

International Initiatives in the Measurement of Health State and Disability

The Work of the Washington Group on Disability Statistics & the Budapest Initiative

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The Washington Group on Disability Statistics (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, and
 - develop principles and standard forms for global indicators of disability.

Role of the Washington Group

- Foster international cooperation in the area of health and disability statistics
- Untangle the web of confusing and conflicting disability estimates
- Develop a short set of general disability measures
- Develop extended set/s of items to measure disability on population surveys
- Address methodological issues associated with disability measurement
- Produce internationally tested measures for use to monitor status of disabled populations.

The WG is Country driven

- Countries have ownership
- The Secretariat for the WG is located at the National Center for Health Statistics
- A rotating Steering Committee oversees the work plan of the WG and preparations for the annual meetings – NCHS has served as chair
- Workgroups lead the development of specific tasks: currently child disability, the environment and participation, and analysis
- Emphasis on evidence and transparency – extensive testing of questions in multiple countries

Membership of the WG

- Current representatives from national statistical authorities include 118 countries and territories
- Past and present representatives of international (5) and national (9) organizations representing persons with disabilities, and several national government and non-government organizations
- Other international organizations

The Budapest Initiative (BI)

- Joint UNECE/WHO/Eurostat Meeting on the Measurement of Health Status
- Task Force established
- Consensus reached
 - Number of classes of measures are needed for full picture of population health
 - Focus on internationally accepted standard set of questions for assessing health state using modern sample surveys

The Budapest Initiative (BI)

- Aim: to achieve internationally comparable measurement of population health states within the framework of official statistics.
- Focus is not on providing a full statistical picture of population health, its determinants, and consequences.
- Focus is on the development of common instruments to measure health state in its multiple dimensions.
- Merged with Washington Group

WG/UNICEF collaboration:

- In 2009 the WG formed a Workgroup on Child Functioning and Disability to develop and test a set of questions on child functioning and disability.
- In 2011 UNICEF joined the workgroup and began collaborating with the WG

Washington Group/Budapest Initiative/UNESCAP/UNICEF Question Development Matrix

Row		Questionnaire Topic/Type	Basic Activity Domains					Body Function Domains			Complex Activity / Participation Domains						
			Vision	Hearing	Mobility	Communication	Cognition/remembering	Upper Body	Learning/understanding	Affect (6)	Pain	Fatigue	ADL/IADL	Getting Along with People	Major Life Activities	Participation in Society	
1	Capacity	Short Set Single Questions (1)						b				b					
2		Extended Set Multiple Questions (1)					a	a		c	a/c	a					
3	Performance	Use of Assistive Devices Micro-E (2)				Sign language											
4		Functioning with Assistance, Micro-E								c							
5		Children and Youth (3)															
6		Age at Onset															
7		Cause															
8		Duration															
9		Impact (limit ability to carry out daily activities)															
10		Meso-Environment (4)	Question Set currently under development														
		6/4/2013															
11		Macro-Environment (5)	To be obtained through other sources, not personal survey data collections														

WG/BI/UNICEF Disability Measures:

WG Short Set: six questions recommended for Censuses.
(Recommended for use in all national censuses in the UN *Principles and Recommendations for Population and Housing Censuses*)

WG/BI Extended Set on Functioning for national surveys.
(Subset to be included on European Health Interview Survey)

WG/UNICEF module on Child Functioning and Disability is currently being tested.

Extended set on the environment is currently under development.

Developed a comparable testing methodology

Building an Infrastructure for Disability Data

- Support the routine collection of disability data within national statistics programs
- Incorporate WG short set into population censuses
- Incorporate WG/BI extended question sets on functioning and WG/UNICEF module on child functioning and disability into population surveys, supplements to surveys, or as the core of a more comprehensive disability survey
- Resulting data can be used to monitor the CRPD and development goals

Development of Comparable Testing Methodology

2008 (July): a joint WG/BI meeting held in Washington, D.C., to discuss extended question set development;

✓ the development of a cognitive test protocol;

2009 (February): ESCAP/WG training, held in Bangkok, to train six ESCAP countries (Cambodia, Kazakhstan, Maldives, Mongolia, Philippines and Sri Lanka) in cognitive and field test procedures and the subsequent cognitive testing in these countries and in Canada, the United States and South Africa (continued)

Development of Comparable Testing Methodology

2009 (May): WG/BI Extended Set Analysis Workshop, held in Washington, D.C.

- ✓ the development of a field test protocol and field testing in the same six ESCAP countries; and

2009 (October): presentation of results from cognitive testing and preliminary field test results to the ninth meeting of the WG in Dar es Salaam.

Development of Comparable Testing Methodology

Coordinated data collection and joint analysis with Q-Notes

2010 Granada Group: European Cognitive Testing of Extended Set in US (English/Spanish), Spain, Germany, Switzerland, Italy, France, Portugal

2010: Training & Cognitive Testing of Extended Set in Oman.

2010/2011: ESCAP Round II Cognitive Testing in Sri Lanka, Cambodia, Philippines, Maldives, Mongolia, Kazakhstan

Development of Comparable Testing Methodology

Cognitive testing of the WG/UNICEF module on child functioning and disability in:

- Mumbai, India: September, 2012
- Belmopan, Belize: January, 2013
- Muscat, Oman: April, 2013

Further cognitive testing planned for Montenegro:
July, 2013

Field testing to follow.

Joint Action -- European Health and Life Expectancy Information system

- ❑ European Commission funded 3 year project to monitor health trends and gaps among EU countries using measures of healthy life expectancy
- ❑ Expand comparisons to include the US and Japan
- ❑ Investigate alternative summary measures of population health for use in calculating healthy life expectancies