

# Mainstreaming Disability Data: The Washington Group on Disability Statistics

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# The State of Disability Data

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- In the past, disability data were of poor quality and varied dramatically cross-nationally.
- The Washington Group on Disability Statistics has developed and tested a variety of tools for collecting reliable, meaningful, and internationally comparable data that have been used by a growing number of countries.
- These tools can be used to monitor the UN CRPD and disaggregate the SDGs if incorporated into national statistical systems.
- Resources and training opportunities exist to support the implementation of these questions.

# How we ask the questions matters!

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# Measuring Disability: 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 Disability: 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 Disability: 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

	Year	%
Canada	1991	14.7
Germany	1992	8.4
Italy	1994	5.0
Netherlands	1986	11.6
Norway	1995	17.8
Sweden	1988	12.1
Spain	1986	15.0
UK	1991	12.2
USA	1994	15.0

## L/M-income countries

	Year	%
Kenya	1989	0.7
Namibia	1991	3.1
Nigeria	1991	0.5
Senegal	1988	1.1
South Africa	1980	0.5
Malawi	1983	2.9
Zambia	1990	0.9
Zimbabwe	1997	1.9

# Where are we today?

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# 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.

# 'Disability' may be a complicated construct...

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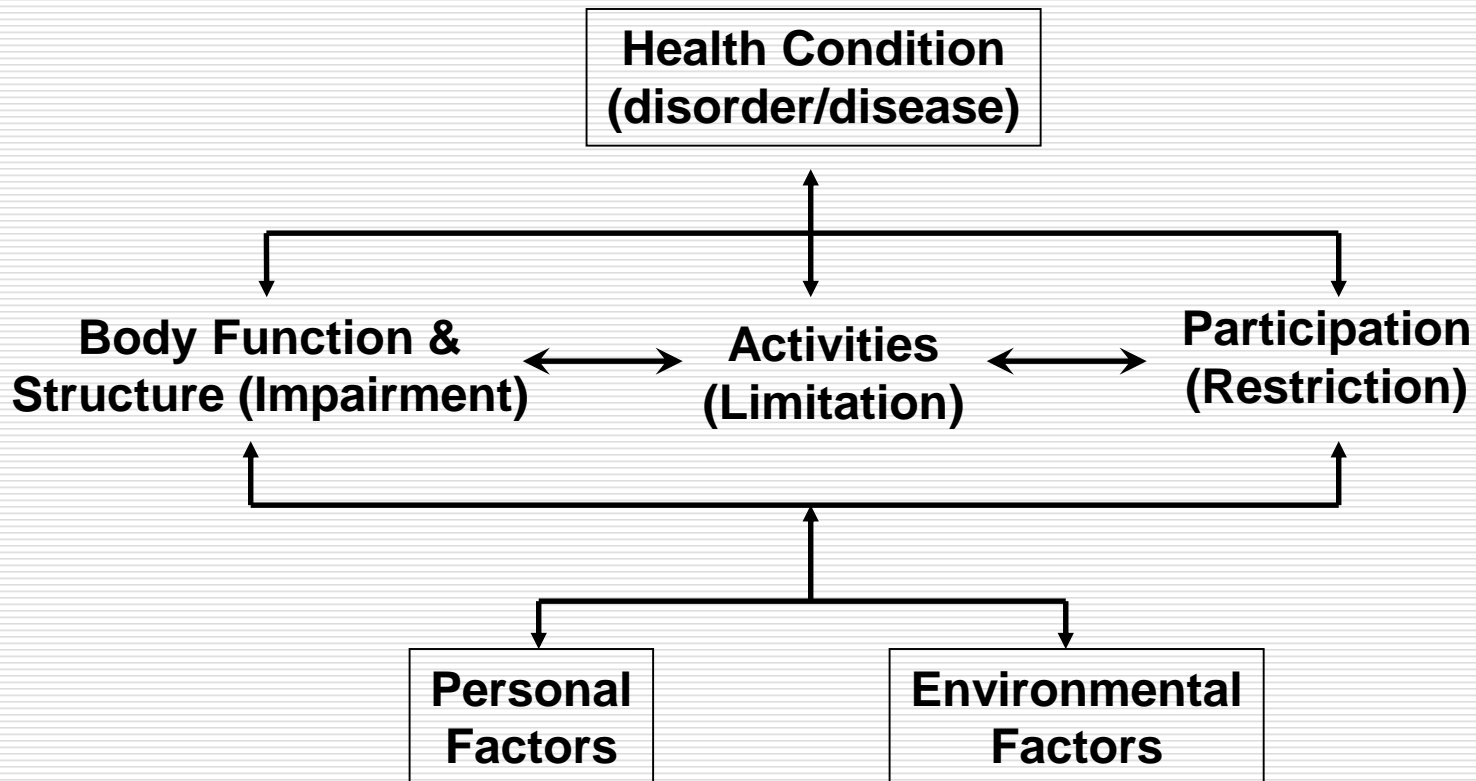
Disability is complicated – incorporates a variety of different components: body functions & structure, limitations in activities (capacity) and restrictions in participation (performance), and also includes characteristics of both the person and their environment.

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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...but the questions used to capture 'disability' in a census or survey are not complicated!!

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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** in an **unaccommodating environment**.

# 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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# Measuring Disabilities: 3 (...back to Zambia)

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- A survey of Living Conditions among People with Disabilities in Zambia (2006) used the WG short set.
- 4 Response categories
- Disability: **at least one domain** that is coded as **a lot of difficulty** or **cannot do it at all**.
  - prevalence **8.5%**

# Testing of the WG SS

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- 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

# What can the WG SS produce?

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## Domain specific outputs:

- a range of functioning based on graded responses on each of the 6 domains

## Overall outputs:

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



# Prevalence (weighted %) by domain and degree of difficulty

**At least:**

<b>Core Domain</b>	<b>Some difficulty</b>	<b>A lot of difficulty</b>	<b>Unable To do it</b>
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

# Disability prevalence USA

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<b>Person with disability has:</b>	<b>n</b>	<b>%</b>
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

# WG Recommendation:

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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 by employment

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

# Disaggregation in U.S. NHIS Data

NHIS 2013, 18-64 years of age  
Weighted %

**Disability Status:**  
WG Short Set  
*Cut-off = a lot of  
difficulty*  
in at least 1 domain

<b>Indicator</b>	Without Disability	With Disability
Employment Status Last Week = Working	73.5	30.8
Current Every Day Smoker	14.5	27.8
Health Insurance Coverage (yes)	79.5	81.0

# Monitoring the UN CRPD and SDGs through data disaggregation

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WG question sets are 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.

# Defining a disability identifier for data disaggregation

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WG questions fulfil two specific data needs:

- to describe disability data as a gradation of functioning based on scaled 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 calculate prevalence and disaggregate outcome indicators (e.g. access to education, employment) by disability status

# Disaggregation requirements

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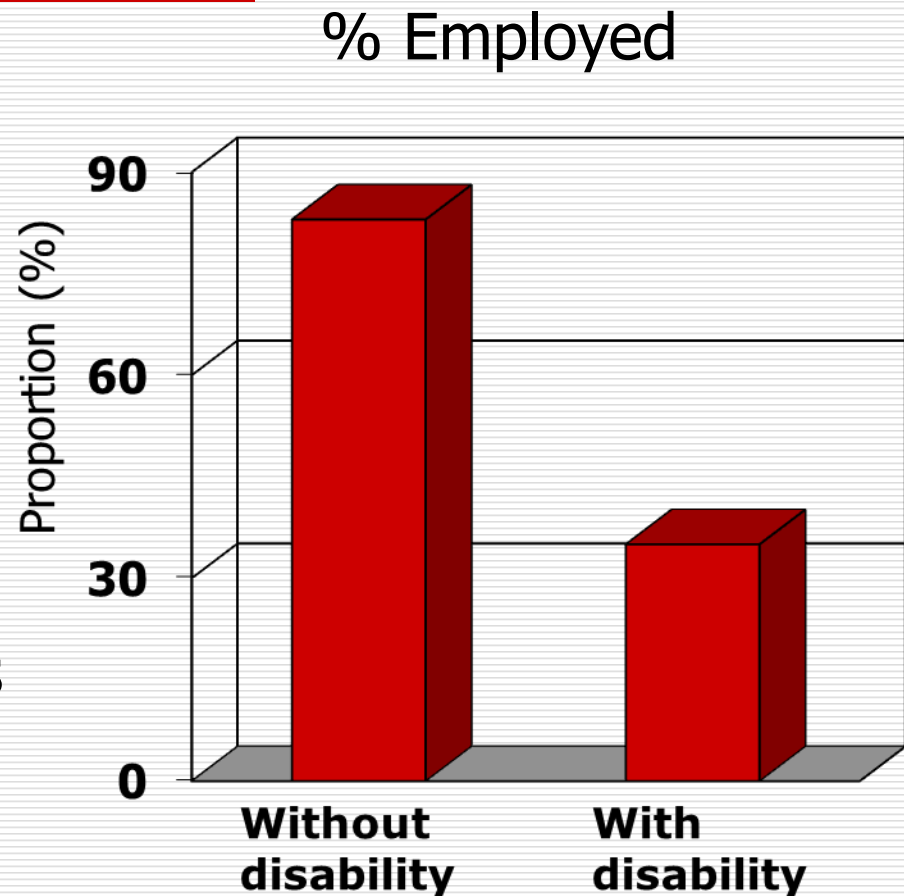
- Need a straightforward and simple way to identify persons with disabilities: the WG questions identify those at greater risk than the general population for limitations in participation.
- Need outcome data (education, employment, income, health care access) from data collections (census/surveys) that also include the above disability identifier.



# Focus on Equalization of Opportunities

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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.



# Mainstreaming disability statistics: The Path to Disaggregation

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- Identify which data collection systems will be used for monitoring population-based SDG indicators
- Include one of the Washington Group question sets in each of these data collection systems
- Once the questions become integrated into core statistical systems
  - Core information on disability becomes available for use by all government agencies and civil society
  - Disaggregating outcomes (education, employment etc.) by disability status becomes routine and sustainable

# Since its adoption in 2006 the WG Short Set...

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- 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.
- And both the US AID and UNICEF have developed disability modules that will operationalize the WG SS for their **Demographic and Health Surveys** (DHS) and **Multiple Indicator Cluster Surveys** (MICS) respectively.

# WG Data Collection Tools: Extended Sets for Adults and Children

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- Extended set on functioning for adults 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/UNICEF Module on Child Functioning:
  - includes questions for children 2-4 and 5-17 years

# WG Data Collection Tools: Participation

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Question sets that focus on the environment and participation:

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

# The Road Ahead

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## Capacity building through 2018

- regional workshops
- implementation and other technical workshops

## Development of guidance documents

- Implementation protocols for data collection
- Data analysis
- Dissemination of results

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For more information about the WG **visit our new website:**

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

Questions:

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

