The 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

- Emphasis on evidence and transparency – <u>extensive testing of data collection tools in multiple countries</u>

- <u>Workgroups</u> carries out the work plan with input from all members

Collaborations

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

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

as well as many National Statistical Offices and both Non-Governmental and Disabled Peoples' Organizations

Summary of annual meetings

1. Washington, DC   2/2002

2. Canada   1/2003
3. Belgium   2/2004
4. Thailand   9/2004
5. Brazil   9/2005
6. Uganda   10/2006
7. Ireland   9/2007
8. Philippines   10/2008
9. Tanzania   10/2009
10. Luxembourg 11/2010

11. Bermuda   11/2011
12. Thailand   10/2012
13. Jordan   10/2013
14. Argentina   10/2014
15. Denmark   10/2015
16. South Africa   12/2016
17. Australia   10/2017
18. Rome, Italy   11/2018

Regional Workshops (2017)

UNSD: on Disability Measurement and Statistics focusing on the 2030 Agenda for Sustainable Development and the 2020 Round of Population and Housing Censuses	UNICEF: on Disability Measurement with a focus on Child Functioning and Disability	WG: on Disability Measurement with a focus on the Implementation of WG tools in National Statistical Systems
Bangkok, Thailand (SE Asia)*	Tunis, Tunisia (National)	Suva, Fiji (South Pacific)
Bridgetown, Barbados (Caribbean)	Geneva, Switzerland (Central Asia)	Casablanca, Morocco (Western Asia)
Kampala, Uganda (Africa)	Westchester, NY (Latin America)	Rome, Italy (non-regional)
Muscat, Oman (Western Asia)	Westchester, NY (SE Asia+)	Port of Spain, Trinidad & Tobago (Caribbean)
Santiago, Chile (Latin America)	Dakar, Senegal (Africa)	Mexico City, Mexico (Latin America)
Almaty, Kazakhstan (Central Asia)		

* No WG representation

WG Regional Workshops (2018)

Implementation Workshops:

- Bangkok, Thailand (SE Asia) April 2018
- Dar es Salaam, Tanzania (Africa) June 2018

DPO Training

- NYC (with UNICEF) June 2018
- Quito, Ecuador December 2018

WG Webinars:

February 2018:

- WG hosted: Review of Major Outcomes from the 17th Washington Group Meeting

April 2018:

- IDA hosted: DPO webinar: Mobilizing Disability Data

May 2018:

- WG hosted: Data Production and Analysis Using the WG Tools

WG Tools:

1. WG Short set - adopted 2006
2. WG Extended set on functioning for adults - adopted 2010
3. WG/UNICEF Child Functioning Module – adopted 2016
4. WG/UNICEF Module on Inclusive Education – cognitive testing continues
5. Module for use in Labor Force Surveys (with ILO) – field testing commenced
6. Module on Psychosocial Functioning - under development
7. Additional module on the environment and participation currently under consideration

Guidelines and documentation:

- Conceptualization and Measurement of Disability (outlining WG Tools)

- WG Short Set Implementation Guidelines

- WG Short Set Question by Question Specifications

- Translation Protocol

- Interviewer Guidelines (under revision)

- Analytic Guidelines WG-SS and WG-ES-F including SPSS and SAS syntax

- Regional guide to improve disability data collection and analysis in Arabic-speaking countries (with ESCWA)

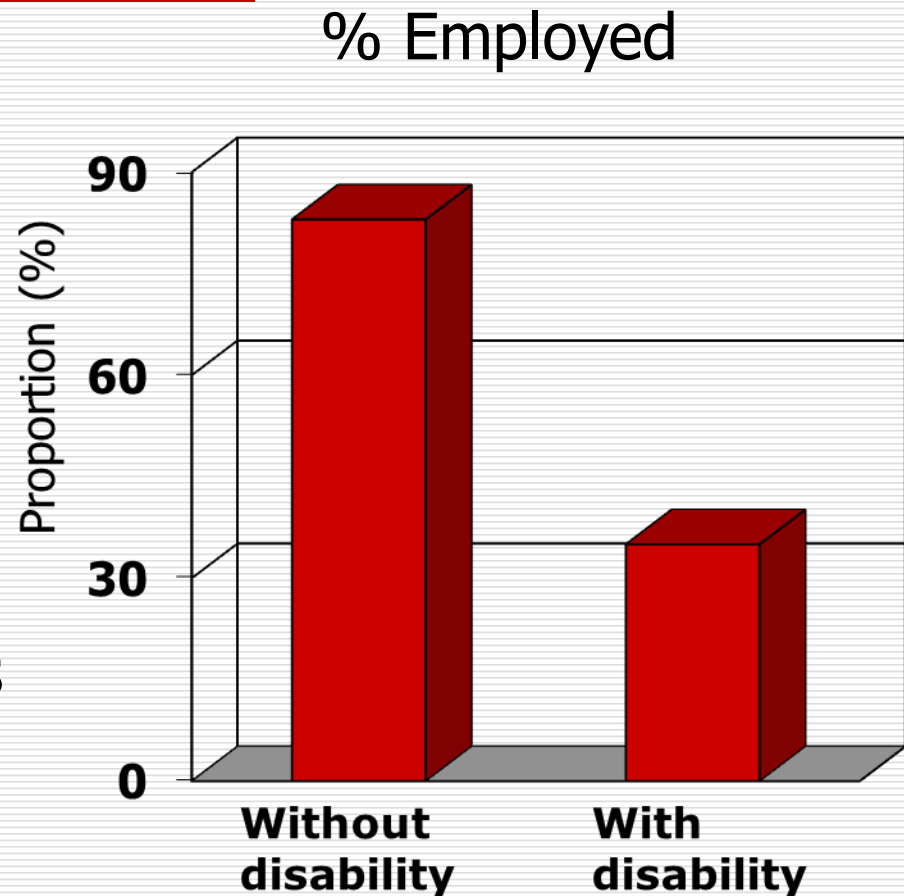- WG-ES-F Question by Question Specifications (finalized)

WG: Workgroups / Leaders

- Analysis / NCHS
- Child Functioning & Inclusive Education / NCHS
- Environmental Factors and Participation / NCHS
- Psychosocial Functioning/ Margie Schneider (South Africa); Elena De Palma (Italy)
- Disability Module for Labor Force Surveys / Daniel Mont (UCL)
- Administrative data / NCHS; Xoliswa Ndamase (South Africa)

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

Monitoring the UN CRPD and SDGs through data disaggregation

Disaggregation requirements

- Need a straightforward and simple way to <u>identify persons with disabilities</u>

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

Monitoring the UN CRPD and SDGs through data disaggregation

WG question sets were 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.

Monitoring the UN CRPD and SDGs through data disaggregation

WG questions fulfil two specific data needs:

- to describe disability data as a <u>continuum</u> of functioning based on graded responses to questions in the functional domains, and

- to define a <u>cut-off</u> (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.

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

Disability Identifiers

DISABILITY1: the level of inclusion is at least one domain is coded *some difficulty* or *a lot of difficulty* or *cannot do at all*.

DISABILITY2: the level of inclusion is at least 2 domains are coded *some difficulty* or any 1 domain is coded *a lot of difficulty* or *cannot do at all.*

DISABILITY3: the level of inclusion is any 1 domain is coded *a lot of difficulty* or *cannot do at all*.
This is the cut-off recommended by the WG.

DISABILITY4: the level of inclusion is any one domain is coded *cannot do 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 (Working)

NHIS 2013 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

WG Data Collection Tools: Extended Sets for Adults (WG-ES-F)

Extended set on functioning for adults adopted 2010

- is comprised of about 35 questions relating to 11 core domains of functioning that were selected based on their universality and commonality across cultures and countries at various stages of economic development.

WG Extended Set:

- includes domains of functioning that were not in the Short Set (upper body functioning, affect, pain, and fatigue)

- includes additional information on the domains already covered by the short set;

- includes information on the use and impact of assistive devices, thereby beginning to establish a link between functioning and the environment.

The Short Set is embedded in the Extended Set.

Disability Identifiers

WG-SS: Short Set: six questions, six domains.

WG-ES1: Complete Extended Set: 25 questions, 11 domains

WG-ES2: Modified Extended Set (WG-ES1 *minus* Pain and Fatigue): 20 questions, 9 domains

WG-ES3: Short Set Enhanced (WG-SS *plus* Upper body, Anxiety and Depression): 12 questions, 9 domains.

Disability prevalence USA

Disability identifier based on:		n	%
WG-SS	6 questions	1872	9.5
WG-ES1	11 domains / 25 questions	3503	17.7
WG-ES2	9 domains / 20 questions	3104	15.4
WG-ES3	9 domains / 12 questions	2384	11.9

WG Data Collection Tools: Child Functioning module (CFM)

WG/UNICEF CFM adopted 2016

- module for 2-4 years of age is comprised of 16 questions covering 8 core domains of functioning

- module for 5-17 years of age is comprised of 24 questions covering 12 core domains of functioning

- Domains were selected based on their universality and commonality across cultures and countries at various stages of economic development.

Selected domains

1. Seeing*
2. Hearing*
3. Mobility**
4. Self-care (5-17)*
5. Dexterity (2-4)
6. Communication*
7. Learning (and Remembering 5-17)*
8. Emotions (5-17)**
9. Behaviour
10. Attention (5-17)
11. Coping with change (5-17)
12. Relationships (5-17)
13. Playing (2-4)

* Comparable WG SS questions
** Comparable WG ES questions

Disability Identifiers

Three levels of difficulty defined:

	Children age 2-4	Children age 5-17
Level 1: Mild to severe	• At least 1 domain is some difficulty, a lot of difficulty or cannot do at all except • Controlling behavior: coded more or a lot more	• At least 1 domain is some difficulty, a lot of difficulty or cannot do at all except • Anxiety and Depression: coded weekly or daily
Level 2: Moderate to severe	• At least 1 domain is a lot of difficulty or cannot do at all except • Controlling behavior: coded more or a lot more	• At least 1 domain is a lot of difficulty or cannot do at all except • Anxiety and Depression: coded daily
Level 3: Severe	• At least 1 domain is cannot do at all except • Controlling behavior: coded a lot more	• At least 1 domain is cannot do at all except • Anxiety and Depression: coded daily

Field testing: Initial Results

Disability Prevalence Rate by Different Cut-offs		
	Samoa	Serbia
Level 1: Mild to severe difficulty		
Age 2-4	15.5	9.4
Age 5-17	9.0	25.0
All Ages	10.4	22.7
Level 2: Moderate to severe difficulty		
Age 2-4	2.9	3.8
Age 5-17	4.3	3.5
All Ages	4.0	3.5
Level 3: Severe difficulty		
Age 2-4	0.8	0.0
Age 5-17	2.4	2.2
All Ages	1.9	1.9
Number aged 2-4	2135	219
Number aged 5-17	7422	1250

Adoption of the WG-SS:

UNICEF:

- deployment of the Child Functioning Module (CFM) in the Multiple Indicator Cluster Surveys (MICS)

US AID:

- development of a disability module to include the WG SS in the Demographic and Health Surveys (DHS)

World Bank:

- scaling up the inclusion of the WG-SS into future WB-sponsored household surveys including the Living Standards Measurement Study (LSMS)

Adoption of the WG-SS:

The WG-SS:

- has been used in censuses or surveys in over 75 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

- has been championed by DPOs and NGOs internationally - in particular IDA, IDDC, HI, Sightsavers, CBM, and others.

The Road Ahead

Capacity building through 2019

- regional implementation workshops

- training workshops for DPOs/NGOs

- webinars

Development of guidance documents

- Implementation protocols for data collection

- Data analysis

- Dissemination of results

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

For more information about the WG visit our new website:
http://www.washingtongroup-disability.com/

Questions:
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