

# Disability Measurement and the Washington Group on Disability Statistics

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# A Brief History of Disability Measurement

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# Measuring Disabilities: 1

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A medical model approach based on identifying and measuring **impairments**.

Questions used to identify persons with disabilities:  
Zambia Census 1990

1. Are you disabled in any way? Yes/No

2. What is your disability?

Blind Yes/No

Deaf/dumb Yes/No

Crippled Yes/No

Mentally retarded Yes/No

**Disability prevalence = 0.9%**

# Measuring Disabilities: 2

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## Zambia Census 2000

“...disability refers to a person who is limited in the kind or amount of activities that he or she can do because of on-going difficulties due to long term physical, mental or health problems.”

# Measuring Disabilities: 2

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Questions used to identify persons with disabilities:  
Zambia Census 2000

1. Are you disabled in any way? Yes/No
2. What is your disability?

Blind	Yes/No
Partially sighted	Yes/No
Deaf/dumb	Yes/No
Hard of hearing	Yes/No
Mentally ill	Yes/No
Ex-Mental	Yes/No
Mentally retarded	Yes/No
Physically handicapped	Yes/No

**Disability prevalence = 2.7%**

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# Global disability prevalence rates\*

High-income countries			L/M-income countries		
	Year	%		Year	%
Canada	1991	14.7			
Germany	1992	8.4	Kenya	1989	0.7
Italy	1994	5.0	Namibia	1991	3.1
Netherlands	1986	11.6	Nigeria	1991	0.5
Norway	1995	17.8	Senegal	1988	1.1
Sweden	1988	12.1	South Africa	1980	0.5
Spain	1986	15.0	Malawi	1983	2.9
UK	1991	12.2	Zambia	1990	0.9
USA	1994	15.0	Zimbabwe	1997	1.9

# The Washington Group (WG): History and Products

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# The Washington Group (WG)

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- 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

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- 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

# WG: Workgroups / Leaders

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

# Summary of annual meetings

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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

# Workshops and Technical Assistance

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Kenya	06/2005	Montenegro*	07/2013
Kyrgyz Republic	12/2006	Samoa*	06/2014
Bosnia & Herzegovina	02/2008	Tunisia*	02/2015
Thailand	04/2008	Switzerland*	07/2015
Macedonia	12/2008	USA*	05/2016
Bangladesh	08/2009	Fiji	07/2016
Oman	10/2010 & 04/2013		
Syria	12/2010		
UAE	05/2011		
Colombia	07/2012 & 08/2013		
India*	09/2012		
Belize*	01/2013		
Jordan*	05/2013		

\*in conjunction with UNICEF

# Collaborations

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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

# Comparable testing methodology:

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- Developed a procedure for question evaluation that includes guidelines for translation and cognitive testing in order to ensure cross-cultural and cross-national comparability
- **Q-Notes** software developed for data entry and analysis of qualitative cognitive interviews
- **Q-Bank** launched as an online repository for reports of question evaluation studies – to ensure transparency
- Publication: Miller K, Willson S, Chepp V, Padilla JL. Cognitive Interviewing Methodology, John Wiley & Sons. 2014

# Report Series of WG activities:

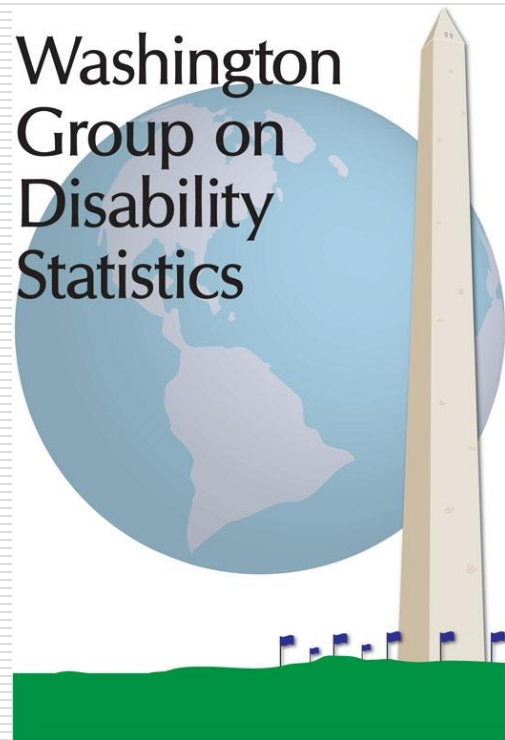
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- Disability Information from Censuses, prepared for DPOs
- Development of an Internationally Comparable Disability Measure for Censuses, prepared for NSOs
- Monitoring the UN CRPD
- Understanding and Interpreting Disability as Measured using the WG Short Set of Questions
- The Measurement of Disability: Recommendations for the 2010 Round of Censuses
- Development of Extended Sets of Disability Measures for Surveys
- Disaggregation by Disability - A way forward (forthcoming)

# The New WG Website:

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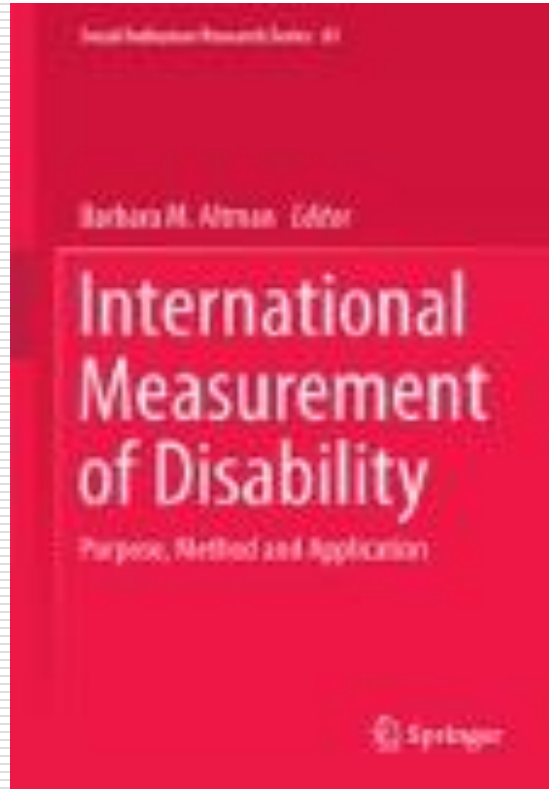
<http://www.washingtongroup-disability.com/>





# Volume on the history and accomplishments of the WG:

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International Measurement of Disability:  
Purpose, Method and Application  
The Work of the Washington Group

B. M. Altman (Editor)  
Springer (Publisher)

Publication: June, 2016

# The definition of disability...

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...has changed over time and is currently conceptualized as the outcome of the interaction between a person with a functional limitation (difficulties doing basic functional activities) and an unaccommodating environment that results in the inability to fully participate in society.

# The complexity of disability

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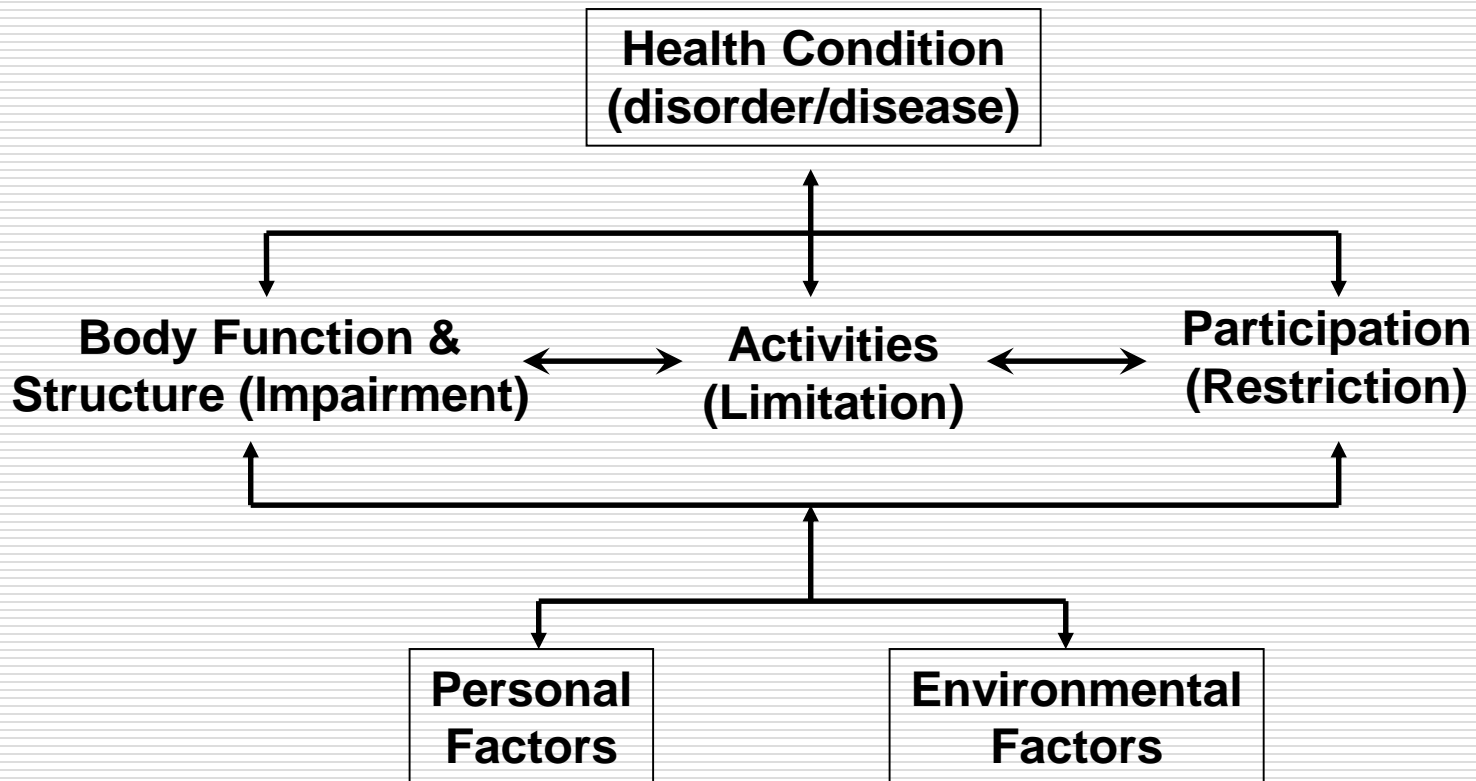
Disability is complicated – incorporates a variety of different components: body functions & structure, limitations in activities (capacity) and restrictions in participation (performance), and also includes characteristics of both the person and their environment.

The language of disability is not specific.

And finally, in some cultures, stigma is associated with disability – creating additional challenges to measurement and ultimately inclusion.

# The ICF Model - 2001

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# Measuring Disabilities: 3

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The WG defined an approach to measuring disability based on identifying those who, because of **difficulties** doing certain **universal, basic actions**, are at greater **risk** than the general population for **limitations in participation**.

# WG Data Collection Tools: Short Set

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## **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

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# Limitations

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- One set of measures will not satisfy multiple needs for disability data
- Excluded populations:
  - Very young children
  - Institutionalized population
  - Homeless
  - Floating populations

# Objectives

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- Identify persons with similar types and degree of limitations in basic actions regardless of nationality or culture
- Represent the majority (*but not all*) persons with limitations in basic actions
- Represent commonly occurring limitations in domains that can be captured in the Census context



# Intended use of data

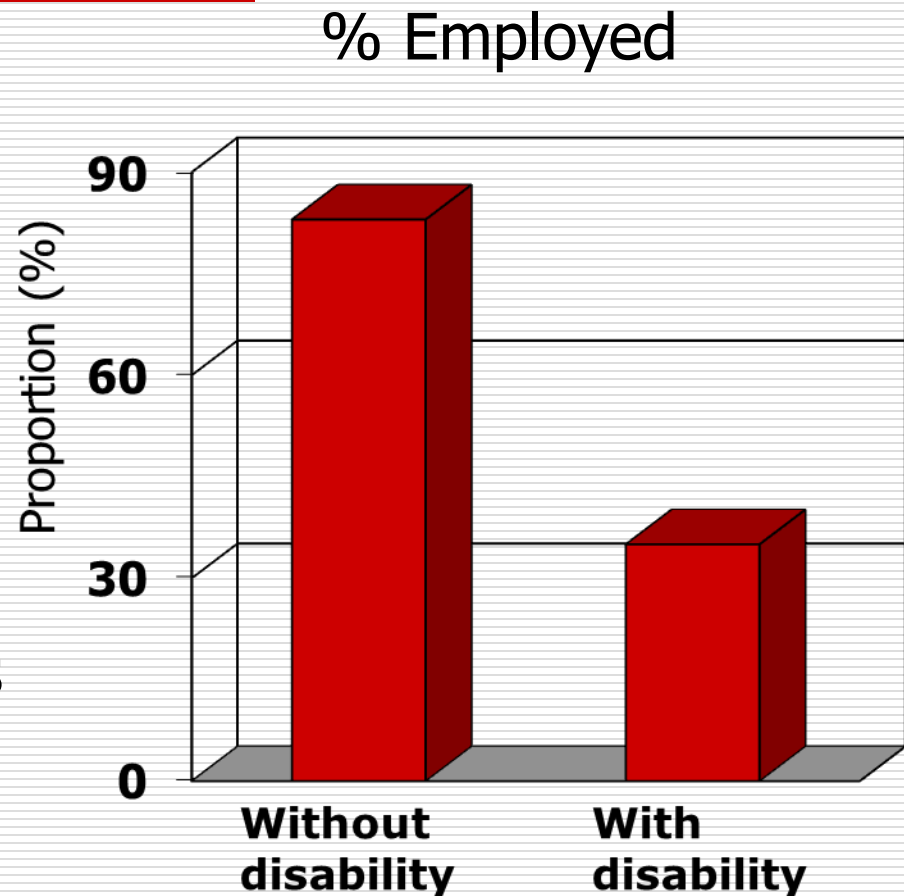
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- Compare levels of participation in employment, education, or family life for those with disability versus those without disability to see if persons with disability have achieved social inclusion
- Monitor effectiveness of programs / policies to promote full participation
- Monitor prevalence trends for persons with limitations in specific basic action domains

# Disaggregation by disability status

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- Seeks to identify all those at greater risk than the general population for limitations in participation.
- Disability used as a dissagregation variable.



# Additional WG Data Collection Tools:

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- 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 in Collaboration with UNICEF: Children

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Question set that focuses 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
  - Domains of functioning: Seeing, Hearing, Mobility, Cognition/Learning, Self-care/Upper body, Communication, Affect, Controlling behavior, Accepting change, Focusing attention, Relationships/Playing

# Mainstreaming disability statistics

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- 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

# WG Data Collection Tools in Collaboration with UNICEF: Education

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Question set that focuses on the environment and participation:

- WG/UNICEF Module on Inclusive Education
  - begins to address the association between environmental barriers and participation
  - Attitudes: societal and cultural norms; perceptions and attitudes of parents, other students and school staff
  - School Environment: physical and academic accessibility
  - Affordability: fees, costs, and competition for resources associated with attendance
  - Out of school: reasons why a child may be out of school

# WG Data Collection Tools in Collaboration with ILO: Employment

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Question set that focuses on the environment and participation:

- Disability module for inclusion on labor force surveys
  - under development in collaboration with ILO

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For more information about the WG:  
[www.cdc.gov/nchs/washington\\_group.htm](http://www.cdc.gov/nchs/washington_group.htm)

Questions:  
[WG\\_Secretariat@cdc.gov](mailto:WG_Secretariat@cdc.gov)

