Mainstreaming Disability Data: The Washington Group on Disability Statistics
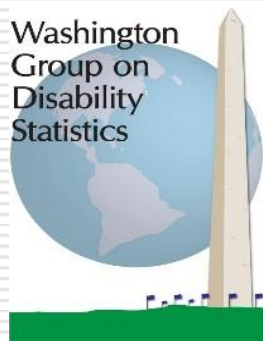
Washington Group on Disability Statistics

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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 <u>Secretariat</u> for the WG is located at NCHS
- A <u>Steering Committee</u> oversees the WG work plan
- <u>Workgroups</u> carries out the work plan with input from all members
- Emphasis on evidence and transparency – <u>extensive testing of data collection tools in multiple countries</u>

WG: Workgroups

- Workgroup on the Analysis of the Extended Set on Functioning
- Workgroup on Child Functioning
- Workgroup on Environmental Factors and Participation
- Workgroup on Mental Health
- Workgroup on Disability Module for Labor Force Surveys

Summary of annual meetings

1. Washington, DC   2/2002

2.	Canada	1/2003	9.	Tanzania	10/2009
3.	Belgium	2/2004	10.	Luxembourg	11/2010
4.	Thailand	9/2004	11.	Bermuda	11/2011
5.	Brazil	9/2005	12.	Thailand	10/2012
6.	Uganda	10/2006	13.	Jordan	10/2013
7.	Ireland	9/2007	14.	Argentina	10/2014
8.	Philippines	10/2008	15.	Denmark	10/2015
			16.	South Africa	12/2016

Workshops and Expert Consultations:

Nairobi, Kenya	06/2005	Mumbai, India*	09/2012
Bishkek, Kyrgyz Republic		Belmopan, Belize*	01/2013
	12/2006	Amman, Jordan	05/2013
Sarajevo, Bosnia & Herzegovina		Podgorica, Montenegro*	07/2013
	02/2008	Apia, Samoa*	06/2014
Bangkok, Thailand	04/2008	Hammamet, Tunisia*	02/2015
Ohrid, Macedonia	11/2008	Geneva, Switzerland*	07/2015
Dhaka, Bangladesh	08/2009	Addis Ababa, Ethiopia	05/2016
Muscat, Oman	10/'10 & 04/'13	NY, New York*	06/2016
Damascus, Syria	12/2010	Nadi, Fiji	07/2016
Sharjah, UAE	05/2011		
Bogotá, Colombia	07/'12 & 08/'13		

*in collaboration 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
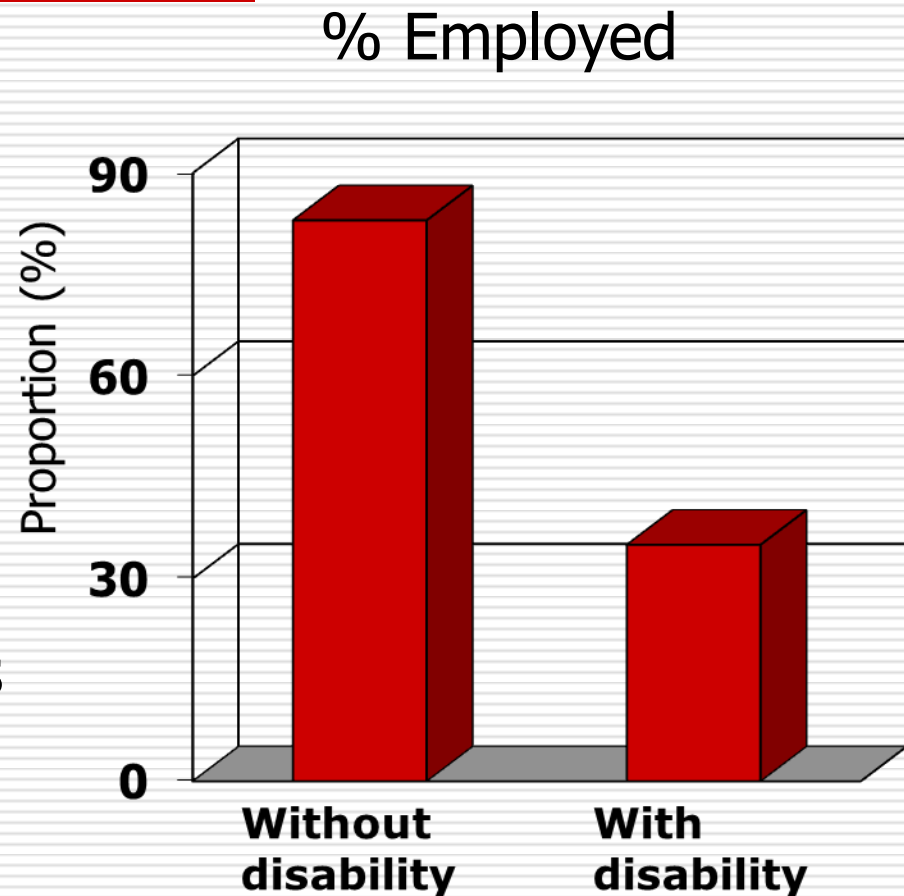
WG Data Collection Tools: Short Set

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

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 <u>dissagregation variable.</u>

% Employed

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

Monitoring the UN CRPD and SDGs through data disaggregation

WG question sets are developed

- to collect internationally comparable data based on the ICF model

The question sets produce data

- That fulfill the monitoring requirements established by the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals.

Disaggregation requirements

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

- Need <u>indicator/outcome data</u> (education, employment, income, health care access) from data collections (census/surveys) that also include the above disability identifier.

WG 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

What can the WG Short Set produce?

Domain specific outputs:

- different categorizations on each domain

- a summary score for each individual domain of functioning

- continuum of functioning on each of the 6 domains

Overall outputs:

- a set of disability scores (based on different cut-offs) suitable for disaggregation

- a recommended disability indicator for disaggregation and international comparisons

Prevalence (weighted %) by domain and degree of difficulty

	At least:		
Core Domain	**Some difficulty**	**A lot of difficulty**	**Unable To do it**
Vision	17.1	2.0	0.2
Hearing	17.2	1.8	0.1
Mobility	17.0	5.7	1.8
Cognition	16.8	2.1	0.1
Self-Care	3.8	0.9	0.3
Communicating	4.8	0.7	0.2

Defining a disability continuum <u>and</u> 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 <u>a set of cut-offs</u>) 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.

Creating the WG disability dichotomy

For purposes of reporting and generating internationally comparable data, the WG has recommended the following cutoff be used to define the population of persons with disabilities:

- The sub-population identified as *with disability* includes those with *at least one domain* that is coded as *a lot of difficulty* or *cannot do it at all*.

Disability prevalence USA

Person with disability has:	n	%
at least 1 Domain is 'some difficulty'	7511	41.9
at least 2 Domains are 'some difficulty'	3672	19.6
at least 1 Domain is 'a lot of difficulty'	1872	9.5
at least 1 Domain is 'unable to do it'	465	2.2

Disability by Employment status

NHIS 2010 Weighted %		Employment Status Last Week 18-64 years of age		
WG Short Set		Overall prevalence	Without disability	With Disability
Cut-off is *a lot of difficulty* or *cannot do* in at least 1 domain		8.9	73.4	29.1
Cut-off is *some difficulty* in at least 2 domains		19.0	74.5	48.4
Cut-off is *some difficulty* in at least 1 domain		38.1	74.9	62.0

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

The Washington Group Short Set...

- has been used in censuses or surveys in over 65 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 and Multiple Indicator Cluster Surveys respectively.

WG Data Collection Tools: Extended Set for Adults

- 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

WG Data Collection Tools: Children

Question set that focus 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

Question set that focus on the environment and participation:

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

WG Data Collection Tools: Participation

Question sets that focus on the environment 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

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 Road Ahead

Capacity building through 2018

- 5-7 regional workshops
- 6-8 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

Washington Group on Disability Statistics