

14th Annual Meeting of the Washington Group on Disability Statistics

Accomplishments, Objectives and
Agenda

Jennifer Madans (U.S.A.)

National Center for Health Statistics/

Washington Group on Disability Statistics

WG Milestones:

1. Agreement to develop short and long sets of internationally comparable disability measures using the ICF as a framework; census questions a priority
2. Equalization of opportunities selected as purpose of short measure
3. Developed a comparable testing methodology
4. Tested and revised questions
5. Short set adopted 2006
6. Extended set on functioning adopted 2010
7. Module on Child Functioning and Disability developed with UNICEF – testing underway
8. Extended set on the environment for children and adults currently under development.

Collaborations:

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

- UNSD (Statistical Division)
- UN DESA (Department of Economic and Social Affairs)
- UNICEF (Children's Fund)
- UN ESCAP (Economic and Social Commission for Asia and the Pacific)
- World Bank
- World Health Organization

as well as many Non-Governmental and Disabled Person's Organizations and National Statistical Offices

Summary of annual meetings

1. Washington, DC	February	2002
2. Ottawa, Canada	January	2003
3. Brussels, Belgium	February	2004
4. Bangkok, Thailand	September	2004
5. Rio de Janeiro, Brazil	September	2005
6. Kampala, Uganda	October	2006
7. Dublin, Ireland	September	2007
8. Manila, Philippines	October	2008
9. Dar es Salaam, Tanzania	October	2009
10. Luxembourg	November	2010
11. Southampton, Bermuda	November	2011
12. Bangkok, Thailand	October	2012
13. Amman, Jordan	October	2013

WG-13 in Amman, Jordan Oct, 2013:

The meeting was attended by 165 persons:

- 16 representing national statistical authorities from 9 countries;
- 140 representatives from universities or national institutes of public health or other national research bodies or ministries;
- 3 representatives from the National Center for Health Statistics (WG Secretariat);
- 3 representatives from organizations representing persons with disabilities; and
- 3 representatives from international organizations (Pacific Islands Forum Secretariat, UNICEF, UN Women)

WG-13 Main Objectives:

- Present analyses of results of country data collection using the WG Short Set
- Present guidelines for analyzing data obtained from the WG Extended Set on Functioning
- Present progress with WG/UNICEF module on child functioning and disability
- Review progress in developing extended set(s) on environmental factors and participation
- Review recent international activities in disability statistics

All these items (and more) will be discussed in detail during WG-14

Workshops and Expert Consultations:

Nairobi, Kenya	June	2005
Bishkek, Kyrgyz Republic	Dec	2006
Sarajevo, Bosnia and Herzegovina	Feb	2008
Bangkok, Thailand	April	2008
Ohrid, Macedonia	Nov	2008
Dhaka, Bangladesh	Aug	2009
Muscat, Oman	Oct 2010 / April 2013,	
Damascus, Syria	Dec	2010
Sharjah, UAE	May	2011
Bogotá, Colombia	July 2012 / August 2013,	
Mumbai, India	Sept	2012
Belmopan, Belize	Jan	2013
Amman, Jordan	May	2013
Podgorica, Montenegro	July	2013
Apia, Samoa	June	2014

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 Convention on the Rights of Persons with Disability
- 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

Publications:

- Measuring Disability and Monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. BMC Public Health 2011, **11**(Suppl 4):S4
- A White Paper on Disability Measurement. Journal for Disability and International Development. 2012, **1**:4-11.
- Disability Statistics: and integral but missing (and misunderstood) component of development work. Nordic Journal of Human Rights, 2013; **31(3)**:306–324
- Methods to Improve International Comparability of Census and Survey Measures of Disability. Disability & Rehabilitation, 2013; **35(13)**:1070-3

WG Book under development

B. Altman (Editor) / Springer (Publisher)

Work on this volume began in 2012.

It will highlight:

- the development and testing of the WG short set;
- experiences of several countries on the use of the WG questions and how this has impacted on national agendas in the area of disability;
- the development and testing of an extended set of questions for use in national surveys;
- the challenges of translation and the importance of generating comparable question sets in different languages and within different cultures;

WG Book under development

- an examination of cognitive testing techniques in a variety of countries;
- results of the first round of censuses in 2010 in countries using the six question set;
- an overview of the work currently underway in the development of a question module on child disability and functioning and the environmental contexts of school participation; and
- a discussion of what the development of cross-nationally comparable data can mean for the improvement of circumstances for all persons with disabilities.

The Road Ahead

UN Statistical Commission

- at the 45th Session of the UNSC, the work of the WG was included as a *discussion item*;
- over 20 countries expressed their support for the work of the WG;
- several indicated that they had used or intended to use the WG SS of questions in their census;
- the commission commended the work of the WG and endorsed its the work program for 2014-2015,
- encouraging continued work on the extended question set on functioning for adult and children; and
- **suggested expanding the scope of work to include data analysis and the dissemination of disability statistics.**

WHO/WB Model Disability Survey: 1

WG continues to collaborate with WHO/WB on the development of a Model Disability Survey (MDS)

- First proposed by WHO/WB in December 2012
- Meetings held in Geneva: December 2012, April 2013 and February 2014
- Development of survey questions
- Cognitive testing of question *design*
 - 2013: USA (NCHS, UoM), and Malawi (Norway)
 - 2014: USA (NCHS, UoM), Cambodia (Norway), China & Nepal (UoM)

WHO/WB Model Disability Survey: 2

The UN Statistical Commission welcomed the collaboration between the WG and the WHO on disability measurement, and encouraged the two parties to work closely together to develop the model disability survey instrument and to meet the objectives of both parties by including in the model survey the questions developed by the Washington Group, with a view to avoiding confusion and duplication of effort in this area.

International Initiatives regarding the WG SS

Recommendations for monitoring:

- UN DESA/UNESCO Expert Group Meeting, Paris, July '14
- Follow-up conference on disability data, London, Oct '14

Adoption in International aid programs:

- UK Department for International Development (DFID)
- US Agency for International Development (USAID)

The 2020 round of censuses:

- UN Department of Economic and Social Affairs (DESA)
 - UN Economic Commission for Europe (ECE)
-

The Road Ahead

- We will continue to work on question development for sub-populations (children), specific areas (mental health, environment & participation), and applications (registry data)
- We will discuss:
 - Capacity building,
 - Training & Technical assistance,
 - Analysis,
 - Implementation, and
 - Dissemination.

Main Objectives for 14th meeting

- present the final up-date of analyses of results of country data collection using the WG Short Set and presentation of the published paper
- review and approve guidelines for analyzing data obtained from the WG Expanded Set on Functioning
- present additional work on the WG/UNICEF module on child functioning and disability
- review progress in development of measures of facilitators and barriers to school participation for children
- new WG initiatives (mental health & registry data workgroups) to present on progress
- review recent international activities in disability statistics

Agenda: Sessions Overview

1. Opening
2. Presentation of results using the WG Short Set
3. Presentation of guidelines for analyzing WG extended set data
4. Methodological issues: development of questions for child/youth functioning, and the measurement of environmental barriers to school participation
5. Summary of the country reports; overview of WG workgroup activities (mental health & registry data); and an update on other WG and collaborative activities
6. Updates on WG governance issues; summarizing the accomplishments of the 14th meeting and next steps and objectives for the 15th meeting