

Data collection and disaggregation on disability: Overview of instruments and methodologies

Background

In recognizing the importance of disability data, the 2030 Sustainable Development Agenda affirms that data should be disaggregated by disability as well as by age, gender, income, ethnicity, race, geographic location, and other characteristics in order to achieve the concept of “leaving no one behind”.¹ In addition, disability data is essential for countries to be able to develop evidenced-based policies to monitor the implementation of the Convention on the rights of persons with disabilities (CRPD) and to measure progress towards national targets, as well as to take stock of the challenges that remain unresolved.

The most effective and sensitive way of understanding disability is to ask questions about difficulties in undertaking specific activities like walking, seeing, or hearing as well as barriers in the environment that may contribute to those limitations.² Depending on the context, resources and purpose of data collection, different tools and methodologies can be applied to collect and disaggregate data by disability. This document outlines some of the most commonly used instruments and discusses their advantages and disadvantages. The instruments presented in this document are both WHO-developed and also tools developed by other entities.

¹ United Nations. 2015. *Transforming our world: the 2030 Agenda for Sustainable Development*. New York, USA.

² World Health Organization, Western Pacific Region (2020) *Disability-inclusive health services toolkit: a resource for health facilities in the Western Pacific Region*.
<https://iris.wpro.who.int/bitstream/handle/10665.1/14639/9789290618928-eng.pdf>

1. Model disability survey

Background

The WHO Model disability survey (MDS) is a valid and reliable general population survey developed by the World Bank and WHO in 2012 and is designed to be a standalone survey.³ The objectives of the MDS are to:

- determine the current distribution of disability in the population;
- estimate the prevalence of severe, moderate and mild disability;
- identify unmet needs of persons with different levels of disability;
- identify what are the barriers and inequalities faced by persons with different levels of disability; and
- provide a country or region with the information necessary for the development of policy priorities.

The MDS is fully based on the International Classification of Functioning, Disability and Health (ICF) and includes both a household as well as an individual questionnaire in a modular structure. Due to this conceptualization, the MDS includes a broad range of indicators of inequality, unmet needs and barriers, and allows direct comparison between groups with differing levels and profiles of disability, including comparison to people without disability.

Currently, two versions of the model disability survey are available:

- a comprehensive survey version (MDS) for standalone implementations as a dedicated disability survey every 5 to 10 years;
- a brief MDS version, developed to be integrated in household surveys such as labour force or living standard surveys that are carried out regularly and are to be used to disaggregate indicators by disability.

MDS has been implemented in more than 15 countries to date.

³ More information about the MDS, manual and implementation guide, as well as country reports can be found on <https://www.who.int/activities/collection-of-data-on-disability>

When to use it?

MDS can be selected when comprehensive information about the distribution of disability in a population is needed as well as information about what environmental factors contribute to the experience of disability. Due to its comprehensive nature and specific analysis strategy, it is recommended that countries seek WHO support in implementing the survey.

Pros and cons

Pros

- it provides in-depth understanding on disability;
- it shows excellent psychometric properties;
- it represents an evolution in the concept of disability measurement because it measures disability as the outcome of interactions between a person with impairments, health conditions or age-related decrements in health and the physical, human-built, attitudinal and socio-political environment in which the person lives;
- it provides information on different levels of disability severity – mild, moderate and severe;
- it offers governments an in-depth tool for short- and long-term planning;
- it is directly linked at the level of the concepts to the ICF;
- it can be used for monitoring CRPD and SDGs.

Cons

- the administration of the full version can take up to 1.5 hours and the brief version up to 30 minutes;
- the Statistical analysis is complex and requires support from WHO.

The MDS manual and implementation guide as well as country reports can be found at <https://www.who.int/activities/collection-of-data-on-disability>.

2. Functioning and disability disaggregation tool (FDD11)

Background

The WHO functioning and disability disaggregation tool (FDD11) is a valid and reliable standalone instrument, comprising 11 questions assessing difficulties that individuals experience when undertaking various activities due to a health problem. These activities include: seeing, hearing, walking or climbing steps, remembering or concentrating, washing all over or dressing, sleeping, performing household tasks, joining community activities, feeling sad, low, worried or anxious, getting along with others, and bodily aches

and pain. The questions in FDD11 are directly derived from the brief version of the MDS and, as such, the tool is fully based on ICF.

FDD11 was created as a separate instrument for three main reasons:

- to allow for a quick integration into existing surveys;
- to capture functioning information when disaggregating by disability;
- to allow for a quick, sound and valid disaggregation by disability.

When to use it?

FDD11 can be used primarily when the focus is disaggregation by disability of indicators or information collected by the survey in which it has been integrated.

Pros and cons

Pros

- It captures functioning across body functions and activities and participation domains.
- It is brief and can be administered quickly.
- It shows excellent psychometric properties.
- It provides prevalence of disability and allow for disaggregation by severity level (no disability, mild, moderate and severe).
- It is directly linked at the level of the concepts to the ICF.
- It is accompanied by a user-friendly Excel file for analysis of data to facilitate countries' use of the tool. The Excel file includes an algorithm that allows data owners to input the data collected through the FDD11 and automatically obtain a metric of disability for disaggregation purposes, as well as the distribution of disability in the population.

Cons

- Does not account for the impact of environmental factors.
- It may be too long for specific purposes such as national census.

The FDD11 Tool can be downloaded at <https://www.who.int/activities/collection-of-data-on-disability>.

3. WHO's Disability Assessment Schedule 2.0 (WHODAS 2.0)

Background

WHODAS 2.0 is a valid and reliable instrument that is grounded in the conceptual framework of the ICF and measures individual's level of functioning in six major life domains:

- cognition – understanding and communicating;
- mobility – moving and getting around;
- self-care – hygiene, dressing, eating and living alone;
- getting along – interacting with other people;
- life activities – domestic responsibilities, leisure, work and school;
- participation – joining in community activities;

WHODAS 2.0 was developed through a collaborative international approach with the aim of developing a single generic instrument for assessing health status and disability across different cultures and settings.⁴

Depending on the information needed, the study design and the time constraints, the user may choose between two versions with different options for administration:

- 36-item version, which is available as interviewer-, self-, and proxy-administered forms, with an average interview time of 20 min;
- 12-item version, which is useful for brief assessments of overall functioning in surveys. It is also available as interviewer-, self-, and proxy-administered forms, with an average interview time of 5 min.

When to use it?

Similarly, to FDD11, WHODAS 2.0 can be used when the focus of the data collection is disaggregation by disability of indicators or information collected in the survey in which it has been integrated. In addition, it has wide use in clinical settings, being administered by health professionals, and also for assessment purposes in the context of disability assessment and determination for disability and social benefits.

⁴ More information can be found on <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/who-disability-assessment-schedule>

Pros and cons

Pros

- it has excellent psychometric properties;
- it is short (especially the 12-item version), simple and easy to administer;
- it has been extensively used and tested in clinical settings;
- it has translations available in multiple languages;
- it is directly linked at the level of the concepts to the ICF.

Cons

- it contains questions concerning activities and participation domains but not on body functions such as pain or environmental barriers;
- the statistical analysis can be difficult to apply in all settings;
- does not account for the impact of environmental factors;
- it is too long to be incorporated in national census.

The WHODAS 2.0 Manual can be found at

[https://www.who.int/publications/i/item/measuring-health-and-disability-manual-for-who-disability-assessment-schedule-\(-whodas-2.0\).](https://www.who.int/publications/i/item/measuring-health-and-disability-manual-for-who-disability-assessment-schedule-(-whodas-2.0).)

4. Washington Group questions

Background

The Washington Group (WG) questions were designed as a set of questions for self- or proxy-reporting of functioning limitations at the individual level. Initially developed to be administered as part of a census, the questions can be included in any existing data collection activity or can be incorporated into smaller-scale surveys that collect data at the individual level. The WG questions are established under the Washington Group, which was constituted under the auspices of the UN Statistical Commission as a City Group.

The short set of WG questions has six questions that can be answered in about two minutes. The extended set has 35 questions and can be answered in 10–12 minutes.

When to use it?

The short set of questions has been widely integrated in national census and incorporated in existing population-based surveys, as well as in humanitarian settings.

Pros and cons

Pros

- it captures functioning across body functions and activity domains;
- it is brief and can be administered quickly;
- it has been tested in several countries;
- it is easy to analyse;
- it is directly linked at the level of the concepts to the ICF;

Cons

- the questions capture body functions and activities, but not participation domains;
- does not account for the impact of environmental factors;
- the tool does not directly address mental health functioning;
- the sensitivity of the questionnaire has been questioned in several studies, which have shown that the tool identifies individuals with more significant disabilities but may miss some with mild or moderate disabilities.⁵

More information about the Washington Group questions can be found at <https://www.washingtongroup-disability.com>.

5. Short questions for disability disaggregation

Background

There are situations when only about one minute is available to collect information on disability (e.g. when the national census only allows 1–2 questions to be included or when collecting basic demographic information about service users through clinical, trauma and emergency care). For these circumstances, the following two questions for disability disaggregation may be used:

⁵ Mactaggart I, Kuper H, Murthy GVS, Oye J, Polack S. Measuring disability in population based surveys: the interrelationship between clinical impairments and reported functional limitations in Cameroon and India. *PLoS One*. 2016;11(10):e0164470.
Australian Bureau of Statistics: analysis of the 2016 supplementary disability survey. Available from: [http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/CA560C19C794A0E1CA25815300186127/\\$File/4450055001.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/CA560C19C794A0E1CA25815300186127/$File/4450055001.pdf). Australia; 2017.
Landes, S.D., Swenor, B.K., & Vaitsiakhovich, N. (2023). Counting disability in the National Health Interview Survey and its consequence: Comparing the American Community Survey to the Washington Group disability measures. *Disability and Health Journal*, 101553.

- Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more? (With response options: “Yes” or “No”.)
- Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities? (With response options: “Yes, a lot”, “Yes, a little” or “Not at all”.)*

* Interviewer guidance

Normal day-to-day activities can include:

- washing and dressing
- household cleaning
- cooking
- shopping for essentials
- using public or private transport
- walking a defined distance
- climbing stairs
- remembering to pay bills
- lifting objects from the ground or a work surface in the kitchen
- moderate manual tasks such as gardening
- gripping objects such as cutlery
- hearing and speaking in a noisy room.

The respondent should answer based on their current activity restriction. They should consider any treatment they receive, medication they take or other devices they use (such as a hearing aid).

These two questions were originally developed by the UK Government Statistical Service Harmonisation Team and were used in the 2021 UK census. They have gone through extensive cognitive testing in 2018 with participants having a range of impairments including psychosocial disabilities and mental health conditions, as well as varying age-related issues. The cognitive testing showed that a two-stage question design can be used in a census rather than a single question asking to identify disability due to better comprehension, acceptability, and reduced respondent burden.

A further consultation survey was performed by the UK Office for National Statistics to understand the impact of using a two-stage question design. A survey was sent out to over 300 individuals and the results from the stakeholder survey showed that a two-stage question was preferred over a single question and that the data can be compared against other existing survey data.⁶

⁶ More information on the harmonization standards set by the UK Office for National Statistics can be found here:

<https://analysisfunction.civilservice.gov.uk/policy-store/long-lasting-health-conditions-and-illness/>
<https://analysisfunction.civilservice.gov.uk/policy-store/activity-restriction/>

When to use it?

The two short questions for disability disaggregation should be used only when there is limited time to collect information on disability, such as in national census, or when collecting basic demographic information about service users through clinical, trauma and emergency care.

Pros and cons

Pros:

- short and easy to administer in different settings – census, population-based surveys or clinical settings;
- validated and cognitively tested;
- well received by persons with disabilities;
- capture information on both physical impairments and mental health conditions as well as activity limitations;

Cons:

- some persons with disabilities may be not identified;
- does not account for the impact of environmental factors.

More information about the two questions can be found at:

<https://www.ons.gov.uk/census/censustransformationprogramme/healthandunpaidcarequestiondevelopmentforcensus2021>

<https://analysisfunction.civilservice.gov.uk/policy-store/measuring-disability-for-the-equality-act-2010/>

<https://analysisfunction.civilservice.gov.uk/policy-store/long-lasting-health-conditions-and-illness/>

<https://analysisfunction.civilservice.gov.uk/policy-store/activity-restriction/>