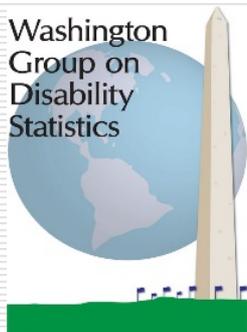


Overview of Disability Measurement and the Washington Group

Mitchell Loeb

National Center for Health Statistics, USA
and
Washington Group on Disability Statistics



Washington Group on Disability Statistics
Implementation Training: Rome, Italy
August 8-10, 2017

The Washington Group

- City Group established by UN Statistical Commission in 2001
- Countries have ownership
 - national statistical offices of 133 countries and territories, 7 international organizations, 6 organizations that represent persons with disabilities
 - Emphasis on evidence and transparency – extensive testing of data collection tools in multiple countries

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
-

How we ask the questions matters!

Challenge

- To write a short set of survey questions that can adequately and accurately capture the complexity of disability

And yet,

- Survey questions must be clear, precise and low burden (on respondent and cost)

As a result,

- Many problematic questions have been used
-

Measuring Disability: 1

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

Questions used to identify persons with disabilities:
Zambia Census 1990

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%

Measuring Disability: 2

Zambia Census 2000

“...disability refers to a person who is limited in the kind or amount of activities that he or she can do because of on-going difficulties due to long term physical, mental or health problems.”

Measuring Disability: 2

Questions used to identify persons with disabilities:
Zambia Census 2000

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			L/M-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

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)
-

Where are we today?

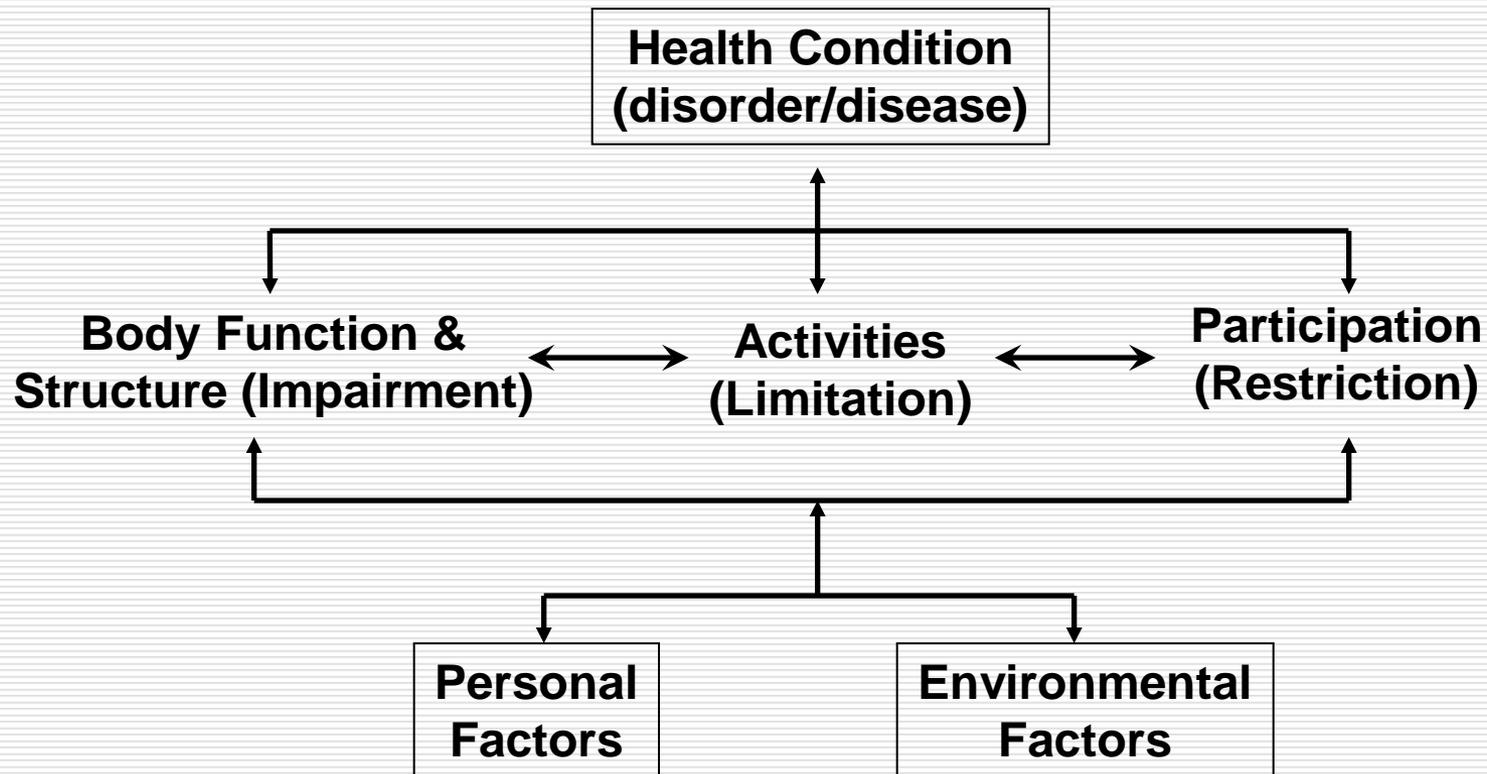
The Social Model of Disability

- Disability conceptualized as the outcome of the interaction between a person's functional limitation (difficulties doing basic functional activities) and an unaccommodating environment that results in the inability to fully participate in society.
 - Not a medical diagnosis or condition
 - Not an impairment

Washington Group Approach

- Identifying people who, because of a health condition, have **difficulties with basic, universal activities** that make them at greater **risk** than the general population for **limitations in participation** in an **unaccommodating environment**.
- Builds on the ICF framework
 - Framework is complex and needs to be deconstructed for data collection
 - ICF codes do not translate into data collection tools

The ICF Model - 2001



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 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' need and must not be 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 Data Collection Tools: 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; 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%**
-

Objectives

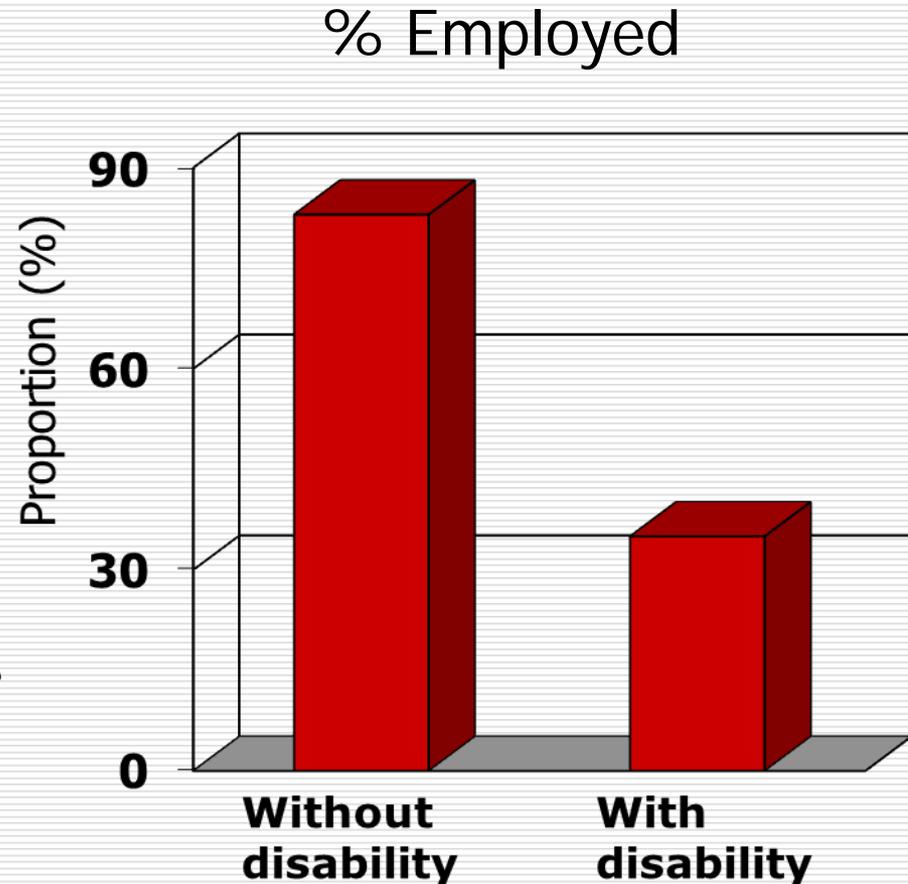
- Identify persons with similar types and degree of limitations in basic actions regardless of nationality or culture
 - Represent the majority (*but not all*) persons with limitations in basic actions
 - Represent commonly occurring limitations in domains that can be captured in the Census context
-

Intended use of 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 / policies to promote full participation
 - Monitor prevalence trends for persons with limitations in specific basic action domains
-

Disaggregation by disability status

- Seeks to identify all those at greater risk than the general population for limitations in participation.
- Disability used as a dissagregation variable.



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.
-

Comparable testing methodology:

- Developed a procedure for question evaluation that includes guidelines for translation and cognitive testing in order to ensure cross-cultural and cross-national comparability
 - **Q-Notes** software developed for data entry and analysis of qualitative cognitive interviews
 - **Q-Bank** launched as an online repository for reports of question evaluation studies – to ensure transparency
 - Publication: Miller K, Willson S, Chepp V, Padilla JL. Cognitive Interviewing Methodology, John Wiley & Sons. 2014
-

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)*
-

Monitoring the UN CRPD and SDGs through data disaggregation

WG question sets are developed:

- to collect internationally comparable data based on the ICF model
- that fulfill the monitoring requirements established by the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals.

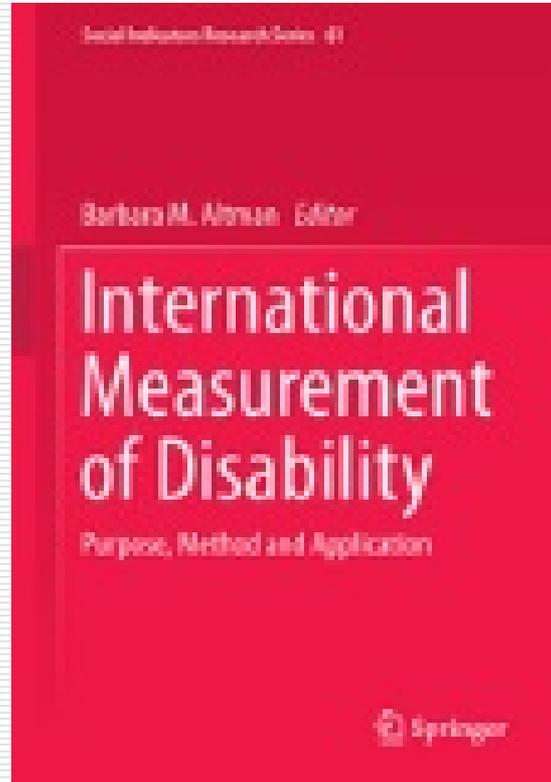
Mainstreaming disability statistics: The Path to Disaggregation

- Identify which data collection systems will be used for monitoring population-based SDG indicators
- Include one of the WG question sets in each of these data collection systems
- Once the questions become integrated into core statistical systems
 - 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

Guidelines and documentation: completed, in preparation, planned

- Conceptualization and Measurement of Disability
- WG question sets Implementation Guidelines
- WG Question by Question Specifications
- Translation Protocol
- Interviewer Guidelines
- Analytic Guidelines including SPSS syntax
- Regional guide to improve disability data collection and analysis in Arab speaking countries (with ESCWA)

Volume on the history and accomplishments of the WG:



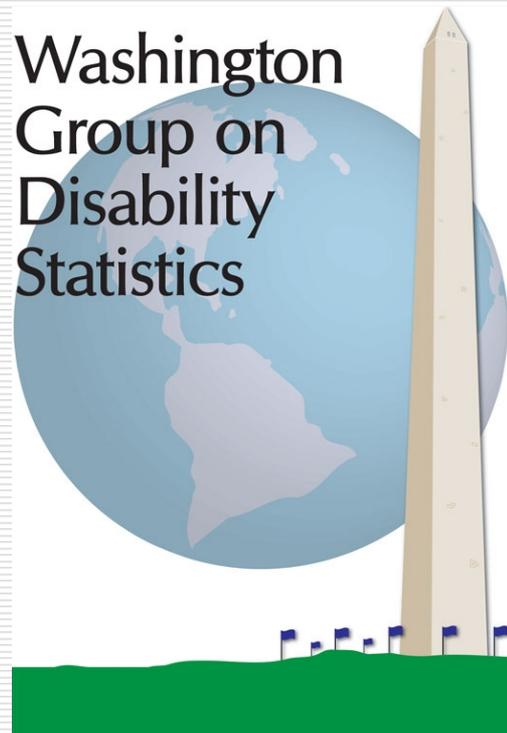
International Measurement of Disability:
Purpose, Method and Application
The Work of the Washington Group

B. M. Altman (Editor)
Springer (Publisher)

Publication: June, 2016

The New WG Website:

<http://www.washingtongroup-disability.com/>



Discussion
