Traveling with the Washington Group: Disability Statistics World-Wide

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Think Before You Measure
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Measuring Health, Functioning and Disability for international comparisons…

The Situation:
- Absence of internationally comparable measures
- Complexity of measuring health and disability
- No agreed upon definition or set of core measures
- No standards for producing the data

The Solution:
- A mechanism to identify the appropriate framework, define a set of core measures and identify ways of obtaining the needed data within the auspices of national statistical offices and international organizations – *The Washington Group; the Budapest Initiative.*
The Washington Group on Disability Statistics (WG): Initial Objectives

• To guide the development of a small set of general disability measures suitable for censuses,

• To recommend one or more extended sets of items to measure disability in population surveys or supplements,

• To use the ICF model as a framework to assist in the development of the measures, and

• To address methodological issues associated with disability measurement.
The WG: 10 Years and Counting

• The WG has held 10 meetings to date in all regions of the world
  • Washington DC, Ottawa, Brussels, Bangkok, Rio de Janeiro, Kampala, Dublin, Manila, Dar el Salaam, Luxembourg
• NSO representatives from 116 countries have participated
• Current members include 109 NSOs, 7 international organizations, 6 DPOs, the UNSD and other U.N. affiliates
• Held two regional workshops: Africa and Latin America
• Participated in five other regional workshops
• Conducted cognitive testing of the short set questions in 15 countries, and the extended set in 15 countries
• On-going provision of technical assistance, methodological training and fostering of international cooperation
The WG Conceptual Model

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

• Common point of reference
• Common vocabulary
• Highlights the environment, the physical, social and attitudinal context of disability
• Includes both activity and participation domains
• Does not provide an operational definition or a way to measure the concepts

Moved away from a medical definition, based on individual pathology/cause/condition, towards a concept based on the consequences of disease for functional capacity and social participation.
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.

**Decision:** ‘Equalization of Opportunity’
Locating Risk in the ICF Model

Health Condition (disorder/disease)

Body Function & Structure (Impairment)

Activity

Participation (Restriction)

Personal Factors

Environmental Factors

WG 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.
Possible Domains and Activities

**Mobility**
- Walking
- Climbing stairs
- Bending or stooping
- Reaching or lifting
- Using hands

**Sensory**
- Seeing
- Hearing

**Communicating**
- Understanding
- Speaking

**Cognitive functions**
- Learning
- Remembering
- Making decisions
- Concentrating

**Emotional functioning**
- Interpersonal interactions
- Psychological well-being

**Other**
- Affect
- Pain
- Fatigue
- Self care
WG Disability Short Set

1-5. How much difficulty do you have:

- seeing even if wearing glasses?
- hearing even if using a hearing aid?
- remembering or concentrating?
- walking or climbing stairs?
- with self-care, such as washing all over or dressing?

6. Because of a physical, mental or health condition, how much difficulty do you have communicating, for example understanding or being understood by others?

   a) No, no difficulty          c) Yes – a lot of difficulty
   b) Yes – some difficulty      d) Cannot do at all
The WG Short Set To Date

Adopted in 2006 by the WG as an outcome of the 6th meeting held in Kampala, Uganda.


Incorporated into censuses throughout the world: Aruba, Bangladesh, China, Czech Republic, Fiji, Israel, Ivory Coast, Kazakhstan, Mexico, Mozambique, Netherlands, Oman, Palestine, Paraguay, Peru, Philippines, Poland, Rwanda, South Africa (2011), Sri Lanka, Uganda, Zimbabwe, with others planned…
Using the WG Short Set to Monitor the UN Convention


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 the UN Convention and, over time, their improvement in meeting the requirements set out under the Convention.
Population Never Attending School, by Disability Status
(15 years of age and over)

<table>
<thead>
<tr>
<th>Country</th>
<th>Without disability</th>
<th>With disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Africa</td>
<td>6</td>
<td>23</td>
</tr>
<tr>
<td>Vietnam</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>Tanzania</td>
<td>10</td>
<td>21</td>
</tr>
<tr>
<td>Zambia</td>
<td>16</td>
<td>23</td>
</tr>
<tr>
<td>Uganda</td>
<td>16</td>
<td>27</td>
</tr>
<tr>
<td>Mozambique</td>
<td>21</td>
<td>38</td>
</tr>
</tbody>
</table>

NOTE: Data are from national surveys collected between 2006 and 2008.
Extended Question Sets: The Next WG Product

Having successfully developed and tested the short set of questions for censuses, the WG moved on to extended sets.

A modular approach:

• Taken together will form a disability survey
• Modules can be used individually or grouped to meet the needs of the data collection
• Joint WG/BI question development
Work on Extended Measures

- Expands the number of domains covered, such as learning, affect, pain and fatigue (joint with BI).
- Goes into greater detail on the same 6 domains covered by the short set of questions (joint with BI) and adds topics: age at onset and impact of the difficulty.
- Begins to construct the links between functioning in core domains without accommodation, functioning with accommodation, environment and participation.
- Initial sets have been cognitively and field tested—joint WB/BI question sets approved at joint Luxembourg meeting (2010).
## Washington Group/Budapest Initiative/UNESCAP Activities and Workplan

<table>
<thead>
<tr>
<th>Questionnaire Topic/Type</th>
<th>Basic Activity Domains</th>
<th>Complex Activity Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Vision (1)</td>
<td>Hearing (1)</td>
</tr>
<tr>
<td>Capacity Performance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short Set</td>
<td>Short Set</td>
<td>Short Set</td>
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<tr>
<td></td>
<td>Extended Set</td>
<td>Extended Set</td>
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<tr>
<td></td>
<td>Use of Assistive</td>
<td>Use of Assistive</td>
</tr>
<tr>
<td></td>
<td>Functioning with</td>
<td>Functioning with</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Row</td>
<td>5</td>
<td>Age at Onset</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>Cause</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>Duration</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>Impact</td>
</tr>
<tr>
<td>Meso-Environment</td>
<td>9</td>
<td>(3)</td>
</tr>
<tr>
<td>Macro-Environment</td>
<td>10</td>
<td>(4)</td>
</tr>
<tr>
<td>ICF Chapter Reference</td>
<td>ICF-1</td>
<td>ICF-1</td>
</tr>
<tr>
<td>Activities/Participation</td>
<td></td>
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</tr>
</tbody>
</table>

To be obtained through other sources, not personal survey data collections

(5) See Note below
<table>
<thead>
<tr>
<th>Basic activity domains</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Use of AD/Micro-Environment</strong></td>
<td><strong>Do you take medication for these feelings?</strong></td>
</tr>
</tbody>
</table>
| **Functioning:** **Extended questions** | **How often do you feel worried, nervous or anxious?**  
- Daily, Weekly, Monthly, A few times a year, Never  
**Thinking about the last time you felt worried, nervous or anxious,**  
how would you describe the level of these feelings?  
- A little, A lot, Somewhere in between a little and a lot  
Would you say this was closer to a little, closer to a lot, or exactly in the middle? |
| **Probe:** | Please tell me which of the following statements, if any, describe your feelings.  
1. My feelings are caused by the type and amount of work I do.  
2. Sometimes the feelings can be so intense that my chest hurts and I have trouble breathing.  
3. These are positive feelings that help me to accomplish goals and be productive.  
4. The feelings sometimes interfere with my life, and I wish that I did not have them.  
5. If I had more money or a better job, I would not have these feelings.  
6. Everybody has these feelings; they are a part of life and are normal.  
7. I have been told by a medical professional that I have anxiety.|
Anxiety Severity

<table>
<thead>
<tr>
<th>How often do you feel worried, nervous or anxious?</th>
<th>A few times a year</th>
<th>Monthly</th>
<th>Weekly</th>
<th>Daily</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A little</td>
<td>1087</td>
<td>423</td>
<td>328</td>
<td>214</td>
<td>2052</td>
</tr>
<tr>
<td>In between</td>
<td>179</td>
<td>126</td>
<td>161</td>
<td>104</td>
<td>570</td>
</tr>
<tr>
<td>A lot</td>
<td>163</td>
<td>86</td>
<td>122</td>
<td>259</td>
<td>630</td>
</tr>
<tr>
<td>Total</td>
<td>1429</td>
<td>635</td>
<td>611</td>
<td>577</td>
<td>3252</td>
</tr>
</tbody>
</table>
## Anxiety

Significant relationships with respondent location

<table>
<thead>
<tr>
<th>Intensity</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A few times a year</td>
</tr>
<tr>
<td>A little</td>
<td><strong>Work</strong>*</td>
</tr>
<tr>
<td></td>
<td>Chest hurts***</td>
</tr>
<tr>
<td></td>
<td>Interfere***</td>
</tr>
<tr>
<td></td>
<td>Economic***</td>
</tr>
<tr>
<td></td>
<td>Limited***</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Closer to a little</td>
<td></td>
</tr>
<tr>
<td>In between</td>
<td>Normal**</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Closer to a lot</td>
<td>Interfere**</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>A lot</td>
<td><strong>Work</strong>*</td>
</tr>
<tr>
<td></td>
<td>Economic**</td>
</tr>
<tr>
<td></td>
<td>Normal***</td>
</tr>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Negative associations shown in yellow text. Positive associations shown in white text. **p<.05, ***p<.005

Based on bivariate logistic regression models in each cell. Models run for cases NOT taking medication.
1. Do you wear glasses?
2. Do you have difficulty seeing, even when wearing glasses?

3. Do you use a hearing aid?
4. Do you have difficulty hearing even when using a hearing aid?
5. Do you have difficulty hearing what is said in a conversation with one other person in a quiet room?
6. Do you have difficulty hearing what is said in a conversation with one other person in a noisier room?

7. Do you have difficulty walking or climbing steps?
8. Do you use any equipment or receive help for getting around?
9. Do you use any of the following [list of aids]?
10. Do you have difficulty walking 100 meters on level ground?
11. Do you have difficulty walking half a km on level ground?
12. Do you have difficulty walking up or down 12 steps?
Extended Question Set

13. Do you have difficulty remembering or concentrating?

14. How often do you feel worried, nervous or anxious?
15. Do you take medication for these feelings?
16. Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings?

17. How often do you feel depressed?
18. Do you take medication for depression?
19. Thinking about the last time you felt depressed, how depressed did you feel?
Testing Protocol: Objectives

- **Cross-cultural comparability**
  - Do the survey questions work consistently across all countries and subgroups?

- **Translation comparability**
  - Do terms (both in the question and in the response set) have the same meaning across countries?

- **Content Validity**
  - Do respondents interpret questions consistently regardless of country, language, or demographic?

- **Item reliability**
  - Do respondents use the same thought processes to answer questions?
    - If not, then, why are there differences? What about the countries, languages or demographic subgroups generate different response processes?
    - How can we “fix” or manage these differences through question design?
Testing Protocol: Methods

Purpose: To develop systematic comparable testing and analysis method.

- Joint and coordinated interviewing
  - Similar protocol
  - Similar sample
  - Understanding of differences (at a minimum)
- Joint and coordinated analysis
  - With interview data
  - Evidence based (as opposed to opinion)
Testing Protocol: Lessons Learned

• Semi-structured cognitive interviews offers critical and unique insight into cross-national question performance

• Transparency is critical:
  • of data from interviews
  • of the process for drawing conclusions

• Data collection oversight

• Better data management
Standardized Testing Conducted

WG Testing To Date:

- 15 countries participating (13 funded via World Bank grant, 2 self-funded)
- Cognitive tests in 12 countries (Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Philippines, Uganda, Mexico, Tanzania, Vietnam)
- Field tests in 2 countries (Gambia, Vietnam)
- Combined cognitive/field test in 3 countries (Argentina, Brazil, Paraguay)

BI Testing: 2006; 7 domains

- 4 countries, 3 languages: Australia, Canada, Italy, U.S.
- Outcome: BI-M1 question set, submitted to Eurostat

BI Testing: 2007; 6 domains (not vision)

- BI-ESS collaborative test (7 countries, 6 languages): Bulgaria, Germany, Portugal, Spain, Switzerland, U.K, U.S.
- Improvements: Evidence-based methodology & systematic comparative analysis of patterns
- Analysis meeting in U.S. February 2008, all participants
Standardized Testing Conducted

WG/BI/UNESCAP Testing 2009:
• Cognitive tests in 9 countries (Canada, Fiji, Germany, Maldives, Sri Lanka, Philippines, Cambodia, United States, Vietnam)
• Field tests in 6 countries (Mongolia, Maldives, Sri Lanka, Philippines, Cambodia, Vietnam)

WG/BI European Testing 2010:
• Cognitive tests in 7 countries (France, Germany, Italy, Portugal, Spain, Switzerland, United States)
Q-Notes

• On-line data entry and analysis tool
• Allows for continuous oversight
• Facilitates quick but thorough analysis
• Designed around analysis principles
Continue development of questions on functioning in core domains

Develop extended sets of questions on the environment and child/youth functioning are in development.

• Will be presented at the annual meeting of the WG in Bermuda in November 2011.

• A plan for further development and testing will also be presented.
Thank You