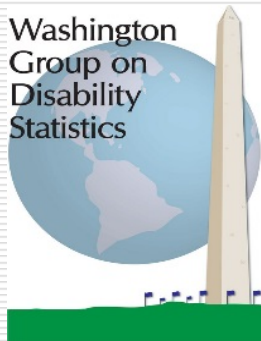


The Washington Group on Disability Statistics



Jennifer H Madans

Associate Director for Science,
National Center for Health Statistics, USA and
Chair, 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
- Emphasis on evidence and transparency – extensive testing of data collection tools in multiple countries
- Workgroups carries out the work plan with input from all members

Collaborations:

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

- UNSD (Statistics Division)
- UN DESA (Department of Economic and Social Affairs)
- UNICEF (Children's Fund)
- ILO (International Labor Organization)
- UN ESCAP / UN ESCWA / UN ECLAC (Economic and Social Commission for Asia and the Pacific/Western Asia/ Latin America and the Caribbean)
- World Bank
- World Health Organization

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

Workshops and Expert Consultations:

Nairobi, Kenya	06/2005	Mumbai, India*	09/2012
Bishkek, Kyrgyz Republic	12/2006	Belmopan, Belize*	01/2013
Sarajevo, Bosnia & Herzegovina		Amman, Jordan	05/2013
	02/2008	Podgorica, Montenegro*	07/2013
Bangkok, Thailand	04/2008	Apia, Samoa*	06/2014
Ohrid, Macedonia	11/2008	Addis Ababa, Ethiopia	05/2016
Dhaka, Bangladesh	08/2009	NY, New York*	06/2016
Muscat, Oman	10/'10 & 04/'13	Bangkok, Thailand	11/2016
Damascus, Syria	12/2010	NY, New York*	07/2017
Sharjah, UAE	05/2011		
Bogotá, Colombia	07/'12 & 08/'13		

*in collaboration with UNICEF

Regional Workshops:

UNSD: on Disability Measurement and Statistics focusing on the 2030 Agenda for Sustainable Development and the 2020 Round of Population and Housing Censuses

Bangkok, Thailand (SE Asia)*

Bridgetown, Barbados
(Caribbean)

Kampala, Uganda (Africa)

Muscat, Oman (Western Asia)

Santiago, Chile (Latin America)

Almaty, Kazakhstan (Central Asia)

* No WG representation

UNICEF: on Disability Measurement with a focus on Child Functioning and Disability

Tunis, Tunisia (National)

Geneva, Switzerland
(Central Asia)

Westchester, NY (Latin America)

Westchester, NY (SE Asia+)

Dakar, Senegal (Africa)

WG: on Disability Measurement with a focus on the Implementation of WG tools in National Statistical Systems

Nadi, Fiji (South Pacific)

Casablanca, Morocco
(Western Asia)

Rome, Italy (non-regional)

Port of Spain, Trinidad & Tobago (Caribbean)

Mexico City, Mexico (Latin America)

SE Asia (planned 2018)




Africa (planned 2018)

Central Asia (planned 2018)

WG: Workgroups / Leaders

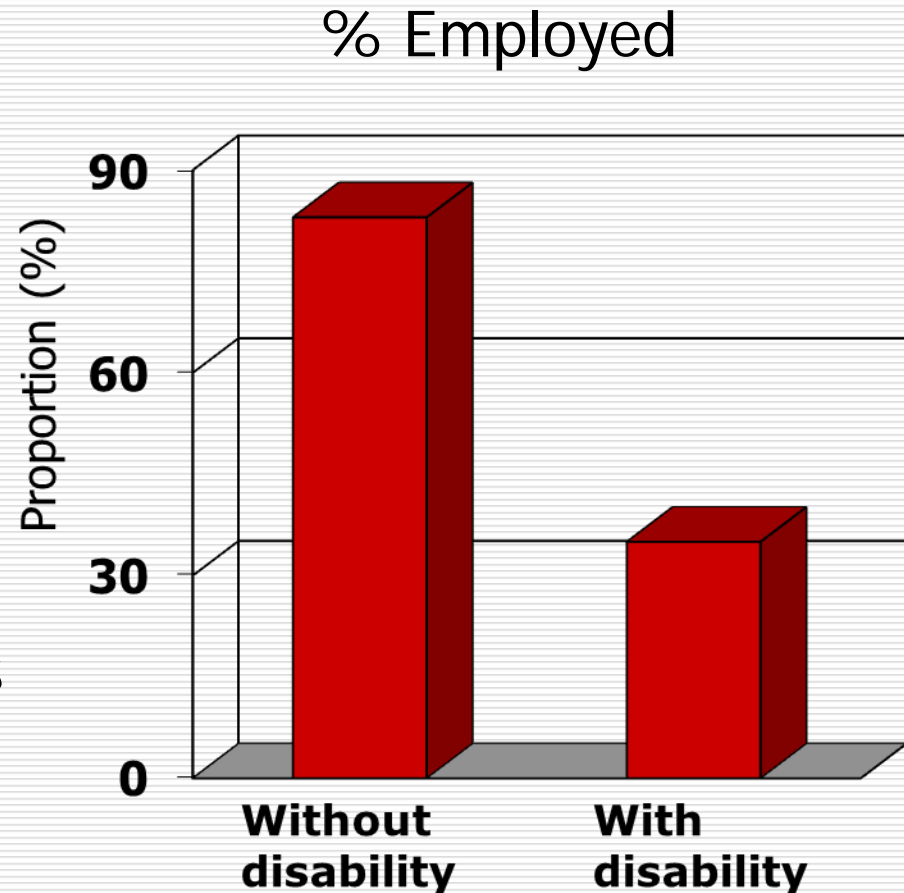
- Analysis of the Extended Set on Functioning / NCHS
- Child Functioning / NCHS
- Environmental Factors and Participation / NCHS
- Mental Health / Margie Schneider, South Africa; Elena De Palma, Italy
- Disability Module for Labor Force Surveys / Daniel Mont, UCL
- Administrative data/?

WG Data Collection Tools:

- Short set on functioning: [adopted in 2006](#) 
 - measures difficulty functioning in 6 universal, basic activities
- Extended set on functioning for adults: [adopted 2010](#) 
- WG/UNICEF Module on Child Functioning: [adopted 2016](#) 
- WG/UNICEF Module on Inclusive Education: [in testing](#)
- WG/ILO Disability module for inclusion on labor force surveys: [in testing](#)
- Module on Mental Health: [under development](#)
- Modules on environment & participation:
[under development](#)

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.



WG Short Set

Short Set questions



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 - no difficulty

Yes - some difficulty

Yes - a lot of difficulty

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

Monitoring the UN CRPD and SDGs through data disaggregation

Disaggregation requirements

- Need a straightforward and simple way to identify persons with disabilities
- Need indicator/outcome data (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 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.

Disability by employment

Person with disability has at least:	Overall prevalence	% working	
		Without disability	With disability
1 Domain 'some difficulty'	35.4	76.6	60.2
2 Domains 'some difficulty'	14.9	74.6	48.5
1 Domain 'a lot of difficulty'	6.6	73.5	30.8
1 Domain 'unable to do it'	1.2	71.4	14.6

The Washington Group 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.

WG Extended Set on Functioning

WG Extended Set:

- is comprised of about 35 questions relating to 11 different core domains of functioning that were selected based on their universality and commonality across cultures and countries at various stages of economic development.
- As with the WG-SS, the domains are intended to identify those at a greater risk than the general population of experiencing restrictions in participation in an unaccommodating environment.

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.

WG Extended Set:

- Difficulties are measured using graded responses and
- cut-offs are established to define a set of disability identifiers for the purposes of determining prevalence or disaggregating outcome indicators (like access to education or employment) by disability status.

Going from SS to Extended set

What are the challenges in going from a single question per domain to multiple questions per domain?

1. To create domain specific indicators for domains with more than one question.
2. To combine multiple domain indicators to determine overall disability identifiers.
3. To determine the 'added value' of multiple questions per domain and of including domains not in the Short Set.

Disability Identifiers

Rather than disability identifiers based on severity cut-off, syntax is provided for the calculation of disability identifiers based on the choice of domains included.

- **WG-SS**: Short Set disability indicator: six question, 6 domains.
- **ES 1**: Complete Extended Set: 25 questions, 11 domains
- **ES 2**: Extended Set MINUS Pain and Fatigue: 20 questions, 9 domains
- **ES 3**: Short Set PLUS Upper body, Anxiety and Depression: 12 questions, 9 domains.

Disability prevalence USA

Disability identifier based on:	n	%
SS_1 WG Short Set: 6 questions	1872	9.5
ES_1 WG-ES: 11 domains / 25 questions	3503	17.7
ES_2 WG-ES: 9 domains / 20 questions	3104	15.4
ES_3 WG-SS Enhanced: 9 domains / 12 questions	2384	11.9

WG/UNICEF Child Functioning Module

Data on child disability varies enormously across the world due to:

1. different priority given to *children* and to *disability* in the political agenda at national level
2. different local resources available for data collection at national level
3. cultural factors (such as differences in values and attitudes towards individuals with disabilities) influence reporting child disability in the surveys
4. lack of a standardized approach to data collection (such as definition of disability, purpose of measurement, data collection method, different age-group bands, etc.)

The result is: No international comparability

Why do we need data on child disability?

Understand the situation of children with disabilities:

prevalence, social circumstances and geographic location, unmet needs and the quality of the support they are receiving.

Assess the role of environmental factors (including societal attitudes and physical barriers) in the experience of disability.

Advocate for the rights of children with disabilities.

Prioritize interventions: inform policies and programs, facilitate the planning of services, and improve participation and quality of life of children with disabilities and their families.

Monitor progress on the UN Convention on the Rights of People with Disabilities (CRPD) and Convention on the Rights of the Child (CRC).

Challenge:

Several reasons why measuring disability among children is different than adults:

- Children are in a process of development and transition
 - not all of the 6 WG short set domains are applicable to young children
 - nor do they cover the full range of domains of particular interest in child development
- Child development does not follow a fixed schedule – there is natural variation in the attainment of functional skills
- Disability measurement often takes place through the filter of a parent or other adult.

UNICEF/WG Collaboration

- Objective of Collaboration: To develop and test a survey module specifically designed to capture child functioning
- 2009 - Workgroup on Child Functioning and Disability created
- 2011 - UNICEF joined the workgroup and began collaborating with the WG

Objectives

- Purpose
 - To to identify the sub-population of children (aged 2-17 years) with functional difficulties. These difficulties may place children at risk of experiencing limited participation in a non-accommodating environment.
- Aim
 - To provide cross-nationally comparable data
 - To be used as part of national population surveys or in addition to specific surveys (e.g., health, education, etc.)

Principles

- Avoided a medical approach
- Used the ICF biopsychosocial model
- Used, when appropriate, questions already tested and adopted by the WG
- Included the reference “Compared with children of the same age...”
- Considered age specificity
- Response options reflected disability continuum

History and development

- WG Workgroup on Child Functioning was established fall 2009 under the leadership of ISTAT (Italy)
- UNICEF joined the Workgroup in early 2011
- First draft module presented Nov. 2011 at 11th WG meeting in Bermuda
- April 2012: Rome technical meeting, revision of the module
- June 2012: Technical Consultation on the Measurement of Child Disability meeting hosted by UNICEF
- October 2012: 12th WG meeting: presentation of the new module
- From September 2012 to April 2016: validation process

Content and structure

- Questions ask about difficulties the child may have in doing certain activities
- Unless noted otherwise, all response categories are:
 - No difficulty
 - Some difficulty
 - A lot of difficulty
 - Cannot do at all

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)

Cognitive Testing

- Cognitive testing
 - January 2013, Belize
 - April 2013, Oman
 - July 2013, Montenegro
 - 2012/13/14/15/16, USA
 - March 2016, India
 - April 2016, Jamaica
- Comparative report completed and decisions made on final set of questions included in field testing

Field Testing (2013-2016)

- Independent field testing on earlier version of the module or subset of questions completed in Haiti (Brown University, 2013), Cameroon & India (London School of Hygiene and Tropical Hygiene, 2013), and Italy (NSO, 2013)
- Field testing of complete version of the module in Samoa (NSO, 2014) and El Salvador (NSO, 2015) with technical assistance from UNICEF/WG
- Module also used in surveys in Zambia (National Disability Survey, NSO, 2014) and Mexico (MICS, 2016)
- Dedicated methodological work in Serbia (NSO, 2016)

Field testing/Data analysis

Three levels of difficulty defined:

	Children age 2-4	Children age 5-17
Level 1: Mild to Severe	<ul style="list-style-type: none">At least 1 domain is some difficulty, a lot of difficulty or cannot do at all exceptControlling behavior: coded more or a lot more	<ul style="list-style-type: none">At least 1 domain is some difficulty, a lot of difficulty or cannot do at all exceptAnxiety and Depression: coded weekly or daily
Level 2: Moderate to Severe	<ul style="list-style-type: none">At least 1 domain is a lot of difficulty or cannot do at all exceptControlling behavior: coded more or a lot more	<ul style="list-style-type: none">At least 1 domain is a lot of difficulty or cannot do at all exceptAnxiety and Depression: coded daily
Level 3: Severe	<ul style="list-style-type: none">At least 1 domain is cannot do at all exceptControlling behavior: coded a lot more	<ul style="list-style-type: none">At least 1 domain is cannot do at all exceptAnxiety and Depression: coded daily

Field testing: Initial Results

Disability Prevalence Rate by Different Cut-offs		
	Samoa	Serbia
Level 1: Mild difficulty		
Age 2-4	15.5	9.4
Age 5-17	9.0	25.0
All Ages	10.4	22.7
Level 2: Moderate 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

Status and Next steps

- WG/UNICEF CFM adopted December 2016
- Release of interviewer guidelines and manual for implementation – 2017/2018
- Series of journal articles (submitted):
 - The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys.
 - I: Background
 - II: Question Development and Pretesting
 - III: Field testing

Mainstreaming Disability Statistics

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

Mainstreaming disability statistics

- US AID: development of a disability module to include the WG Short Set in the Demographic and Health Surveys (DHS)
- UNICEF: deployment of the Module on Child Functioning in the Multiple Indicator Cluster Surveys (MICS)

Selected other activities:

- Handicap International: initiatives in the Andean region, east Africa, in emergency response situations; and training (development of e-learning modules)
- Global Action on Disability (GLAD) Network: to provide support and coordination in enhancing the inclusion of persons with disabilities in international development and humanitarian action.

The Road Ahead

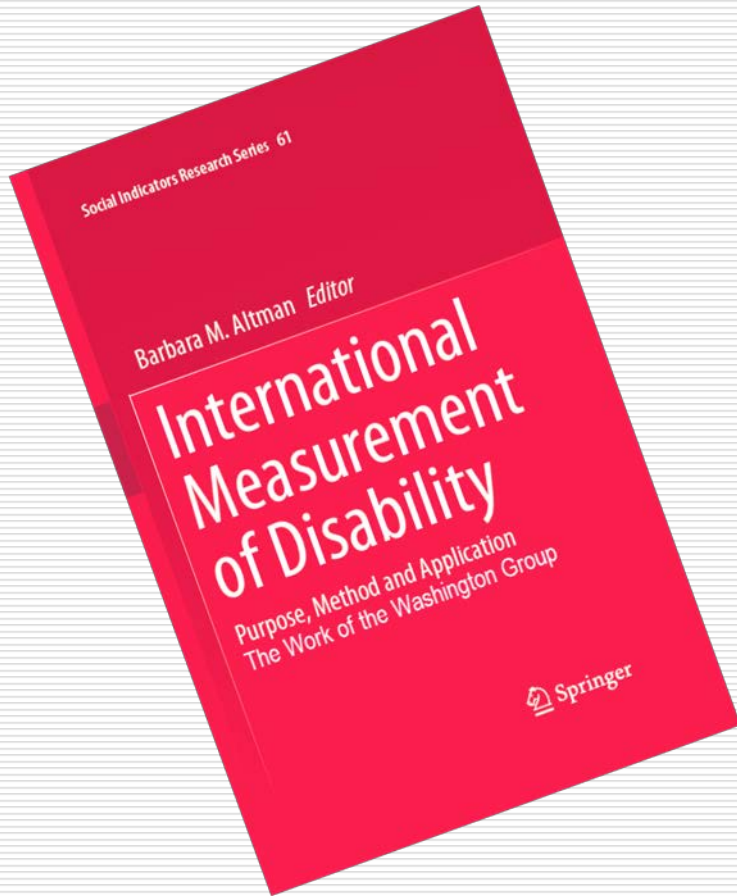
Capacity building through 2018

- 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

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/>

The screenshot shows the homepage of the Washington Group on Disability Statistics. The header features the organization's name in green. A left-hand navigation menu lists various sections: ABOUT, NEWS, BLOG, METHODOLOGY, QUESTION SETS, IMPLEMENTATION, INTERNATIONAL MONITORING, RESOURCES, EXAMPLES: USING THE WG, WORK GROUPS, REGIONAL INFORMATION, MEETINGS & TRAINING, FREQUENTLY ASKED QUESTIONS, SUPPORT, and CONTACT. The main content area is titled "WASHINGTON GROUP ON DISABILITY STATISTICS" and contains introductory text about the group's mission and funding. A "News" section highlights recent training events and a webinar. At the bottom, there are four image-based links for "Methodology", "Question Sets", "Examples", and "Digital Training".

WASHINGTON GROUP ON DISABILITY STATISTICS

The Washington Group on Disability Statistics (WG) is a UN city group established under the United Nations Statistical Commission. The WG was constituted to address the urgent need for cross-nationally comparable population based measures of disability. Its mandate is the promotion and co-ordination of international co-operation in the area of health statistics focusing on disability data collection tools suitable for censuses and national surveys.

The WG has sought to foster international collaboration, and in particular, to insure that its efforts are broad-based and inclusive of voices from developing countries from every region of the world. Representatives of National Statistical Offices around the world, as well as Disabled People's Organizations (DPO), and other international organizations are encouraged to participate in the WG.

With funding from the **Australian Department of Foreign Affairs and Trade** the Washington Group on Disability Statistics (WG) is launching this new website, with the support of the **Leonard Cheshire Disability and Inclusive Development Centre** at University College London.

New Blog "Training on How to Ask "Disability" Questions on Censuses and Surveys"

[Search the Washington Group Website](#)

News

Training has taken place in Trinidad and Tobago and Mexico City for the Caribbean and South/Central American regions

A new blog post from Daniel Mont is now available, "[Training on How to Ask "Disability" Questions on Censuses and Surveys](#)"

"[Disability Statistics in Humanitarian Action](#)" – Handicap International has released a webpage detailing how they are using the WG Qs in their humanitarian work.

The Washington Group presented their first training for Non-Government Organisations in London (March 16 2017) – the event is now available to watch online, closed captioning is available. [Webinar of NGO training in London](#)

Methodology **Question Sets** **Examples** **Digital Training**

Questions: WG_Secretariat@cdc.gov