Disability Measurement and the Washington Group on Disability Statistics

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National Center for Health Statistics, USA and Washington Group on Disability Statistics
A Brief History of Disability Measurement
Measuring Disabilities: 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 Disabilities: 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 Disabilities: 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
   - Partially sighted
   - Deaf/dumb
   - Hard of hearing
   - Mentally ill
   - Ex-Mental
   - Mentally retarded
   - Physically handicapped

Disability prevalence = 2.7%

01/06/2017
## Global disability prevalence rates*

<table>
<thead>
<tr>
<th>High-income countries</th>
<th>Year</th>
<th>%</th>
<th>L/M-income countries</th>
<th>Year</th>
<th>%</th>
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<td>Senegal</td>
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<td>Norway</td>
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<td>1994</td>
<td>15.0</td>
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* Sources and methodologies are country specific
The Washington Group (WG): 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
  - 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, 6 organizations that represent persons with disabilities

- The **Secretariat** for the WG is located at NCHS

- A **Steering Committee** oversees the WG work plan

- **Workgroups** carry out the work plan with input from all members

- Emphasis on evidence and transparency – extensive testing of data collection tools in multiple countries
WG: Workgroups / Leaders

- Workgroup on the Analysis of the Extended Set on Functioning / NCHS
- Workgroup on Child Functioning / NCHS
- Workgroup on Environmental Factors and Participation / NCHS
- Workgroup on Mental Health / Margie Schneider, South Africa; Elena De Palma, Italy
- Workgroup on Disability Module for Labor Force Surveys / Daniel Mont, UCL

01/06/2017
Summary of annual meetings


## Workshops and Technical Assistance

<table>
<thead>
<tr>
<th>Country</th>
<th>Date</th>
<th>Country</th>
<th>Date</th>
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<td>Jordan*</td>
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*in conjunction with UNICEF
Collaborations

The WG has a long history of collaboration with other international organizations:

• UN Statistics Division
• UN Secretariat for the CRPD
• UNICEF
• UN ESCAP
• World Bank
• ILO
• World Health Organization

as well as many National Statistical Offices and both Non-Governmental and Disabled Person’s Organizations
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
Report Series of WG activities:

- Disability Information from Censuses, prepared for DPOs
- Development of an Internationally Comparable Disability Measure for Censuses, prepared for NSOs
- Monitoring the UN CRPD
- Understanding and Interpreting Disability as Measured using the WG Short Set of Questions
- The Measurement of Disability: Recommendations for the 2010 Round of Censuses
- Development of Extended Sets of Disability Measures for Surveys
- Disaggregation by Disability - A way forward (forthcoming)
The New WG Website:

http://www.washingtongroup-disability.com/
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 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.
The complexity of disability

Disability is complicated – incorporates a variety of different components: body functions & structure, limitations in activities (capacity) and restrictions in participation (performance), and also 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 ICF Model - 2001

Measuring Disabilities: 3

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; Some difficulty; A lot of difficulty; Cannot do at all
Limitations

• One set of measures will not satisfy multiple needs for disability data

• Excluded populations:
  • Very young children
  • Institutionalized population
  • Homeless
  • Floating populations
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 disaggregation variable.
Additional WG Data Collection Tools:

- Extended set on functioning adopted 2010
  - expands on the Short Set adding information on upper body functioning, affect, pain and fatigue and adding more questions per domain;
  - begins to explore the association between functioning and the environment: use of assistive devices/aids, and functioning with and without assistance
Question set that focuses on special case of disability and functioning among children and youth:

- **WG/UNICEF Module on Child Functioning:**
  - includes questions for children 2-4 and 5-17 years
  - Domains of functioning: Seeing, Hearing, Mobility, Cognition/Learning, Self-care/Upper body, Communication, Affect, Controlling behavior, Accepting change, Focusing attention, Relationships/Playing
Mainstreaming disability statistics

- WG questions can be added to any on-going data collections;
  - Can be used in any national or subnational survey (health, labor force, income & expenditure, DHS, MICS etc.)

- Once the WG questions become integrated into core statistical systems – disaggregating outcomes (education, employment etc.) by disability status becomes routine
Question set that focuses on the environment and participation:

- **WG/UNICEF Module on Inclusive Education**
  - begins to address the association between environmental barriers and participation

- **Attitudes**: societal and cultural norms; perceptions and attitudes of parents, other students and school staff

- **School Environment**: physical and academic accessibility

- **Affordability**: fees, costs, and competition for resources associated with attendance

- **Out of school**: reasons why a child may be out of school
WG Data Collection Tools in Collaboration with ILO: Employment

Question set that focuses on the environment and participation:

- Disability module for inclusion on labor force surveys
  - under development in collaboration with ILO
For more information about the WG:
www.cdc.gov/nchs/washington_group.htm

Questions:
WG_Secretariat@cdc.gov