WHO’s current work on disability data

Alarcos Cieza
Disability and Rehabilitation
WHO Geneva

ciezaa@who.int
Persons with disabilities have to be able to participate in society “on an equal basis with others”

**Article 31 - Statistics and data collection**
Statistical and research data for policy implementation
• Regional and national agendas

• UN Organizations
1. Improving access to health services
2. Strengthening rehabilitation, assistive technology, support services, and community-based rehabilitation
3. Strengthening collection of disability data and research
Purposes for collecting disability data

1. To determine the overall population **prevalence** of disability;

2. To identify the **existence and extent of the inequality**;

3. To **monitor** the effectiveness of concrete actions and policies at the national level; and

4. To **formulate policy recommendations**.
Where all these data should come from?
Disability Data

Censuses 1), 2), 3)

Country Specific Surveys 1), 2), 3), 4)

Disability Surveys 1), 2), 3), 4)

Purposes for collecting disability data

1. To determine the overall population prevalence of disability;

2. To identify the existence and extent of the inequality;

3. To monitor the effectiveness of concrete actions and policies at the national level; and

4. To formulate policy recommendations.

Administrative data --
What is about disability data coming from registers?

Not useful for disability prevalence
WHO is working on …

<table>
<thead>
<tr>
<th>Censuses</th>
<th>Country Specific Surveys</th>
<th>Disability Surveys</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Brief MDS</td>
<td>MDS</td>
</tr>
</tbody>
</table>
• What are the data collection approaches?

• Which disability data are we collecting?
Key ICF Concepts

Intrinsic capacity of the body

The result of the interaction of capacity with the environment and the person
Key ICF Concepts

**Capacity** is the inherent or intrinsic feature of a person to do an action or execute a task “under the skin”

**Performance** is the doing of an action or execution of a task in the actual context of the individual “the lived experience”
Why is it fundamental to have information about both? 

Intrinsic capacity of the body 

The result of the interaction of capacity with the environment and the person
Which information on disability is needed?

Health condition

Impairment in body functions & structures

Capacity

Activity limitation

Participation restriction
Which information on disability is needed?

Performance

Health condition

Impairment in body functions & structures

Activity limitation

Participation restriction

Environmental factors

Personal factors
How much of a problem is getting out of your home for you?

<table>
<thead>
<tr>
<th></th>
<th>1 None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 Extreme</th>
<th>8 Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
How much difficulty do you have moving around because of your health?

<table>
<thead>
<tr>
<th></th>
<th>1 None</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 Extreme</th>
<th>8 Don’t Know</th>
</tr>
</thead>
</table>

The answer marked is 5 Extreme.
Model Disability Survey (MDS)
Fundamental modules

Section 3000 A
Environmental factors

Section 4000
Performance

Section 5000
Health Conditions & Capacity

Section 3000 B
Personal assistance, assistive devices, facilitators
Development process

**PHASE ONE**

**MAPPING & DRAFTING**

- A) Review available surveys
- B) Statistical analysis with microdata
- C) Draft of a Zero MDS version
- D) Expert Consensus
- E) Alpha Version

**PHASE TWO**

**TESTING & FURTHER DEVELOPMENT**

- Cognitive testing
- Pilot studies

**PHASE THREE**

**IMPLEMENTATION**

National Disability Surveys:

- MDS as stand alone survey
- Addition of Brief MDS existing surveys and data collection platforms

Timeline:

- Nov 2011
- Dec 2012
- Aug 2013
- Nov 2014
Development process

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**Nov 2011** to **Dec 2012**

**PHASE TWO**

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- Pilot studies

**Aug 2013**

**PHASE THREE**

**IMPLEMENTATION**

National Disability Surveys:
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**Nov 2014**
179 Health and Disability Surveys

AMRO N=22
AFRO N=16
EMRO N=2
EURO N=109
SEARO N=7
WPRO N=23
Preparatory phase

• http://disabilitysurvey.checkdesign.de/


Development process

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Cognitive testing


Institutions

• National Center for Health Statistics, US
• Institute for Survey Research, University of Michigan, US
• Statistics Norway, Norway
• Institute for Public Health and Health Services Research, Ludwig-Maximilians-University Munich, Germany

Countries

• US, Cambodia, Malawi, Nepal, China and UK
<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>RESPONSIBLE INSTITUTION</th>
<th>DATA COLLECTION</th>
<th>SAMPLE SIZE ADULTS</th>
<th>SAMPLE SIZE CHILDREN</th>
<th>STATUS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cambodia</td>
<td>• Statistics Norway (SN) • National Institute of Statistics Cambodia • WHO</td>
<td>Aug 2014</td>
<td>500</td>
<td>500</td>
<td>• Data analyses completed • Report being prepared by SN</td>
</tr>
<tr>
<td>Malawi</td>
<td>• Statistics Norway (SN)</td>
<td>Mar 2015</td>
<td>500</td>
<td>500</td>
<td>• Data analyses pending</td>
</tr>
<tr>
<td>Pakistan</td>
<td>• Ministry of Health • Pakistan Bait-ul-Mal* • WHO</td>
<td>Feb &amp; Mar 2015</td>
<td>3977</td>
<td>-</td>
<td>• Data analyses completed • Report available</td>
</tr>
<tr>
<td>Oman</td>
<td>• Ministry of Health • WHO</td>
<td>Oct &amp; Nov 2015</td>
<td>300</td>
<td>300</td>
<td>• Data collection completed • National survey being planned</td>
</tr>
<tr>
<td>Brazil</td>
<td>• Ministry of Health • WHO - OPAS</td>
<td>Middle 2016</td>
<td>2000</td>
<td>tbd</td>
<td>• In planning • Test for inclusion of modules in the national health survey of 2017</td>
</tr>
</tbody>
</table>

*Pakistan Bait-Ul-Mal (PBM) is one of the major public sector organizations and has been delivering since 1992 Social Protection program in terms of cash, in-kinds, care and services addressing almost every needy segment of the society.
VERSION ZERO (Dec 2012)

Expert meeting - 5th Dec 2012

ALPHA VERSION

Expert appraisal Norway - March 2013

First revised Alpha version (March 2013)

Expert Meeting - 29-30 April 2013

Second Revision of the Alpha Version (May 2013)

1st Round of Cognitive Testing

Revised Alpha version - 1st round cognitive testing (Oct 2013)

2nd Round of Cognitive Testing

Revised Alpha version - 2nd round cognitive testing (July 2014)

Preparatory work national survey Chile (Nov 2014)

Revised Alpha version after preparation in Chile (Nov 2014)

MDS Group Intern Meeting, July 2015 – results pilot studies (Cambodia, Pakistan, Malawi) and preparation for the national surveys (Sri Lanka and Chile)

CURRENT MDS ALPHA VERSION (July 2015)
**Development process**

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**Timeline:**
- Nov 2011 to Dec 2012
- Aug 2013
- Nov 2014
National Surveys – 2015

CHILE
- Data Collection: June to August 2015
- Sample: 12,000 individual interviews

SRI LANKA
- Data Collection: February to April 2015
- Sample: 3,000 households
National Surveys

**PANAMA**
Planned data collection: October–December 2016

**PHILLIPINES**
Planned data collection: January – February 2017

**Pakistan**
Planned data collection: 2017
Regional Surveys

DUBAI, United Arab Emirates
Planned data collection: October-November 2016

ADAMAWA, CAMEROON
Data collection: April–June 2016

Tehsil Pindi Gheb, Pakistan
Data collection: April–June 2016
Included in existing surveys

Chile
- MDS Brief Version
- National Health Survey 2016

BRAZIL
- MDS Brief version
- National Health Survey 2017
Model Disability Survey (MDS)
Intrinsic capacity of the body

The result of the interaction of capacity with the environment and the person
Both capacity and performance are in a **continuum** and are **unidimensional**.
Both capacity and performance are in a continuum and are unidimensional.
CHILE (N=12265)

Capacity

Performance

21.4%

12.5%

8.3%

8.9%
CHILE (N=12265)

Capacity

Performance

8.3%  21.4%

8.9%
GOAL 11

11.2.1 Proportion of population that has convenient access to public transport

% who have problems using transportation

Chile

Capacity

- Low: 13%
- Moderate: 26%
- Severe: 57%

Experienced barriers
GOAL 8

Chile & Sri Lanka

% who have problems getting things done at work

Experienced Barriers at the workplace
GOAL 6

Sri Lanka

6.2.1 Proportion of population using safely managed sanitation services

% who find hard or very hard to use the toilet of the dwelling
Collaboration between WHO and countries

• Close collaboration with the countries
  – Training
  – Analyses
  – Reporting

• We encourage the collaboration among the statistical office, ministries and UN organizations