

The Importance & Feasibility of Disaggregation by Disability Status

Monitoring the UNCRPD and SDGs



Jennifer H Madans

Associate Director for Science,
National Center for Health Statistics, USA and
Chair, Washington Group on Disability Statistics

Disability and the SDGs

The SDGs are built on the principle of leaving no one behind

- People with disabilities are the most disadvantaged and the most at risk of being left behind
- Disaggregation by disability status is necessary to ensure the equalization of opportunities and equitable development
- Due to lack of available and universally acceptable data collection tools, disability was not included in the MDGs
- Reliable and tested tools are now available

UNCRPD: Article 31 - Statistics and data collection

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.
2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Requirements to disaggregate indicators by disability status

Data collection tools are needed to fulfil two specific data requirements:

- to describe disability as a continuum of functioning based on graded responses to questions in functional domains, and
- to define a cut-off (or a set of cut-offs) that can be agreed upon internationally to disaggregate the outcome indicators (e.g. access to education, employment) by disability status

This allows for the calculation of prevalence rates and for disaggregation.

Disaggregation tools developed by the Washington Group

- Washington Group Short Set
- Washington Group Extended Set for Adults
- Washington Group/UNICEF Child Functioning Module
- Other topic specific modules that combine the WG SS and the Extended Set for Adults (e.g. employment)

Primary Disaggregation Tool for Censuses and Standard Surveys: Washington Group Short Set

Because of a Health problem:

- 1) Do you have difficulty **seeing** even if wearing glasses?
- 2) Do you have difficulty **hearing** even if using a hearing aid?
- 3) Do you have difficulty **walking** or **climbing** stairs?
- 4) Do you have difficulty **remembering** or **concentrating**?
- 5) Do you have difficulty with (**self-care** such as) washing all over or dressing?
- 6) Using your usual language, do you have difficulty **communicating** (for example understanding or being understood by others)?

Response categories:

No difficulty; Some difficulty; A lot of difficulty; Cannot do at all

Since then the Washington Group Short Set...

- has been used in censuses or surveys in over 65 countries
- has been promoted by international aid programs, (DFID/UK and DFAT/Australia), as the means to collect disability data in all programs and projects,
- has been introduced as the means for collecting disability data by the UN Statistical Division (UNSD) and the UN Economic Commission for Europe for the 2020 round of censuses.
- And both the US AID and UNICEF have developed disability modules that will operationalize the WG SS for their Demographic and Health Surveys and Multiple Indicator Cluster Surveys respectively.

Disability prevalence USA: (n=16777; ages 18+) (NHIS: 2013)

Person with disability has:	n	%
at least 1 Domain is 'some difficulty'	7511	41.9
at least 2 Domains are 'some difficulty'	3672	19.6
at least 1 Domain is 'a lot of difficulty'	1872	9.5
at least 1 Domain is 'unable to do it'	465	2.2

Disaggregation in US NHIS data

NHIS 2013: 18-64 years of age
Weighted %

Disability status:
WG Short set: *Cut-off is at least a lot of difficulty in at least 1 domain*

	Without disability	With Disability
Employment Status Last Week=Working	73.5	30.8
Current every day smoker	14.5	27.8
Covered by health insurance? (Yes)	79.5	81.0

Most common indicators that can be disaggregated by disability

Indicator Number	Description of indicator (more than 10 countries can produce)	Number of Countries (out of 32)
1.1.1	Proportion of population below the international poverty line, by sex, age, employment status and geographical location (urban/rural)	11
1.2.1	Proportion of population living below the national poverty line, by sex and age	11
6.1.1	Proportion of population using safely managed drinking water services	11
7.1.1	Percentage of population with access to electricity	11
8.6.1	Proportion of youth (aged 15-24 years) not in education, employment or training	14

Standardized Approach to Monitoring

- By standardizing disability data collection instruments it will be possible to provide comparable data cross-nationally for populations living in a variety of cultures;
- Data can be used to assess a country's compliance with development goals and the UN Convention on the Rights of Persons with Disabilities and, over time, improvement in meeting these goals

Mainstreaming disability statistics: The Path to Disaggregation

- Identify which data collection systems will be used for monitoring population-based SDG indicators
- Include one of the Washington Group Question sets in each of these data collection systems
- Once the questions become integrated into core statistical systems
 - Core information on disability becomes available for use by all government agencies and civil society
 - Disaggregating outcomes (education, employment etc.) by disability status becomes routine and sustainable