

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
- The Secretariat for the WG is located at the National Center for Health Statistics
- A rotating Steering Committee oversees the work plan of the WG and preparations for the annual meetings
- Workgroups lead the development of specific tasks: currently child disability, the environment and participation, and analysis
- Emphasis on evidence and transparency – extensive testing of questions in multiple countries

Membership of the WG

- Current representatives from national statistical authorities include 118 countries and territories
- Past and present representatives of international and national organizations representing persons with disabilities, and several national government and non-government organizations
- Other international organizations including among others: EUROSTAT, ILO, OECD, World Bank, WHO, UNICEF, and UNESCAP

Report Series of WG activities:

- Disability Information from Censuses, prepared for DPOs
- Development of an Internationally Comparable Disability Measure for Censuses, prepared for NSOs
- Monitoring the UN Convention on the Rights of Persons with Disability
- 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

Report to UN Statistical Commission

The WG regularly reports to the UN Statistical Commission

- at the 45th Session of the UNSC (2014), the work of the WG was included as a *discussion item*;
- over 20 countries expressed their support for the work of the WG;
- several indicated that they had used or intended to use the WG SS of questions in their census

WG Products

WG Disability Measures:

Short Set of Questions – six questions recommended for Censuses. (Recommended for use in all national censuses in the UN *Principles and Recommendations for Population and Housing Censuses*)

Extended questions set on functioning for national surveys. (Subset to be included on European Health Interview Survey)

A module on Child Functioning and Disability is currently being tested.

A module on Inclusive Education is under development

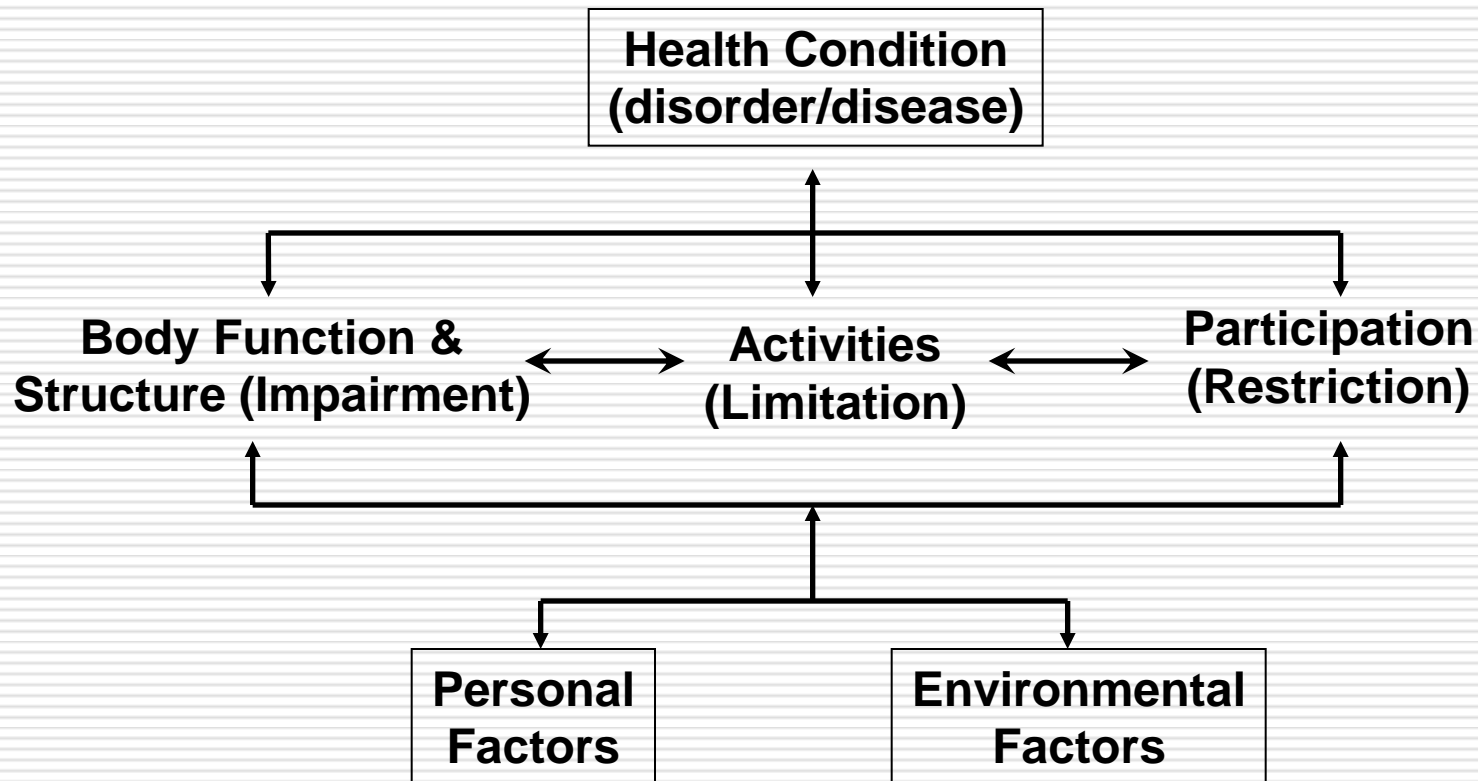
The complexity of disability

Disability is a complicated topic – incorporating 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 often depends on the purpose chosen for the definition and measurement.

And finally, there is the issue of stigma associated with disability that in some cultures creates additional barriers to inclusion.

The ICF Model – 2001



Begin with a Conceptual Model...

The International Classification of Functioning, Disability and Health (ICF) was selected as the conceptual model:

- Common point of reference
- Common vocabulary
- Does not provide an operational definition or a way to measure the concepts

...from *Concept* to *Operational Definition*

The Definitional Paradox

- There is no single **operational** definition of disability
- Different operational definitions lead to different estimates
- The question you are trying to answer (**the purpose**) will determine which definition to use
- Need to **understand the choices** that are being made when choosing a definition

Purpose of Data Collection

3 major classes of purposes at aggregate level:

- Service provision
- Monitoring functioning in the population
- Assess equalization of opportunities/ participation

2 criteria for selection of a purpose:

- Relevance - particularly for policy makers and program officials
- Feasibility - especially for international comparability

Purpose: Assessing equalization of opportunities

- Locate the definition of disability at the most basic level of activity/participation in core domains
- This level is associated with the ability or inability to carry out basic bodily operations at the level of the whole person (i.e. walking, climbing stairs, lifting packages, seeing a friend across the room)

Benefits of this approach

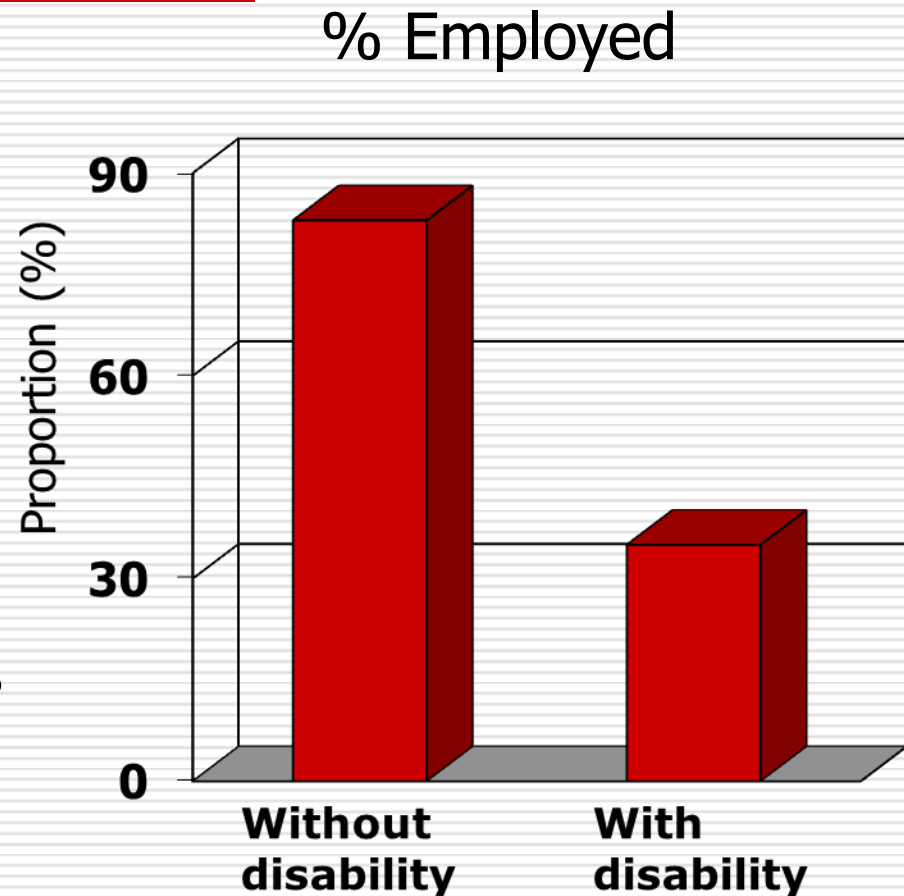
- Development of a demographic means of understanding disability (can compare persons with and without disability)
- Connection between disability and participation can be made during data analysis
- Effectiveness of programs / policies to promote full participation can be monitored

Criteria for inclusion of domains

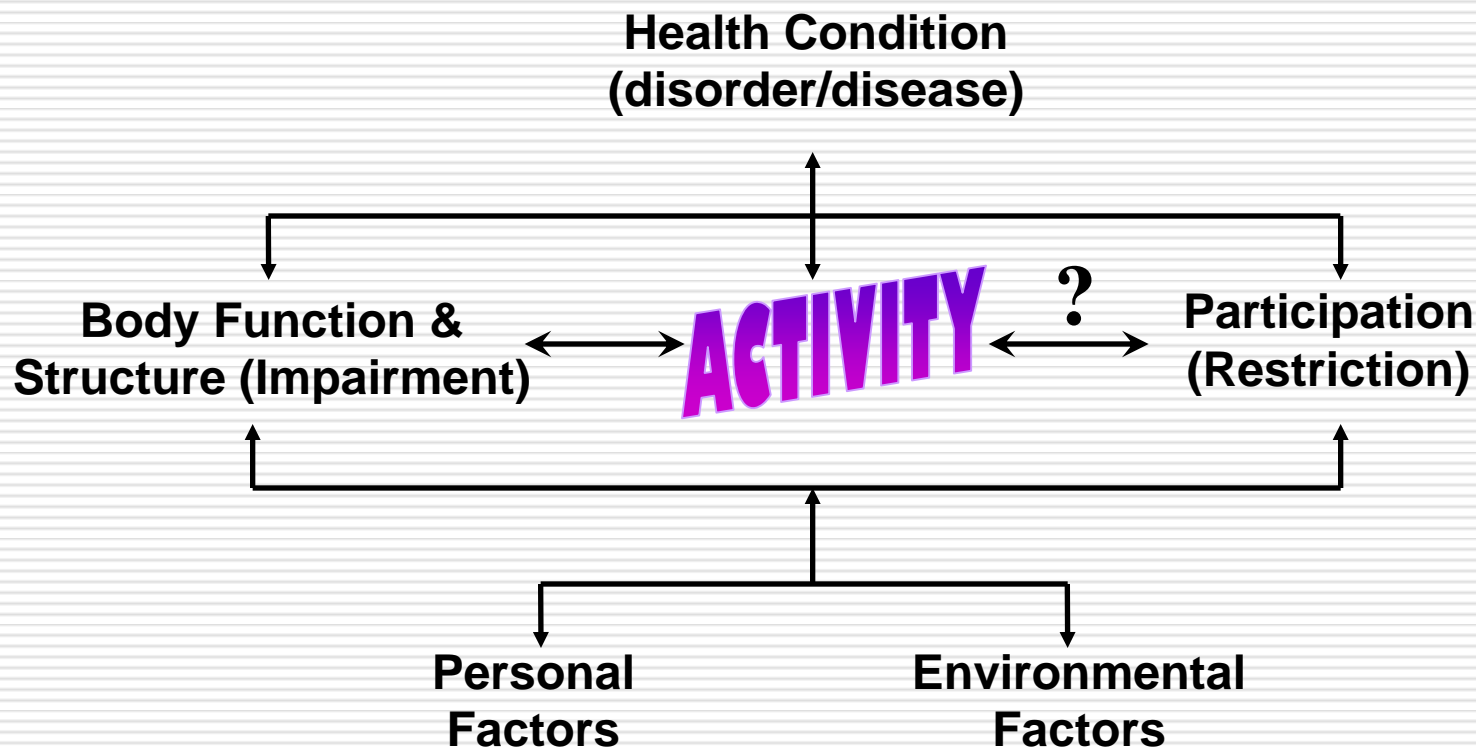
- Cross cultural comparability
- Suitability for self-report
- Parsimony
- Validity across various methodological modes

WG Short Set Purpose: Equalization of Opportunities

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



Locating Risk in the ICF Model



...from *Operational Definition* to *Measurement*

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 Measures:

Measuring Disabilities: 1

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

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

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%

Global disability prevalence rates*

High-income countries			L/M-income countries		
	Year	%		Year	%
Canada	1991	14.7	Brazil	1991	0.9
Germany	1992	8.4	Chile	1992	2.2
Italy	1994	5.0	Colombia	1993	1.8
Netherlands	1986	11.6	El Salvador	1992	1.6
Norway	1995	17.8	Panama	1990	1.3
Sweden	1988	12.1	Peru	1993	1.3
Spain	1986	15.0			
UK	1991	12.2			
USA	1994	15.0			

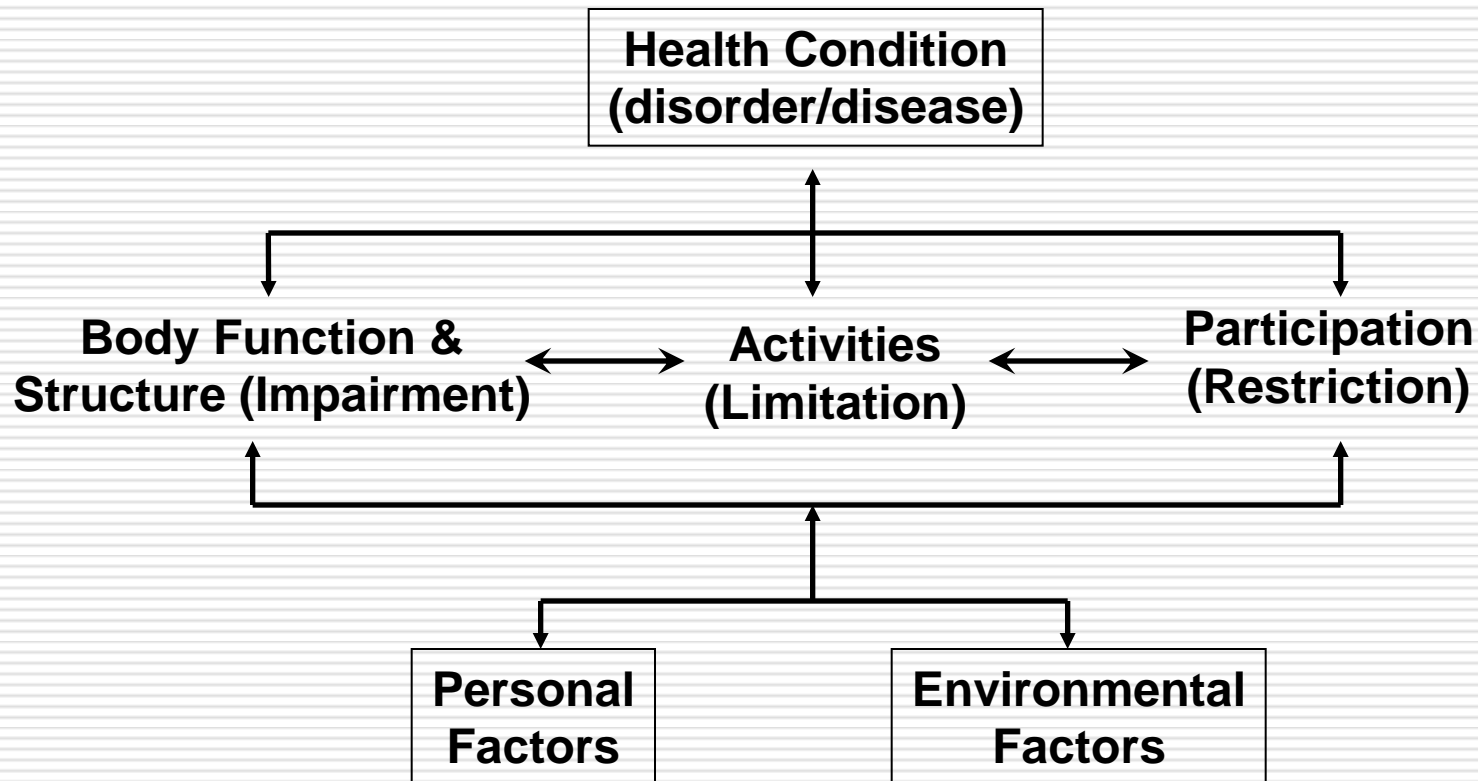
* Sources and methodologies are country specific

Global disability prevalence rates

ESCAP/The Sub-Continent

	Year	%	Questions used to identify persons with disabilities:
Bangladesh	1982	0.8	Blind, crippled, deaf/dumb, mentally handicapped, other
Pakistan	1981	0.5	Blind, crippled, deaf/dumb, mentally retarded, insane, other
India	1981	0.2	Is there a physically handicapped person in the household? If so, indicate the number of those who are totally (1) blind (2) crippled (3) dumb
Sri Lanka	1981	0.5	Blind, deaf/dumb, loss/paralysis of hand(s) or leg(s)
Thailand	1990	0.3	Blind, deaf/dumb, armless, legless, mentally retarded, insanity, paralyzed, other

The ICF Model - 2001



Measuring Disabilities: 3

An approach based on identifying those at greater **risk** than the general population for **limitations** in **participation**.

The development of questions based on **difficulties** doing certain **basic actions**.

Measuring Disability: 3

Because of a Health problem:

- 1) Do you have difficulty **seeing** even if wearing glasses?
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- 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

Measuring Disabilities: 3

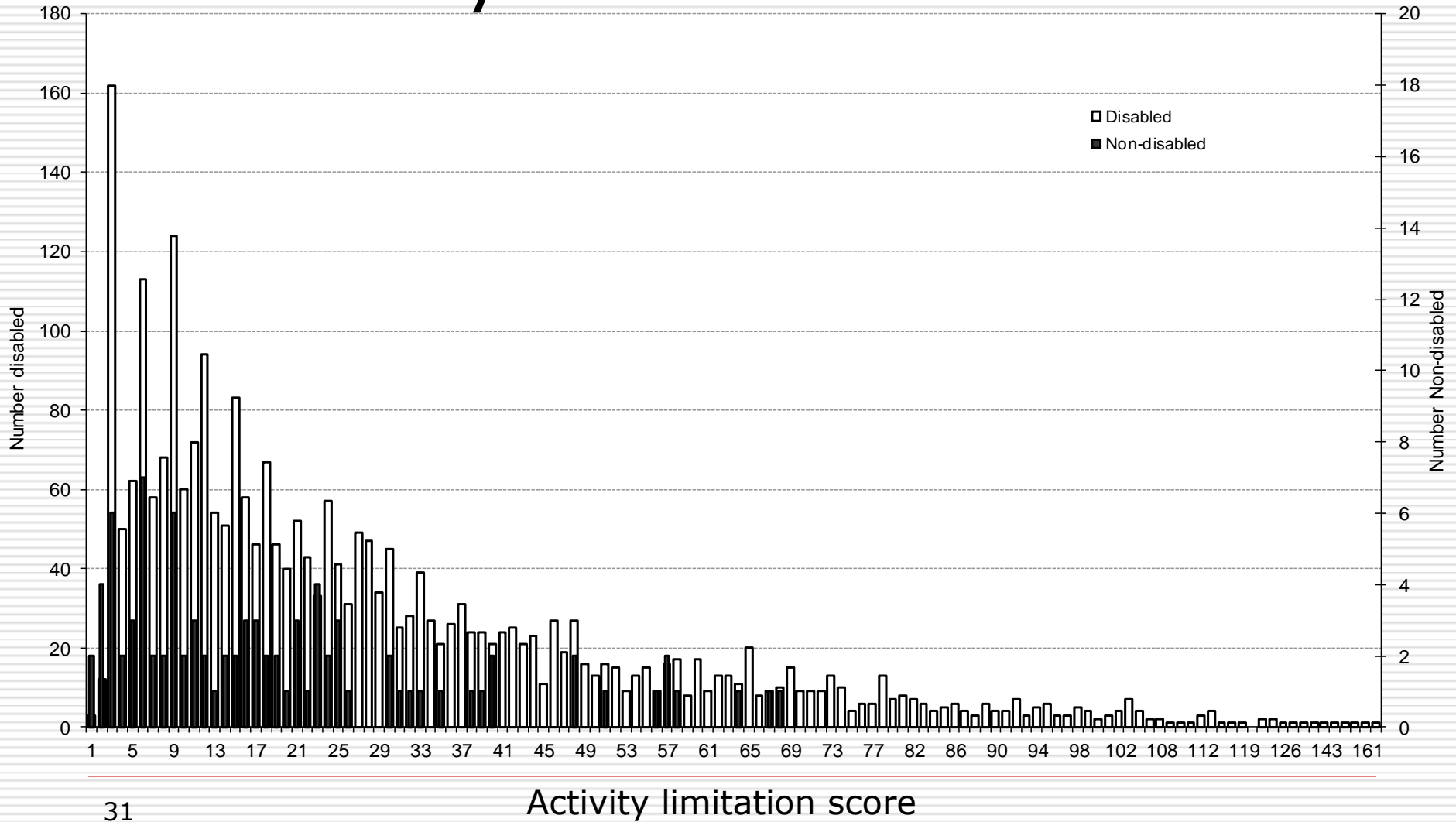
- A survey of Living Conditions among People with Disabilities in Zambia (2006) used the WG short set.
- 4 Response categories
- Disability: **at least one domain** that is coded as **a lot of difficulty** or **cannot do it at all**.
 - prevalence **8.5%**

Defining a disability continuum and a disability dichotomy

The WG questions fulfil two specific data needs:
to describe disability data as a continuum of functioning from no difficulty to some difficulty, a lot of difficulty and unable to do at all, and

to define a cut-off (or a set of cut-offs) that can be agreed upon internationally in order to disaggregate other information (e.g. access to education, employment) by disability status

A disability continuum



Severity within domains of functioning - Zambia

At least:

Core Domain	Some difficulty	A lot of difficulty	Unable To do it
Vision	4.7	2.6	0.5
Hearing	3.7	2.3	0.5
Mobility	5.1	3.8	0.8
Remembering	2.0	1.5	0.3
Self-Care	2.0	1.3	0.4
Communicating	2.1	1.4	0.5

Severity in Population - Zambia

Person with disability has:	n	%
at least 1 Domain is 'some difficulty'	4053	14.5
at least 2 Domains are 'some difficulty'	3090	11.0
at least 1 Domain is 'a lot of difficulty'	2368	8.5
at least 1 Domain is 'unable to do it'	673	2.4

Creating a disability dichotomy

- The WG recommends that the following cutoff be used to define the populations with and without disabilities for the purpose of international reporting and comparability.
- The sub-population *with disability* includes everyone with at least **one** domain that is coded as *a lot of difficulty* or *cannot do it at all*.

Creating a disability dichotomy

- Responses to the 6 questions range from 1: no difficulty to 4: cannot do at all
- If responses at all 6 questions are 1 or 2 – i.e. the person has no difficulty or only some difficulty over the 6 domains, then the individual is considered as *without disability*.
- If any one (or more) of the 6 domain responses is 3: a lot of difficulty or 4: cannot do at all – then the person is considered as *with disability*.

Limitations (I)

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

Limitations (II)

- It is not our purpose to:
 - identify every person with a disability within every community
 - replicate a population evaluated across a wider range of domains that would be possible with other forms of data collection

Objectives

- 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

Adoption of the WG-6

The WG routinely monitors the collection of disability data internationally, and annually requests detailed information from representatives from NSOs:

- survey periodicity,
- sample size and frame,
- mode of data collection,
- language(s) used,
- the actual questions/response options used
- and prevalence data.

Overview of disability data

In the most recent review, 43 countries submitted tabular data:

- 8 Middle East
- 10 North/South America
- 7 Europe
- 12 Asia/Pacific
- 6 Africa

For census data:

Aruba (using 6 questions) and Israel (using 4 questions) used the WG questions as intended; with the recommended cut-off (Aruba 6.9% / Israel 6.4%)

Turkey replaced the self-care domain with an upper body question; and using the recommended response categories, reported a prevalence rate of 6.9%.

For survey data:

Six countries used the WG short set of questions in recent surveys: Maldives [2009], Bangladesh [2010], Israel [2010], Zambia [2006], South Africa [2009/10/11] and USA [2010/11/12/13]

Maldives (9.6%), Zambia (8.5%) USA (8.9%, 8.5%, 7.9%, 9.5%) and South Africa (ca. 4%)

Bangladesh used a lower threshold (some difficulty) – prevalence rate was 9.1%.

Israel used 5 domains on those 20 years and over – prevalence rate was 15%

However...

Even the best questions....

Because of a Health problem:

- 1) Do you have difficulty **seeing** even if wearing glasses?
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- 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

...will fail if a screener is added

Is the person *suffering* from any difficulty/*disability* in the carrying out everyday activities? (prevalence 3.2%)

...or if the wording of the question is negative

Terms such as *disabilities* and *handicaps* are viewed as negative and tend to underreport disabilities.

Suffering may be associated with disease or illness but not necessarily with the life experiences of a person with disability. This language may also negatively influence the self-reporting of functional difficulties.

Response categories

Avoid **Yes/No** response dichotomies.

They tend to force the respondent into a category they may not want to self-identify with – Given the option, they may choose **'No'**

Scaled response are preferable:

- **No/Yes, a little/Yes, a lot/Cannot do at all**

It has been shown that scaled responses improve the respondents' ability to report.

Development of Extended Set Disability Measures:

Washington Group/Budapest Initiative/UNESCAP/UNICEF Question Development Matrix

Row		Questionnaire Topic/Type	Basic Activity Domains						Body Function Domains			Complex Activity / Participation Domains					
			Vision	Hearing	Mobility	Communication	Cognition/remembering	Upper Body	Learning/understanding	Affect (6)	Pain	Fatigue	ADL/IADL	Getting Along with People	Major Life Activities	Participation in Society	
1	Capacity	Short Set Single Questions (1)							b				b				
		Extended Set Multiple Questions (1)					a	a		c	a/c	a					
3	Performance	Use of Assistive Devices Micro-E (2)				Sign language											
		Functioning with Assistance, Micro-E								c							
5		Children and Youth (3)															
6		Age at Onset															
7		Cause															
8		Duration															
9		Impact (limit ability to carry out daily activities)											N/A	N/A	N/A	N/A	
10		Meso-Environment (4)	Question Set currently under development														
11		Macro-Environment (5)	To be obtained through other sources, not personal survey data collections														

1. Extended Set on Functioning (WB/BI/UNESCAP)

First set of extended questions on functioning

- Expands the number of domains covered adding upper body functioning, affect, pain, and fatigue
- Provides more in-depth information on each domain
- Begins to lay the groundwork for constructing links between functioning in core domains without accommodation, functioning with accommodation, environment & participation

2. WG/UNICEF Module on Child Functioning and Disability:

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

Domains of functioning:

- seeing
- hearing
- mobility
- self-care
- communication
- learning
- emotions
- behaviour
- attention
- coping with change
- relationships
- playing

3. WG/UNICEF Module on Inclusive Education:

UNICEF and the WG have begun a similar process to identify facilitators and barriers to school participation for children with disability.

Framework for question development

Getting to school

Includes transportation, environmental and social safety, and weather/seasonality.

Accessibility within the school

Includes physical accessibility (entryway, corridors, bathrooms, lunch room, classroom, common areas etc.), information accessibility, communication accessibility, and programs accessibility/adaptability.

Framework for question development

Affordability

Includes fees, costs and competition for resources associated with attendance, availability of types of assistance (financial, assistive devices, rehabilitation), and non-educational benefits (e.g., meals).

Attitudes

Includes parents' perceptions of disability, their perceptions of other's attitudes towards disability, societal and cultural norms, children's attitudes towards disability, and school staff's perceptions of disability.

Disability Statistics to Monitor Development Goals and the UN Convention on the Rights of Persons with Disabilities...

Need for National Data to Support Monitoring

National Data on population with disabilities is necessary to both implement and monitor development goals and the Convention.

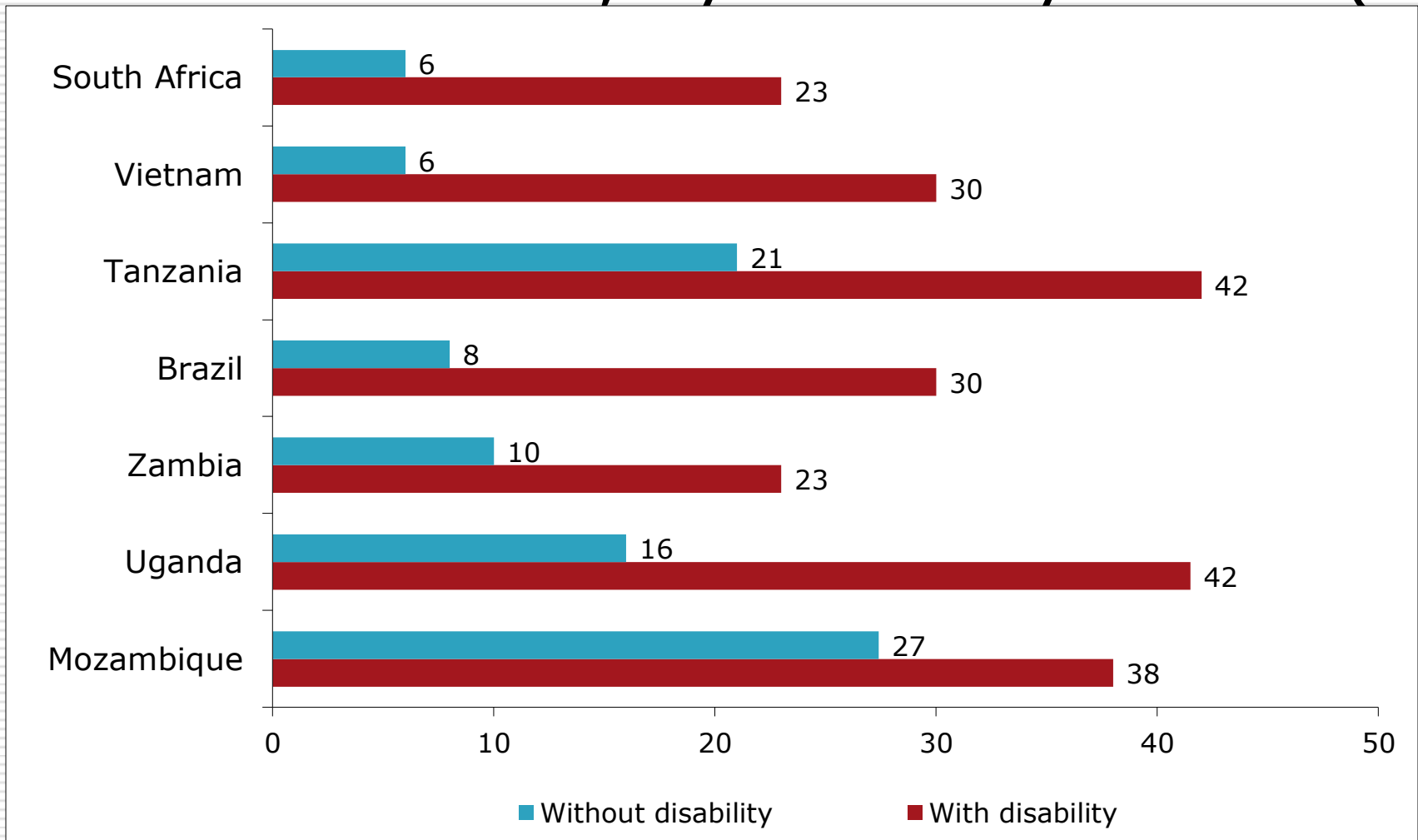
The International Classification of Functioning, Disability and Health (ICF) provides a commonly accepted model to support national data collection.

The Washington Group work seeks to provide internationally comparable data based on the ICF Model to fulfill the monitoring function.

Standardized Approach to Monitoring

- By standardizing these questions it will be possible to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources;
- Data can be used to assess a country's compliance with development goals the Convention and, over time, their improvement in meeting requirement

Population aged 15 years + who never attended school, by disability status (%)



To summarize:

Past Failures – Current Success

- International disability statistics were in disarray – multiple, non-comparable, improbable estimates
- Multiple attempts to fix the situation were not successful
- Growing need for quality information both in country and internationally
- Status quo was not acceptable
- Pressure from multiple constituencies
- Lack of strong data collection tradition in many countries

Past Failures – Current Success

- Why has the Washington Group experienced success?

Past Failures – Current Success

- Member driven group
- Objectives and rules of engagement set at first meeting
 - Input from all attending on high priority objectives
 - Meeting format goal driven
 - Governance policies developed
- Funding from the World Bank received at key point in process
- Funding from DFAT will allow this work to continue

Workshops & Expert Consultations:

Nairobi, Kenya	June	2005
Bishkek, Kyrgyz Republic	Dec	2006
Sarajevo, Bosnia and Herzegovina	Feb	2008
Bangkok, Thailand	April	2008
Ohrid, Macedonia	Nov	2008
Dhaka, Bangladesh	Aug	2009
Muscat, Oman	Oct	2010 / April 2013
Damascus, Syria	Dec	2010
Sharjah, UAE	May	2011
Bogotá, Colombia	July	2012 / Aug 2013
Mumbai, India	Sept	2012
Belmopan, Belize	Jan	2013
Amman, Jordan	May	2013
Podgorica, Montenegro	July	2013
Apia, Samoa	June	2014

Publications:

- Measuring Disability and Monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. BMC Public Health 2011, **11**(Suppl 4):S4
- A White Paper on Disability Measurement. Journal for Disability and International Development. 2012, **1**:4-11.
- Disability Statistics: and integral but missing (and misunderstood) component of development work. Nordic Journal of Human Rights, 2013; **31(3)**:306–324
- Methods to Improve International Comparability of Census and Survey Measures of Disability. Disability & Rehabilitation, 2013; **35(13)**:1070-3

WG Book under development

B. Altman (Editor) / Springer (Publisher)

Work on this volume began in 2012.

It will highlight:

- the development and testing of the WG short set;
- experiences of several countries on the use of the WG questions and how this has impacted on national agendas in the area of disability;
- the development and testing of an extended set of questions for use in national surveys;
- the challenges of translation and the importance of generating comparable question sets in different languages and within different cultures;

WG Book under development

- an examination of cognitive testing techniques in a variety of countries;
- results of the first round of censuses in 2010 in countries using the six question set;
- an overview of the work currently underway in the development of a question module on child disability and functioning and the environmental contexts of school participation; and
- a discussion of what the development of cross-nationally comparable data can mean for the improvement of circumstances for all persons with disabilities.

For more information...

- The WG reports to the UN Statistical Commission. The WG annual report to the Commission is available at:

<http://unstats.un.org/unsd/statcom/doc14/2014-10-WashingtonGroup-E.pdf>

- Executive summary of last 14 WG meetings posted on the WG website along with presentations & papers from the meetings:

http://www.cdc.gov/nchs/washington_group.htm