WG Short Set Disability Measure for Censuses and Surveys:

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Challenge

How to measure the broad experience of disability through a limited number of questions in a consistent and comparable way?

The Disablement Process ca.1980

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%

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	%
Brazil	1991	0.9
Chile	1992	2.2
Colombia	1993	1.8
El Salvador	1992	1.6
Panama	1990	1.3
Peru	1993	1.3

*** Sources and methodologies are country specific**

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

*** Sources and methodologies are country specific**

Global disability prevalence rates†

High-income countries			L/M-income countries		
	Year	**%**		**Year**	**%**
Canada	1991	14.7	Turkey*	1985	1.4
Germany	1992	8.4	Oman*	1993	1.9
Italy	1994	5.0	Egypt*	1976	0.3
Netherlands	1986	11.6	Morocco*	1982	1.1
Norway	1995	17.8	Gaza Strip	1996	2.1
Sweden	1988	12.1	Iraq*	1977	0.9
Spain	1986	15.0	Jordan*	1994	1.2
UK*	1991	12.2	Lebanon	1994	1.0
USA	1994	15.0	Syria	1993	0.8

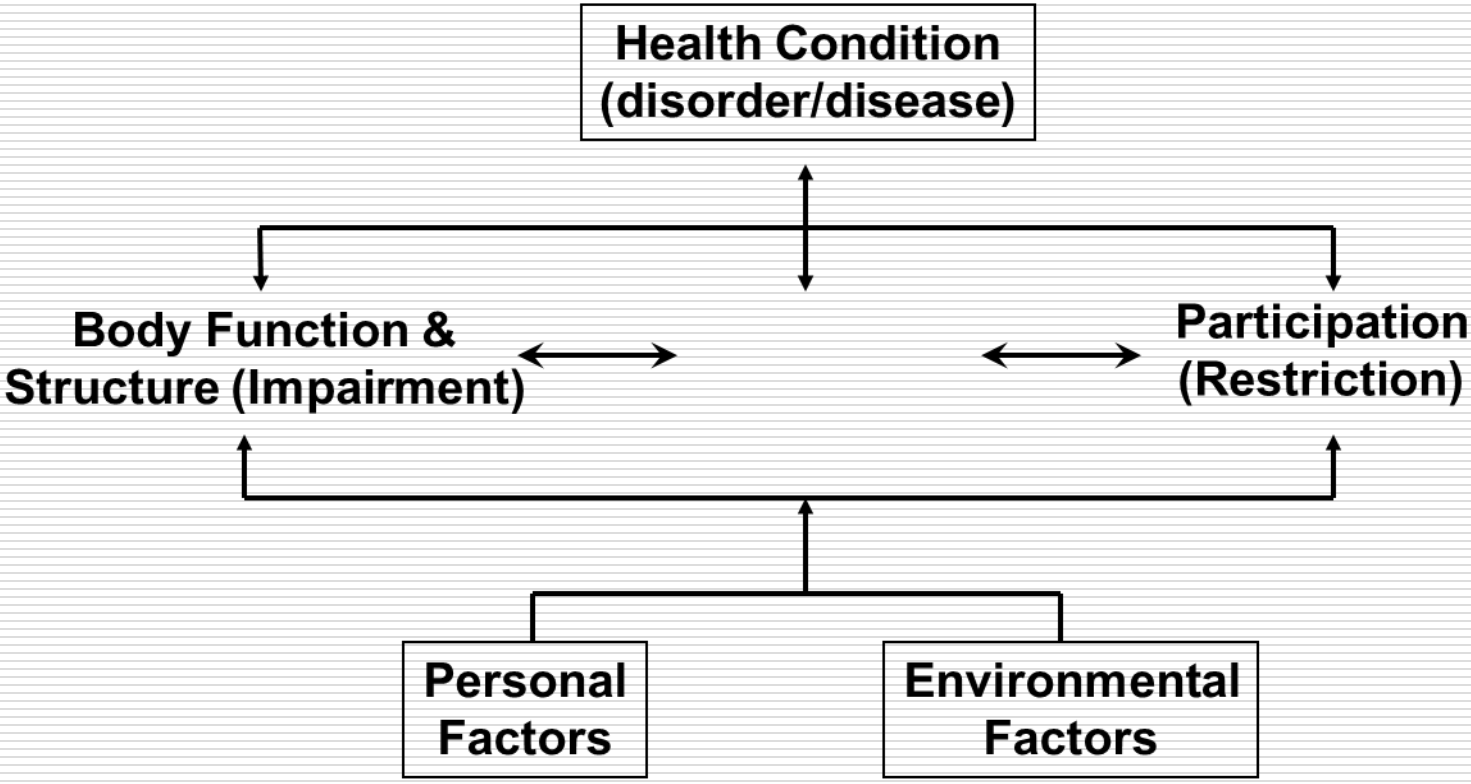
† Sources and methodologies are country specific
*** Census**

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



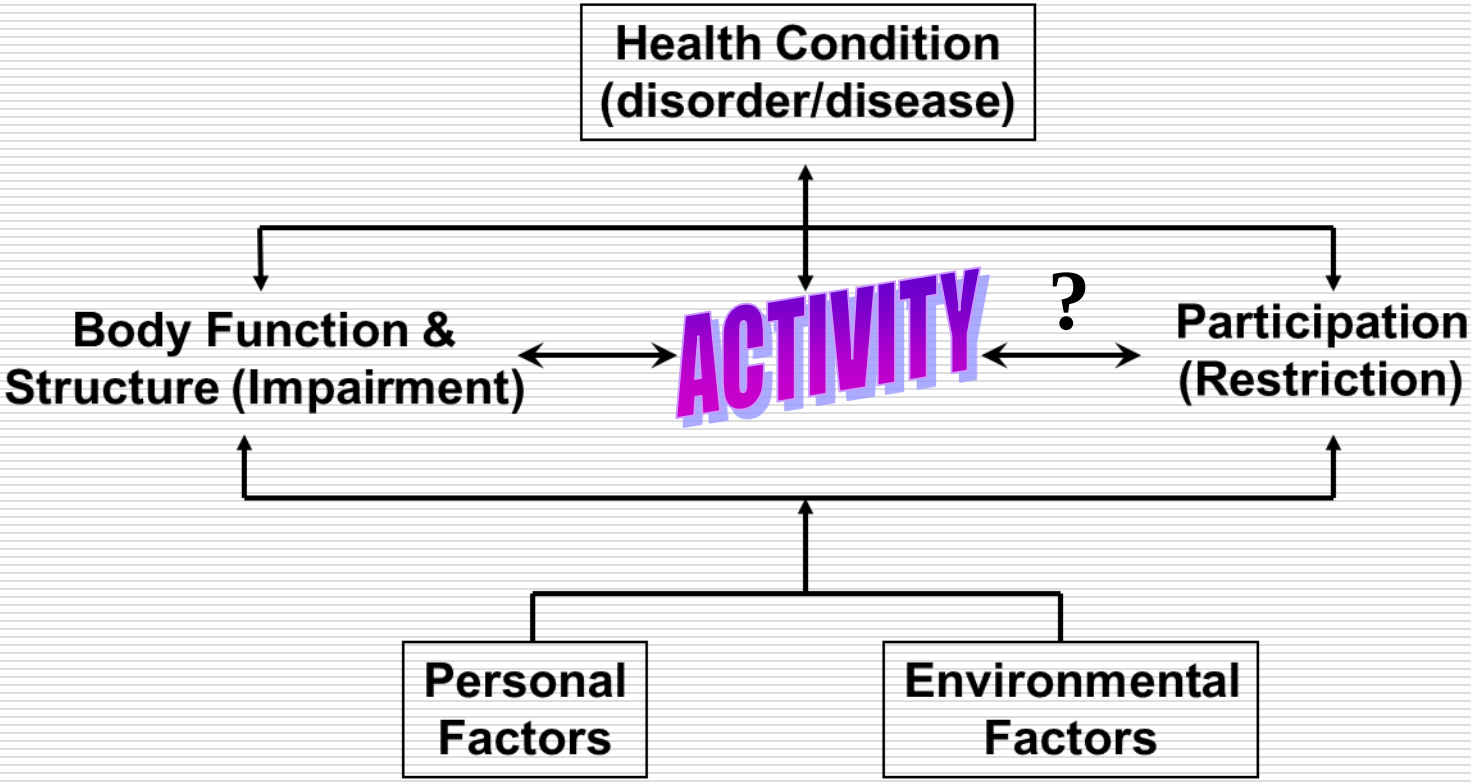
Source: World Health Organization, 2001

Measuring Disabilities: 2

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**.

Locating Risk in the ICF Model



Source: World Health Organization, 2001

Measuring Disability: 2

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

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%

Severity in Population (%)

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

Severity within Domains of Functioning

		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

WG Recommendation:

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 *disabled* includes everyone with *at least one domain* that is coded as *a lot of difficulty* or *cannot do it at all*.

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

The WG routinely monitors the collection of disability data internationally, and annually requests detailed information from National Statistical Offices on:

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

Annually about 120 countries receive requests to report on national activities that relate to disability statistics.

Responses are voluntary – and in the last round, responses (including both those that provided data and those that did not) were received from 64 countries. This represents a response rate of about 53%.

Data supplemented with information provided by countries attending an Arab Institute for Training and Research in Statistics (AITRS) sponsored disability seminar in held in Damascus, Syria, December, 2010.

Two countries (Zambia and South Africa) provided data independently.

Overview of disability data

43 countries are represented:

- Middle East: 8 (Morocco, Oman, Israel, Jordan, Egypt, Palestine, Yemen, Iran)
- North/South America: 10 (Canada, USA, Panama, Aruba, Dominican Republic, Mexico, Argentina, Peru, Bermuda, Costa Rica)
- Europe: 7 (Poland, Lithuania, Spain, Netherlands, Norway, Hungary, Turkey)
- Asia/Pacific: 12 (Mongolia, Bangladesh, Australia, New Zealand, Cambodia, Maldives, Thailand, Japan, Togo, Philippines, China-Macao, Republic of Korea)
- Africa: 6 (Lesotho, Malawi, Mauritius, South Africa, Zambia, Ghana)

Census results were reported by 25 countries while 24 countries reported survey results.

Five countries reported multiple results Argentina/2, Israel/2, Hungary/2, Mexico/2 and Peru/3

Some countries reported census or survey data that pre-date the 2006 adoption of the WG short set of questions;

and there was a clear distinction between countries that took a more medical model approach to identifying disability on their census or survey.

Results:

Prevalence rates ranged from below 1% to over 10%

- census 0.4-12.9
- survey 1.4-16.6

Lower rates predominated among censuses and surveys that pre-dated the WG, and relied on lists of impairments or types of disability in their questionnaires (medical model).

Results:

Higher rates were reported from countries that operationalized the social model, limitation of activity approach

Censuses and surveys that took place post 2006 more often operationalized the social model of disability and used an activity limitation approach to measurement.

For census data:

Only 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 used 6 questions that were similar to, but not identical with the WG questions. They replaced the self-care domain with an upper body question; and reported a prevalence rate of 6.9%.

For census data:

Several other countries employed modifications of the WG questions with varying results: Malawi, Mexico and Philippines all used the WG approach but used a dichotomous Yes/No response option and reported prevalence rates of 4.0%, 4.1% and 3.1% respectively.

For survey data:

Prevalence rates derived from surveys were generally higher than those from censuses but ranged from less than 5% to greater than 10%.

Generally, low disability prevalence rates (1.4% - 5.4%) were reported from countries that used an impairment-based approach to the measurement of disability.

Activity limitations:

17 countries presented various means of collecting disability data using an activity limitation approach.

4 countries included long lists of activities that generated prevalence rates that were higher than most: 7.1% - 16.6%.

Activity limitations:

5 countries used the WG short set of questions in recent surveys: Maldives, Bangladesh, Israel, Zambia and South Africa.

Maldives (9.6%), Zambia (8.5%) and South Africa (ca. 4%) each used the WG short set as written and the response options as recommended.

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

We have found that while countries have reported disparate disability prevalence rates; those that use the WG *as intended* (Israel [census/2008]; Aruba [census/2010]; Zambia [survey/2006]; and Maldives [survey/2009) have reported disability prevalence rates that are comparable: 6.4%, 6.9%, 8.5%, and 9.6% respectively.

However…

Even the best 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

…will fail if a screener is added

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

The Importance of Wording

The most detailed disability survey, using a carefully designed and relatively complete set of questions covering a wide range of topics, is limited when the initial questions used to identify the persons with disability are poorly designed.

Wording

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.

Wording

Also the use of qualifiers like *long-term*, *severe* or *permanent* with respect to the difficulty in functioning will at best result in the reporting of only the most severe disabilities.

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.

Response categories

Disability is not an “all or nothing” concept.

People are not identified as having a disability based upon a medical condition, but rather are classified according to a detailed description of their functioning within various domains.

Multiple questions and a range of response options allows for the capture of the continuum of disability.

Self-report and the perception of disability

Two persons with the same impairment may have completely different perceptions of disability.