

Overview of Disability Measurement and the Washington Group Short Set

Jennifer H. Madans

Associate Director for Science,
National Center for Health Statistics, USA

and

Chair, Washington Group on Disability Statistics

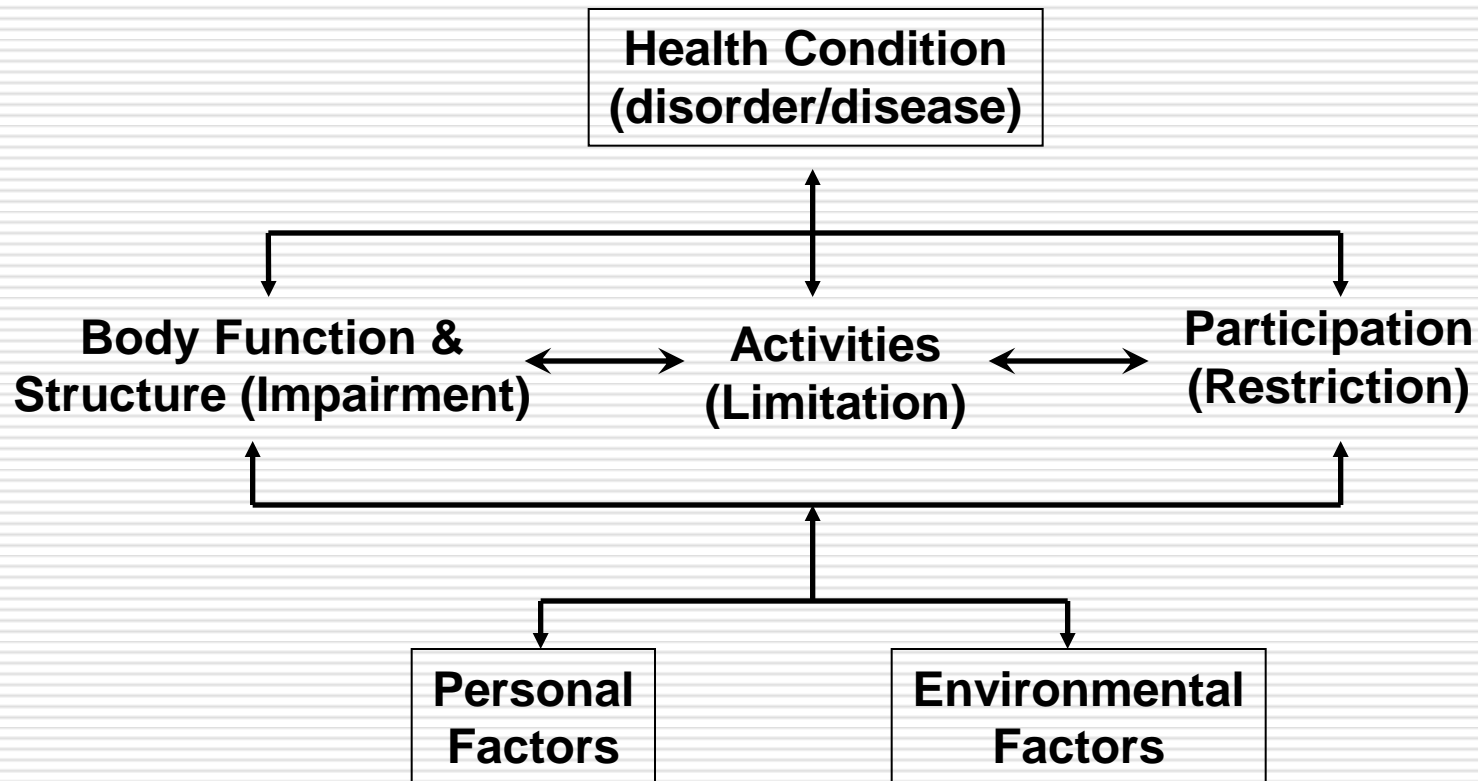


International Training Workshop on Disability for NGOs
Lincoln's Inn Fields, London, UK
March 16, 2017

The State of Disability Data

- In the past, disability data were of poor quality and varied dramatically cross-nationally
 - The Washington Group on Disability Statistics has developed and tested a variety of tools for collecting reliable, meaningful, and internationally comparable data that have been used by a growing number of countries
 - These tools can be used to monitor the UNCRPD and disaggregate the SDGs if incorporated into national statistical systems
 - Resources and training opportunities exist to support the implementation of these questions
-

The ICF Model - 2001



How we ask the questions matters!

Challenge

- Not possible to write a short set of survey questions that can adequately and accurately capture the intricacies of this model

And yet,

- Survey questions must be short, clear, and precise

As a result,

- Many problematic questions have been used
-

Problematic Questions

Do you have a health condition or impairment that limits the amount or type of (*fill in activity, such as work*) you can do?

- Confounds impairments and environment
 - Inconsistent interpretation
 - Cannot be used to disaggregate: by only identifying people being excluded, we miss those who are at risk of exclusion
-

Problematic Questions

Why are you unemployed (not in school, etc.)?

- No job openings
- Don't have necessary skills
- Lack of transportation
- Disability

- A response of "disability" provides no information on function or barriers leaving no policy relevant response options
 - Confounds impairments and environment, for example what if a person lacks transportation because it is not accessible?
 - Will people answer in a consistent fashion? How will we know?
 - Measures outcome; cannot be used for disaggregation (successful adaptors missed)
-

Problematic Questions

Questions used to identify persons with disabilities in the 1990 Zambia Census:

- | | |
|---------------------------------|--------|
| 1. Are you disabled in any way? | Yes/No |
| 2. What is your disability? | |
| Blind | Yes/No |
| Deaf / dumb | Yes/No |
| Crippled | Yes/No |
| Mentally retarded | Yes/No |

Disability prevalence = 0.9%

A medical model approach based on identifying and measuring **impairments**.

Problematic Questions

Questions used to identify persons with disabilities in the 2000 Zambia Census:

- | | |
|---------------------------------|--------|
| 1. Are you disabled in any way? | Yes/No |
| 2. What is your disability? | |
| Blind | Yes/No |
| Partially sighted | Yes/No |
| Deaf / dumb | Yes/No |
| Hard of hearing | Yes/No |
| Mentally ill | Yes/No |
| Ex-Mental | Yes/No |
| Mentally retarded | Yes/No |
| Physically handicapped | Yes/No |

Disability prevalence = 2.7%

Global Disability Prevalence Rates*

High-income countries			Low/Mid-income countries		
	Year	%		Year	%
Canada	1991	14.7			
Germany	1992	8.4	Kenya	1989	0.7
Italy	1994	5.0	Namibia	1991	3.1
Netherlands	1986	11.6	Nigeria	1991	0.5
Norway	1995	17.8	Senegal	1988	1.1
Sweden	1988	12.1	South Africa	1980	0.5
Spain	1986	15.0	Malawi	1983	2.9
UK	1991	12.2	Zambia	1990	0.9
USA	1994	15.0	Zimbabwe	1997	1.9

* Sources and methodologies are country-specific.

Washington Group Objective

Develop questions that capture a part of the ICF model and can be used in an important, meaningful, and internationally-comparable manner.

While these questions may only capture a part of the social model of disability, they can be used in conjunction with other data to undertake analysis consistent with the social model of disability.

The Washington Group: History and Products

The Washington Group (WG)

- June 2001: UN International Seminar on the Measurement of Disability
 - WG established as a City Group under the aegis of the UN Statistical Commission to:
 - address the need for population based measures of disability,
 - foster international cooperation in the area of health and disability statistics,
 - produce internationally tested measures to monitor status of persons with disability, and
 - incorporate disability into national statistical systems.
-

The WG is Country-Driven

- Countries have ownership:
 - Representatives include the National Statistical Offices of 133 countries and territories, 7 international organizations, and 6 organizations that represent persons with disabilities
 - The Secretariat for the WG is located at NCHS (USA).
 - A Steering Committee oversees the WG work plan.
 - Work Groups carry out the work plan, with input from all members.
 - Emphasis on evidence and transparency, with extensive testing of data collection tools in multiple countries.
-

The Definition of Disability...

...has changed over time and is currently conceptualized as the outcome of the interaction between a person with a functional limitation (difficulties doing basic functional activities) and an unaccommodating environment that results in the inability to fully participate in society.

'Disability' may be a complicated construct...

Disability is complex:

- incorporates a variety of different components: body functions & structure, limitations in activities (capacity) and restrictions in participation (performance), and
- includes characteristics of both the person and their environment.

The language of disability is *not* specific.

And finally, in some cultures, stigma is associated with disability – creating additional challenges to measurement and ultimately inclusion.

The questions used to capture 'disability' are not complicated!

The WG defined an approach to measuring disability based on identifying those who:

- because of **difficulties** doing certain **universal, basic actions**,
 - are at greater **risk** than the general population
 - for **limitations in participation**.
-

WG Short Set on Functioning (WG-SS)

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 - no difficulty

Yes - some difficulty

Yes - a lot of difficulty

Cannot do at all

Measuring Disability: (...back to Zambia)

- A survey of Living Conditions among People with Disabilities in Zambia (2006) used the WG-SS.
 - 6 questions, each with 4 response categories
 - Disability cut-off chosen:
 - at least one functioning domain that is coded as a lot of difficulty or cannot do it at all
 - Prevalence **8.5%**
-

Advantages

- Functional approach;
 - Tested successfully in many countries (low, middle, and high income);
 - Designed to be internationally comparable;
 - Identifies most people with disabilities;
 - Can easily be added to existing censuses and surveys or to project based data;
 - Approximately 1.25 minutes to administer.
-

WG Questions Adopted Widely

- Used in censuses or surveys in over 78 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.
 - Adopted as the way to disaggregate data for the Incheon Strategy on Making the Right Real in Asia.
 - Recommended by UN DESA's Disability Data Experts Group as way of disaggregating the SDGs by disability.
-

Limitations of WG Short Set Questions

- Not appropriate for children under age 5, and misses some children with developmental issues age 5-18
 - Misses those with psychosocial issues that do not affect communication or self-care
 - Does not capture age of onset
 - Does not capture environmental barriers
 - Does not address functioning with and without assistive devices
-

Filling the Gaps: Other WG Tools

1. WG Extended Set on Functioning (WG-ES) includes questions... *(tested and finalized)*
 - to get at psychosocial issues
 - to begin to get at the use of assistive devices
 2. UNICEF/WG Children questions *(tested and finalized)*
 - appropriate for children age 2-17
 - gets at full range of childhood disability
 3. Environment *(under development)*
 - UNICEF/WG Inclusive Educational module *(being tested)*
 - ILO/WG Employment – *(being tested)*
 4. WG Work Group on Mental Health *(early stages)*
-

Short Set Objectives

- Identify persons with similar types and degree of limitations in basic actions regardless of nationality or culture;
 - Represent the majority (*but not all*) persons with limitations in basic actions; and
 - Represent commonly occurring limitations in domains that can be captured in the census context.
-

Intended Use of the Data

- Compare levels of participation in employment, education, or family life for those *with* disability versus those *without* disability to see if persons with disability have achieved social inclusion.
 - Monitor effectiveness of programs and policies to promote full participation.
 - Monitor prevalence trends for persons with limitations in specific basic action domains.
-

Discussion
