days 4. Every day 7. Don't know.
2. Thinking about the last time [you/he/she] had pain, how much pain did [you/he/she] have? Would you say 1. A little 2. A lot 3. Somewhere in between a little and a lot 7. Don't know.

3. In the past 3 months, how often did [you/he/she] feel very tired or exhausted?
Would you say 1. Never. 2. Some days 3. Most days 4. Every day 7. Don't know
4. Thinking about the last time [you/he/she] felt very tired or exhausted, how long did it last?
Would you say 1. Some of the day 2. Most of the day 3. All of the day 7. Don't know.
5. Thinking about the last time [you/he/she] felt this way, how would you describe the level of tiredness?
Would you say 1. A little 2. A lot 3. Somewhere in between a little and a lot 7. Don't know.

e. Disability Screening Questions- Canada

The following are the filter questions that are asked to all respondents. There are additional screening questions for individuals who positively answer any of the following.

1. Do you have any difficulty seeing or hearing?
No, Sometimes, Often, Always.
2. Do you have any difficulty walking, using stairs, using your hands or fingers, or doing other physical activities?
No, Sometimes, Often, Always.
3. Do you have any difficulty learning, remembering or concentrating?
No, Sometimes, Often, Always.
4. Do you have any emotional, psychological or mental health conditions? These may include anxiety, depression, bipolar disorder, substance abuse, anorexia, as well as other conditions.
No, Sometimes, Often, Always.
5. Do you have any other health problem or long-term condition that has lasted or is expected to last for six months or more?
Yes – Specify, No.
[If No, End the DSQ: the person is considered not to have a disability. Otherwise, Go to 6.]
6. How often does this health problem or condition limit your daily activities?
Never, Rarely, Sometimes, Often, Always.

f. Census of Population and Housing- Australia

1. Does the person ever need someone to help with, or be with them for, self-care activities?
2. Does the person ever need someone to help with, or be with them for, body movement activities?
3. Does the person ever need someone to help with, or be with them for, communication activities?
4. What are the reasons for the need for assistance or supervision shown in Questions [1, 2 and 3]?

g. Model Disability Survey- Brief

The following does not include the questions on capacity and health conditions and assistive products.

Environmental factors

1. Do places where you socialize and engage in community activities make it easy or hard for you to do this?
2. Do the shops, banks and post office in your neighborhood make it easy or hard for you to use them?
3. Does the transportation you need or want to use make it easy or hard for you to use it?
4. Does your dwelling, including the toilet, make it easy or hard for you to live there?
5. Should you need help, how easy is it for you to get help from a close family member (including your partner)?
6. Should you need help, how easy is it for you to get help from friends and co-workers?

7. Should you need help, how easy is it for you to get help from neighbors?

Responses for each question: 1 (very easy), 2, 3, 4, 5 (very hard), Don't know.

Functioning

1. How much of a problem is walking a kilometer for you?
2. How much of a problem is getting where you want to go for you?
3. How much of a problem is being clean and dressed?
4. How much of a problem is toileting?
5. How much of a problem is looking after your health, eating well, exercising or taking your medicines?
6. How much of a problem is feeling tired and not having enough energy?
7. How much of a problem is coping with all the things you have to do?
8. How much of a problem is remembering to do the important things in your day-to-day life?
9. How much of a problem do you have with getting your household tasks done?
10. How much of a problem do you have with joining community activities, such as festivities, religious or other activities?
11. How much of a problem is using public or private transportation?
12. How much of a problem is getting things done as required at work or school?
[If the respondent is currently not working or in school, not applicable.]

Responses for each question: 1 (none), 2, 3, 4, 5 (extreme), Don't know.

Personal assistance

1. Do you have someone to assist you with your day to day activities at home or outside?
[If No go to 3]
2. Do you think you need additional assistance with your day to day activities at home or outside?
[If No go to 3]
3. Do you think you need someone to assist you?

Responses for each question: Yes, No.

h. WHODAS 2.0- 12 items

The 12 questions below are followed by questions on how many days the difficulties were present.

In the past 30 days, how much difficulty did you have in:

1. Standing for long periods such as 30 minutes?
2. Taking care of your household responsibilities?
3. Learning a new task, for example, learning how to get to a new place?
4. How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?
5. How much have you been emotionally affected by your health problems?
6. Concentrating on doing something for ten minutes?
7. Walking a long distance such as a kilometre [or equivalent]?

8. Washing your whole body?
9. Getting dressed?
10. Dealing with people you do not know?
11. Maintaining a friendship?
12. Your day-to-day work?

Responses for each question: None, Mild, Moderate, Severe, Extreme (or cannot do).

i. Survey of Health, Ageing and retirement in Europe

The following are the questions on activity limitations only. A visual prompt card is also used.

Please tell me whether you have any difficulty doing each of the everyday activities on this card. Exclude any difficulties that you expect to last less than three months.

1. Walking 100 metres.
2. Sitting for about two hours.
3. Getting up from a chair after sitting for long periods.
4. Climbing several flights of stairs without resting.
5. Climbing one flight of stairs without resting.
6. Stooping, kneeling, or crouching.
7. Reaching or extending your arms above shoulder level.
8. Pulling or pushing large objects like a living room chair.
9. Lifting or carrying weights over 10 pounds/5 kilos, like a heavy bag of groceries.
10. Picking up a small coin from a table.
11. None of these.

Further questions:

Please tell me if you have any difficulty with these activities because of a physical, mental, emotional or memory problem. Again, exclude any difficulties you expect to last less than three months.

1. Dressing, including putting on shoes and socks.
2. Walking across a room.
3. Bathing or showering.
4. Eating, such as cutting up your food.
5. Getting in or out of bed.
6. Using the toilet, including getting up or down.
7. Using a map to figure out how to get around in a strange place.
8. Preparing a hot meal.
9. Shopping for groceries.
10. Making telephone calls.

11. Taking medications.
12. Doing work around the house or garden.
13. Managing money, such as paying bills and keeping track of expenses.
14. Leaving the house independently and accessing transportation services.
15. Doing personal laundry.

j. CMIST

The following does not include the related action items based on the responses to the questions on needs. The CMIST items for identifying needs are in a checklist format.

Communication

1. Access to auxiliary communication service.
2. Access to auxiliary communication device.
3. Replacement of communication equipment.

Maintaining Health

1. Special diet.
2. Food allergies.
3. Medical supplies and/or equipment for every day care (including medications) *not* related to mobility.
4. Assistance with medical care normally provided in the home setting.
5. Allergies (environmental or other high risk).
6. Support for pregnant women.
7. Support for nursing mothers.
8. Infant care availability.
9. Access to a quiet area.
10. Access to a temperature-controlled areas.
11. Mental health care (e.g. anxiety and stress management).

Independence

1. Durable medical equipment for individuals with conditions that affect mobility.
2. Power source to charge battery-powered assistive devices.
3. Bariatric accommodations.
4. Service animal accommodations.
5. Infant supplies and/or equipment.
6. Services, support and self-determination
7. Adult personal assistance services.
8. Child personal assistance services.

Transportation

1. Transportation to designated facility for medical care or treatment.
2. Transportation for non-medical appointment.

k. Individual rehabilitation assessment form

The following are the 'functional limitation' / 'independence evaluation' questions only.

Is it difficult for you to do the following on your own:

1. Bathing.
2. Dressing.
3. Eating/Drinking.
4. Using toilets.
5. Moving short distance.
6. Moving long distance.
7. Communicating.
8. Community activities.
9. Playing (children).

Response categories: Do alone, Do alone with assistive device, Do with helper, Don't do.

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