Mainstreaming Disability Data: The Washington Group on Disability Statistics

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

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

- UN Statistics Division
- UN Secretariat for the CRPD
- UNICEF
- UN ESCAP / ESCWA
- World Bank
- ILO
- World Health Organization

as well as many National Statistical Offices and both Non-Governmental and Disabled Person’s Organizations
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# Workshops and Expert Consultations:

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*in collaboration with UNICEF*
WG: Workgroups

Existing Workgroups on:
- the Analysis of the Extended Set on Functioning
- Child Functioning
- Mental Health
- Disability Module for Labor Force Surveys

Proposed Workgroups on:
- Collecting disability data through administrative records
- Further disability data analysis
- The measurement of participation and the environment
WG Data Collection Tools: Short Set

Question set that focus on measuring difficulty functioning in universal, basic activities:

- Short set on functioning adopted in 2006
  - Domains of functioning:
    Seeing, Hearing, Mobility, Cognition, Self-care, Communication
  - Response categories:
    No difficulty; Some difficulty; A lot of difficulty; Cannot do at all
Testing of the WG SS

- Cognitive testing of the short set questions was carried out in 2006 in fifteen countries:
  Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda, Vietnam

- This was followed by field testing in five countries:
  Argentina, Brazil, Gambia, Paraguay, Vietnam
Since its adoption in 2006 the WG Short Set...

- has been 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.
- And both the US AID and UNICEF have developed disability modules that will operationalize the WG SS for their Demographic and Health Surveys (DHS) and Multiple Indicator Cluster Surveys (MICS) respectively.
WG Data Collection Tools: Extended Sets for Adults and Children

- Extended set on functioning for adults 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
- WG/UNICEF Module on Child Functioning:
  - includes questions for children 2-4 and 5-17 years
Question sets that focus on the environment and participation:

- **WG/UNICEF Module on Inclusive Education**
  - begins to address the association between environmental barriers and participation
- **Disability module for inclusion on labor force surveys**
  - currently under development in collaboration with ILO
- **Module on environment & participation**
  - under development
  - measuring the environment indirectly through participation in selected activities: family, social and civic domains
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.
Defining a disability continuum and a disability dichotomy

WG questions fulfil two specific data needs:

• to describe disability data as a continuum of functioning based on graded responses to questions in the functional domains, and

• to define a cut-off (or a set of cut-offs) that can be agreed upon internationally in order to disaggregate outcome indicators (e.g. access to education, employment) by disability status

This allows for the calculation of prevalence rates and disaggregation.
Disaggregation requirements

- Need a straightforward and simple way to identify persons with disabilities: the WG questions identify those at greater risk than the general population for limitations in participation.

- Need outcome data (education, employment, income, health care access) from data collections (census/surveys) that also include the above disability identifier.
Focus on Equalization of Opportunities

- Seeks to identify all those at greater risk than the general population for limitations in participation.
- Disability used as a dissagregation variable.
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 Washington Group question sets in each of these data collection systems
- Once the questions become integrated into core statistical systems
  - Core 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
The Road Ahead

Capacity building through 2018

• regional workshops
• implementation and other technical workshops

Development of guidance documents

• Implementation protocols for data collection
• Data analysis
• Dissemination of results
For more information about the WG visit our new website:
http://www.washingtongroup-disability.com/

Questions:
WG_Secretariat@cdc.gov