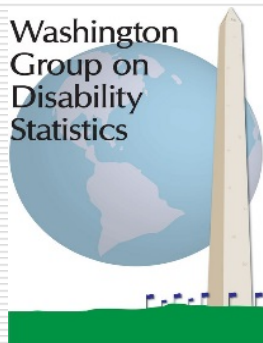


The Washington Group on Disability Statistics



Jennifer H Madans

Associate Director for Science,
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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

WG: Workgroups / Leaders

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

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
19. Argentina 09/2019

Determining the Purpose of Disability Measurement

Three major classes of purposes were recognized for identifying persons with disabilities at the aggregate level.

Each may require a specific set of questions.

- **To provide services**, including the development of programs and policies for service provision and the evaluation of these programs and services
- **To monitor the level of functioning** in the population
- **To assess equalization of opportunities.**

Criteria for Choice of Purpose

Choice of purpose on which to base disability data collection had to meet two main criteria:

1. **Relevance**: for policy makers and program officials
2. **Feasibility**: especially for international comparability

WG Approach to Disability Measurement

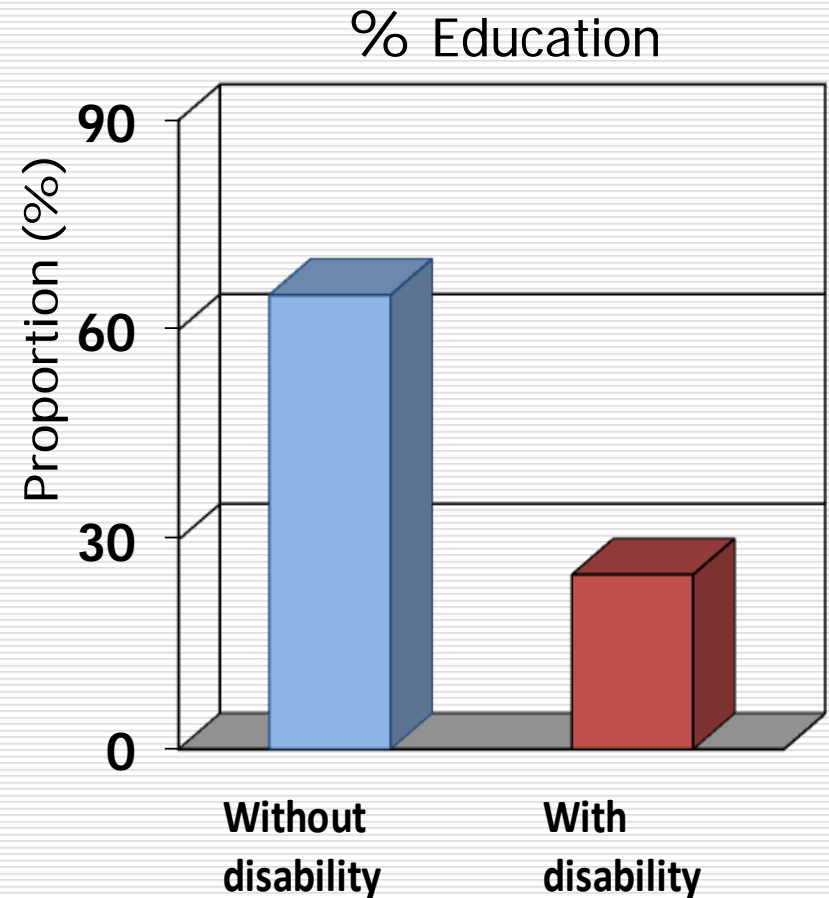
The WG chose to assess the **equalization of opportunities** by identifying people who, because of a health condition,

- have **difficulties with basic, universal activities** that
- place them at **greater risk** than the general population
- for **limitations in participation** in an **unaccommodating environment**.

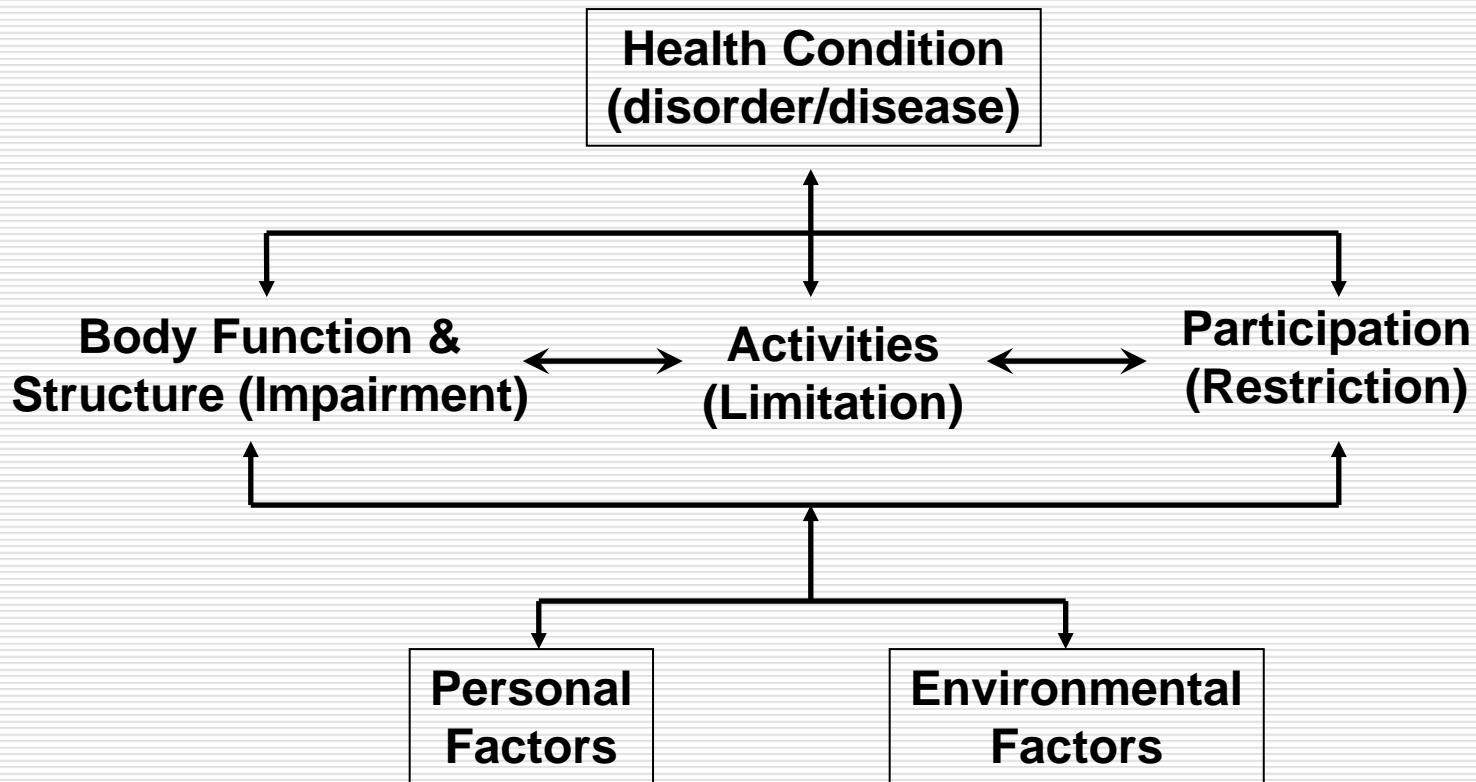
Focus on Equalization of Opportunities

Disability used as a dissagregation variable.

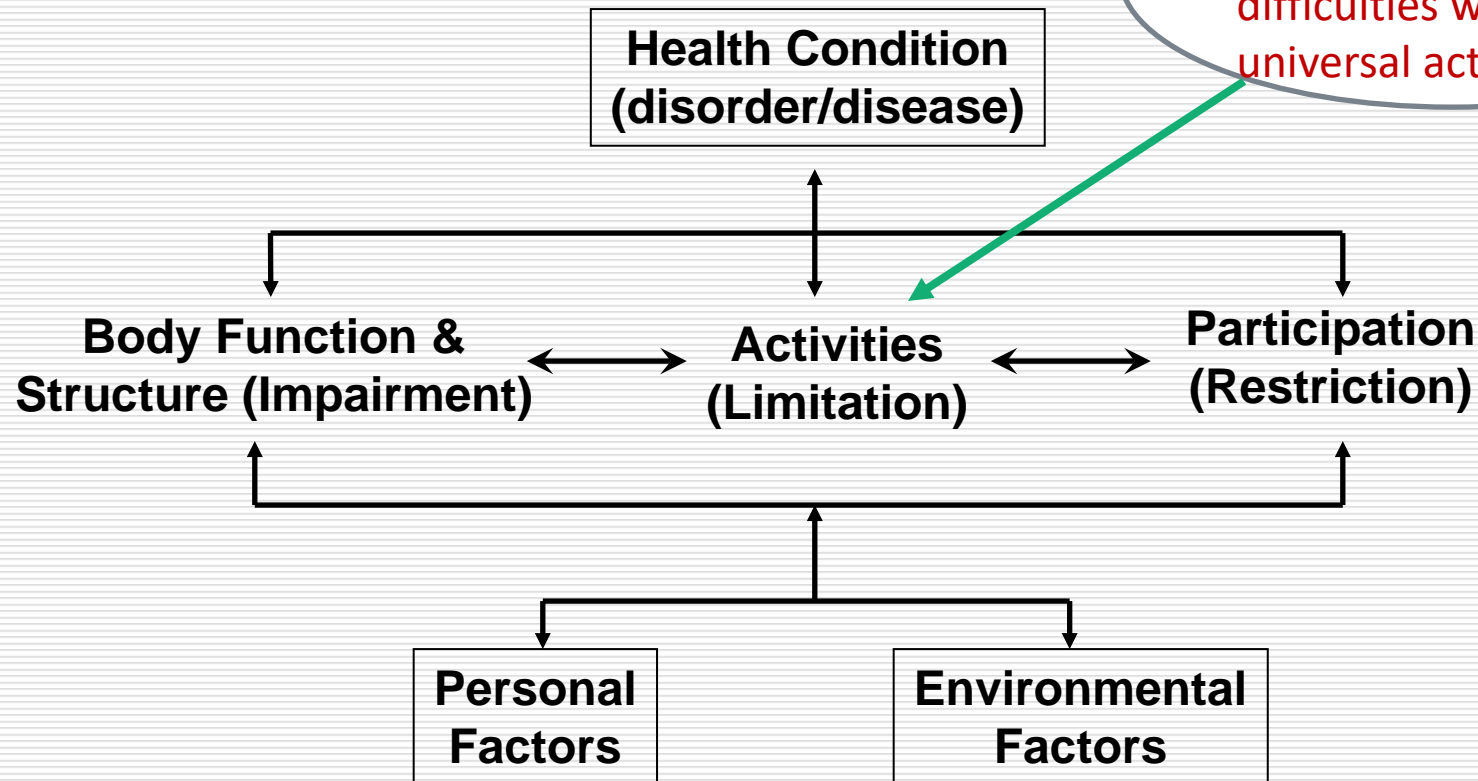
Data collected will fulfill the monitoring requirements established by the *UN Convention on the Rights of Persons with Disabilities* and the *Sustainable Development Goals*



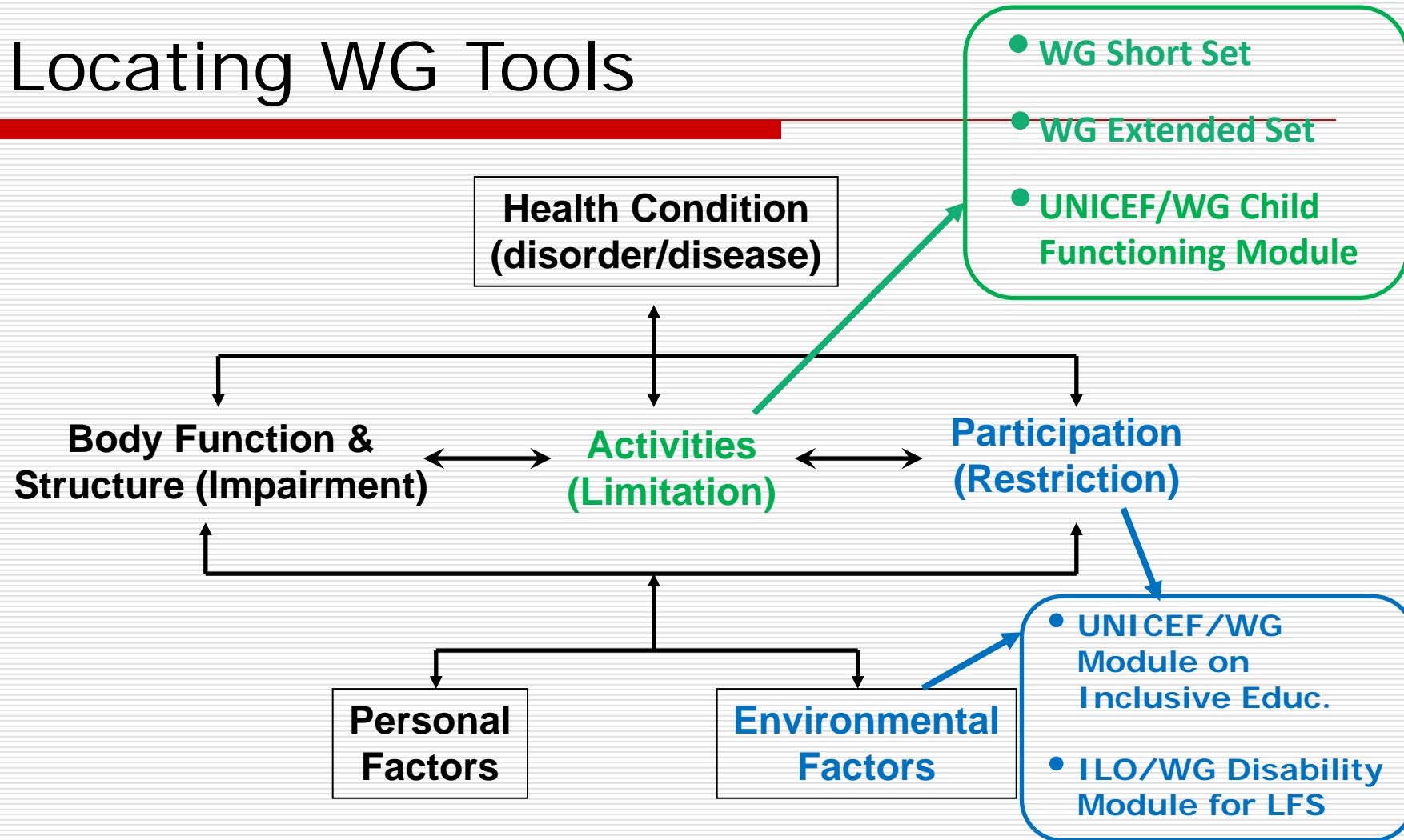
The ICF Model: A Framework for Question Design



Locating the WG Approach



Locating WG Tools



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

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.

Adoption of the WG-SS:

UNICEF:

- deployment of the Child Functioning Module (CFM) and WG SS 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)

Resources: Guidelines and documentation (Completed)

- Data Collection Tools Developed by the WG (Conceptualization and Measurement of Disability)
- WG Short Set Implementation Guidelines (Includes some FAQs and Do's & Don'ts)
- WG Short Set Question by Question Specifications
- Translation Protocol
- Cognitive Testing of Translated Questionnaires
- Analytic Guidelines WG-SS and WG-ES-F including SPSS and SAS syntax (also available in CPro)

Available in: Spanish, Russian, Arabic & French

Resources: Guidelines and documentation (2019)

- Interviewer Guidelines (under revision)
- WG-ES-F Question by Question Specifications (finalized)
- Translations of WG question modules in the official UN languages

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 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
<i>Cut-off is a lot of difficulty or cannot do in at least 1 domain</i>	8.9	73.4	29.1
Cut-off is <i>some difficulty</i> in at least 2 domains	19.0	74.5	48.4
Cut-off is <i>some difficulty</i> 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 Status Indicators

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
 8. Remembering (5-17)*
 9. Psychosocial (Anxiety/Depression) (5-17)**
 10. Behaviour
 11. Concentrating/Focusing Attention (5-17)
 12. Coping with change (5-17)
 13. Relationships (5-17) *
 14. Playing (2-4) **
- * Comparable WG SS questions
** Comparable WG ES questions

Disability Status Indicators - CFM

Three levels of difficulty defined:

WG
cut-off



	Children age 2-4	Children age 5-17
Level 1	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all except Controlling behavior: coded a lot more 	<ul style="list-style-type: none"> At least 1 domain is a lot of difficulty or cannot do at all except Anxiety and Depression: coded daily
Level 3	<ul style="list-style-type: none"> At least 1 domain is cannot do at all except Controlling behavior: coded a lot more 	<ul style="list-style-type: none"> At least 1 domain is cannot do at all except Anxiety and Depression: coded daily

Additional WG Data Collection Tools

- WG/UNICEF Module on Inclusive Education – final testing stage
- WG/ILO Disability Module for Labor Force Surveys – final testing stage
- Module on Psychosocial Functioning - under development
- Module on other aspects of the environment and participation - currently under consideration

The Road Ahead

Capacity building:

- Development of regional centers of expertise
- Training workshops for NSOs as well as DPOs/NGOs
- Webinars

Completion 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:

<http://www.washingtongroup-disability.com/>

Questions:

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