Development of Disability Measures for Surveys:  
The Extended Set on Functioning  

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Washington Group on Disability Statistics (WG), Budapest Initiative (BI) &  
United Nations Economic & Social Commission for Asia & the Pacific  
(UNESCAP)

Introduction: Measuring disability
Disability represents a complex process and is not a single, static state. It refers to the outcome of the interaction of a person and his/her environment (physical, social, cultural or legislative) and represents a measure of the negative impact of environmental factors on one’s ability to participate. The complexity of the concept has resulted in the proliferation of statistics on disability that are neither comparable nor easy to interpret. Furthermore, disability data are collected for different purposes, such as to estimate the prevalence of physical impairments or to plan for the provision of services. Each purpose elicits a different statistic and even when the intention is to measure the same concept, the actual questions used differ in ways that severely limit comparability.

Furthermore, different data collection formats require different means to collect data. For example, censuses are necessarily short, and restrictions are placed on space that in turn limits the number of questions asked to capture the construct of interest. Surveys, on the other hand, may focus broadly on aspects of health, education and/or labor practices – or may focus more specifically on, for example, disability. For surveys more time is allotted to data collection, more questions are asked and more detailed information is collected. Each format requires its own set of questions.

The development of a short set of disability questions suitable for censuses has been completed and is documented in greater detail elsewhere (see: http://www.cdc.gov/nchs/data/washington_group/meeting8/NSO_report.pdf ). This document will introduce the work of the Washington Group on Disability Statistics (WG), the Budapest Initiative (BI) and the United Nations Economic & Social Commission for Asia & the Pacific (UNESCAP) and chart the development of an extended set of disability questions for surveys that focus on functioning (ES-F).

The Washington Group on Disability Statistics (WG) chose to develop questions that would address the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family/civic life.

WG questions are designed to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources. The WG short set of questions were developed primarily for use in National Censuses or surveys focuses on topics other than disability such as labor force or living standards surveys where space for questions is limited. The WG short set of questions, structured within the framework of the International Classification of Functioning, Disability and Health (ICF), has been shown to produce
internationally comparable data [1]. It is intended that these questions will identify the majority of persons in the population who are at greater risk than the general population of experiencing limited or restricted participation in society. The questions cover six domains of functioning: seeing, hearing, walking, cognition, self care, and communication.

In 2008, the United Nations Statistical Division (UNSD) presented Principles and Recommendations for Population and Housing Censuses (2nd Revision) – a document that endorses the approach taken by the WG regarding the measurement of disability. (See: Section VI-8: Disability Characteristics pages 178-183; available online at: http://unstats.un.org/unsd/demographic/sources/census/docs/P&R_Rev2.pdf ). The WG then turned to the development of extended sets of questions for surveys.

The Budapest Initiative (BI), established 2005, is a collaboration of, among others, the World Health Organization (WHO), United Nations Economic Commission for Europe (UNECE), and Eurostat. This consortium was charged with the task of developing a short form questionnaire intended to provide the basis for the collection of comparable standardized information on population health focusing on health state for inclusion in the European Health Interview Survey (EHIS). The BI defines health state in terms of functioning in a core set of health domains; and, like the WG, the BI has based the development of its questionnaire on a conceptual framework: the ICF.

The first set of questions developed by the BI – referred to as the Budapest Initiative-Mark 1 (BI-M1) – addressed functional domains that met a specific set of criteria. These related to relevance and feasibility as well as certain measurement characteristics. The domains and questions had to be plausible and reasonable, to span the main aspects of health experienced by the population, and to be seen as significant aspects of individuals’ health. Furthermore, the parsimonious question set had to be suitable for use in health interview surveys, maintain a consistent meaning in different social contexts, and be able to demonstrate a reasonable degree of heterogeneity within the population being surveyed. BI-M1 was completed in 2007 but it was recognized that additional work was needed so that additional key domains could be included.

Background & the Development of Extended Set Questions:
In 2008, the work being conducted by the WG, the BI and UNESCAP was brought together under a common umbrella.

Work on extended sets of disability questions began with the creation of a matrix (Appendix 1) designed to be a framework to guide the development of these question sets. The columns of the matrix include a full range of functional domains (the core set of six domains covered by the short set of questions plus additional domains) and the rows describe the type of information obtained for each domain. Such as the use of assistive devices/aids, functioning with and without the use of devices/aids where applicable, age at onset of functional difficulty and the impact of the difficulty on certain life activities. Additional rows address the impact of various aspects of the environment that may influence functioning and/or participation.

Guided by the matrix, work on the first extended set of questions on functioning (ES-F) progressed as follows:
(a) the review of existing question sets already in use in other surveys (national or research) with the goal of expanding upon the six WG short set domains (vision, hearing, cognition, mobility, self care, and communication) to include additional functional domains (upper body functioning, affect, pain, and fatigue) and more information per domain (for example, functioning with and without assistance);
(b) a joint WG/BI meeting held in Washington, D.C., in July 2008, to continue to develop the extended question set;
(c) the development of a cognitive test protocol;
(d) UNESCAP/ WG training, held from 16 to 20 February 2009, in Bangkok, to train six UNESCAP countries (Cambodia, Kazakhstan, Maldives, Mongolia, the Philippines and Sri Lanka) in cognitive and field test procedures and the subsequent cognitive testing in these countries and in Canada, the United States and South Africa;
(e) WG Extended Set Analysis Workshop, held in Washington, D.C., in May 2009;
(f) the development of a field test protocol and field testing in the same six UNESCAP countries; and
(g) the presentation of results from cognitive testing and preliminary field test results to the ninth meeting of the WG in Dar es Salaam.
(h) Efforts to finalize an extended set of disability questions were presented at the 10th Meeting of the WG held in Luxembourg in November, 2010.

Work is also underway on other extended sets such as a set specifically targeted to children and one focusing on the environment.

**Question evaluation:** A notable challenge in developing survey questions to measure functioning and health state is to account for the numerous ways that respondents across differing cultures, languages and socio-economic conditions might interpret and process those questions. The challenge is further heightened because functioning is a particularly complex concept, involving numerous and varied meanings, attitudes and types of experiences across individuals and socio-cultural sub-populations. Because social context and cultural circumstances inform the way respondents interpret, consider and ultimately respond to questions, these differences can lead to systematic measurement error in survey data. Rather than interpreting differences in survey estimates as response process bias, they can be wrongfully construed as real differences in the phenomena of study.

In evaluating questions for both the BI and the WG, three large scale evaluation studies were conducted. The first study was an evaluation of the WG short set of six disability questions intended for censuses. Fifteen countries took part in this study: Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda and Vietnam. The results of this first evaluation have been published [1]. The WG extended set and the BI health state set were analyzed in two separate studies: the UNESCAP Study mentioned above, and the Granada Group Study. The Granada Group, consisting of France, Germany, Italy, Portugal, Spain, Switzerland and the US, took a somewhat different approach in looking at the same set of extended questions. While the Group collected cognitive data from qualitative interviews, and analyzed these along the same lines as the UNESCAP project, their
approach focused on the further development of question evaluation methodology and best practices in cognitive research methodology.

The following functional domains have been included in the WG ES-F: vision, hearing, mobility, cognition, affect (anxiety & depression), pain, fatigue, communication and upper body functioning. The BI-M2 includes the same domains but communication and upper body are optional. The WG ES-F also includes additional questions within some domains that are not in the BI-M2.

Based on the results of the cognitive and filed testing from both the UNESCAP region and the Granada Group, the BI has recently recommended that the BI-M2 be included in the 2014 European Health Interview Survey (EHIS) as a complete set or section. This would facilitate both international comparability on the individual domains and the computation of summary measures of health state.

The final extended question set (WG ES-F and BI-M2) is appended (Appendix 2) and results of the WG/BI/UNESCAP testing of the extended set of questions are available at: http://www.unescap.org/stat/disability/analysis/

References:

APPENDIX 1: Matrix
Washington Group/Budapest Initiative/UNESCAP Question Development

<table>
<thead>
<tr>
<th>Questionnaire Topic/Type</th>
<th>Basic Activity Domains</th>
<th>Complex Activity Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Short Set Single Questions (1)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Extended Set Multiple Questions (1)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Use of Assistive Devices Micro-E (2)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Functioning with Assistance, Micro-E</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Age at Onset</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Cause</td>
<td>Questions cognitively tested but not included on ESCAP field test</td>
</tr>
<tr>
<td>7</td>
<td>Duration</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Impact (limit ability to carry out daily activities)</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Meso-Environment (3)</td>
<td>Question Set currently under development</td>
</tr>
<tr>
<td>10</td>
<td>Macro-Environment (4)</td>
<td>To be obtained through other sources, not personal survey data collections</td>
</tr>
</tbody>
</table>

ICF Chapter Reference - Activities/Participation: ICF-1, ICF-1, ICF-3, ICF-1, ICF-1, ICF-1, ICF-1, ICF-1, ICF-1, ICF-1, ICF-1, ICF-1, ICF-1

SEVERITY is captured in response categories: no difficulty; some difficulty; a lot of difficulty; cannot do it at all

NOTES:
1. Measurement is WITHOUT the use of assistive devices or other help with the exception of VISION glasses/lenses) and HEARING (hearing aids). These are both measured WITHOUT the use of assistive devices and thus do NOT represent true measures of Capacity. Extended Set multiple questions are captured under Performance (Row 4).
2. Micro environment - technical and personal assistance that follows the person wherever they go (e.g. wheelchair, eye glasses, personal attendant). ICF Environment Chapter 1 & 3
3. Meso environment - the environment beyond the person (e.g. transportation infrastructure, accessibility, service provision at local level, attitudes of others). ICF Environment Chapters 2 & 4
4. Meso environmental questions may also be non-domain specific.
5. Macro environment - that which affects a whole country, such as policies and legislation, general societal attitudes and practices. ICF Environment Chapter 5
6. Macro-environmental questions are NOT domain specific.
7. Pain and Fatigue are not obvious functional domains (nor are they included in the ICF) however they are included here as domains that impact functioning
   a) tested and rejected one question for children / one question for adults
   b) available for special populations
   c) No mention of functioning with/without assistive devices
   d) Upper body short set question is the ADL short set question
   e) Respondents are instructed to answer according to whatever medication they are taking.

ADL (Activities of Daily Living): e.g. walking inside the home, standing from a chair, getting into and out of bed, eating, and dressing
IADL (Instrumental Activities of Daily Living): e.g. doing chores around the house, preparing meals, and managing money
Getting along with people: involves interpersonal interactions and relationships (socializing and interacting with others) and includes dealing with family, friends, persons in authority
Major Life Activities include: working inside or outside the home to earn an income and support the family or going to school and achieving educational goals
Participation in Society: includes joining in community/family gatherings, religious/civic activities and leisure/sports events
APPENDIX 2: WG/BI/UNESCAP Extended Question Set on Functioning

Washington Group - Extended Question Set on Functioning (WG ES-F)
(Version 9 November 2011)
(Proposal endorsed at the joint Washington Group / Budapest Initiative Task Force Meeting, 3-5 November 2010, Luxembourg)

Preamble to the WG ES-F:
Ext provided in [] may be used at the discretion of the country / survey organization.

Interviewer read: "Now I am going to ask you some [additional] questions about your ability to do certain activities, and how you have been feeling. [Although some of these questions may seem similar to ones you have already answered, it is important that we ask them all.]"

NOTE: The WG Short Set (WG SS) is a subset of the WG ES-F and is indicated in red.

Budapest Initiative – Mark 2 (BI-M2)
A Survey Module for Measuring Health State (Version 19 January 2011)
(Proposal endorsed by the Joint UNECE/WHO/Eurostat Task Force on Measuring Health State, at the joint Washington Group / Budapest Initiative Task Force Meeting, 3-5 November 2010, Luxembourg)

Preamble to the BI-M2:
Interviewer read: "Now I am going to ask you some [further] questions about [your/his/her] general mental and physical health. These questions deal with [your/his/her] ability to do different daily activities, as well as with how [you have/he has/she has] been feeling. [Although some of these questions may seem similar to ones you have already answered, it is important that we ask them all.]"

NOTE: The BI-M2 is a subset of the WG ES-F. BI-M2 questions are indicated with an asterisk (*) in the question set that follows.

NOTE: All questions include the following response categories: 7. Refused 9. Don’t know
VISION

VIS_1*  [Do/Does] [you/he/she] wear glasses?
   1. Yes
   2. No

VIS_2*  [Do/Does] [you/he/she] have difficulty seeing, [If VIS_1 = 1: even when wearing [your/his/her] glasses]? Would you say… [Read response categories]
   1. No difficulty
   2. Some difficulty
   3. A lot of difficulty
   4. Cannot do at all / Unable to do

[Note: This item is Question 1 in the WG Short Set.]

OPTIONAL Vision questions:

VIS_3  [Do/does] [you/he/she] have difficulty clearly seeing someone’s face across a room [If VIS_1 = 1: even when wearing [your/his/her] glasses]? Would you say… [Read response categories]
   1. No difficulty
   2. Some difficulty
   3. A lot of difficulty
   4. Cannot do at all / Unable to do

VIS_4  [Do/does] [you/he/she] have difficulty clearly seeing the picture on a coin [If VIS_1 = 1: even when wearing [your/his/her] glasses]? Would you say… [Read response categories]?
   1. No difficulty
   2. Some difficulty
   3. A lot of difficulty
   4. Cannot do at all / Unable to do

[Note: Countries may choose to replace “the picture of a coin” with an equivalent item.]
HEAR_1* [Do/Does] [you/he/she] use a hearing aid?

1. Yes
2. No

HEAR_2* [Do/Does] [you/he/she] have difficulty hearing, [If HEAR_1 = 1: even when using a hearing aid(s)]? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

[Note: This item is Question 2 in the WG Short Set.]

OPTIONAL Hearing questions (HEAR_4 and HEAR_5 are NOT considered optional on the BI_M2):

HEAR_3 How often [do/does] [you/he/she] use [your/his/her] hearing aid(s)? Would you say… [Read response categories]

1. All of the time
2. Some of the time
3. Rarely
4. Never

HEAR_4 [Do/does] [you/he/she] have difficulty hearing what is said in a conversation with one other person in a quiet room [If HEAR_1 = 1: even when using [your/his/her] hearing aid(s)]? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

HEAR_5 [Do/does] [you/he/she] have difficulty hearing what is said in a conversation with one other person in a noisier room [If HEAR_1 = 1: even when using [your/his/her] hearing aid(s)]? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do
MOBILITY

MOB_1* [Do/Does] [you/he/she] have difficulty walking or climbing steps? Would you say…
[Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

[Note: This item is Question 3 in the WG Short Set.]

MOB_2* [Do/does] [you/he/she] use any equipment or receive help for getting around?

1. Yes
2. No (Skip to MOB_4.)
7. Refused / 9. Don’t know (Skip to MOB_4.)

MOB_3* [Do/does] [you/he/she] use any of the following?

Interviewer: Read the following list and record all affirmative responses:

<table>
<thead>
<tr>
<th></th>
<th>1. Yes</th>
<th>2. No</th>
<th>7. Refused</th>
<th>9 Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Cane or walking stick?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. Walker or Zimmer frame?</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>C. Crutches?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D. Wheelchair or scooter?</td>
<td></td>
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<tr>
<td>E. Artificial limb (leg/foot)?</td>
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<tr>
<td>F. Someone’s assistance?</td>
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<td></td>
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<tr>
<td>G. Other (please specify):</td>
<td></td>
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</tbody>
</table>

MOB_4* [Do/Does] [you/he/she] have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [If MOB_2 = 1: without the use of [your/his/her] aid]? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do (Skip to MOB_6.)

[Note: Allow national equivalents for 100 metres.]

MOB_5* [Do/Does] [you/he/she] have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [If MOB_2 = 1: without the use of [your/his/her] aid]? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

[Note: Allow national equivalents for 500 metres.]
MOB_6*  [Do/Does] [you/he/she] have difficulty walking up or down 12 steps? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

If MOB_2 = 2, skip to next section.
If MOB_3 = D “Wheelchair”, skip to next section.

MOB_7  [Do/Does] [you/he/she] have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using [your/his/her] aid? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do (skip MOB_8)

MOB_8  [Do/Does] [you/he/she] have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using [your/his/her] aid? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

COMMUNICATION

COM_1*  Using [your/his/her] usual language, [do/does] [you/he/she] have difficulty communicating, for example understanding or being understood? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

[Note: This item is Question 6 in the WG Short Set.]

[NOTE: This question is OPTIONAL on the BI_M2]

COM_2  [Do/does] [you/he/she] use sign language?

1. Yes
2. No
COGNITION (REMEMBERING)

COG_1* [Do/does] [you/he/she] have difficulty remembering or concentrating? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

[Note: This item is Question 4 in the WG Short Set.]

OPTIONAL Cognition questions:

COG_2 [Do/does] [you/he/she] have difficulty remembering, concentrating, or both? Would you say… [Read response categories]

1. Difficulty remembering only
2. Difficulty concentrating only (skip to next section)
3. Difficulty with both remembering and concentrating

COG_3 How often [do/does] [you/he/she] have difficulty remembering? Would you say… [Read response categories]

1. Sometimes
2. Often
3. All of the time

COG_4 [Do/does] [you/he/she] have difficulty remembering a few things, a lot of things, or almost everything? Would you say… [Read response categories]

1. A few things
2. A lot of things
3. Almost everything
SELF-CARE

SC_1  [Do/does] [you/he/she] have difficulty with self-care, such as washing all over or dressing? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

[Note: This item is Question 5 in the WG Short Set.]

UPPER BODY

UB_1*  [Do/Does] [you/he/she] have difficulty raising a 2 liter bottle of water or soda from waist to eye level? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

UB_2*  [Do/Does] [you/he/she] have difficulty using [your/his/her] hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles? Would you say… [Read response categories]

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all / Unable to do

[NOTE: These questions are OPTIONAL on the BI_M2]
AFFECT
(ANXIETY AND DEPRESSION)

Proxy respondents may be omitted from this section, at country’s discretion.

Interviewer: If respondent asks whether they are to answer about their emotional states after taking mood-regulating medications, say: “Please answer according to whatever medication [you were/he was/she was] taking.”

ANX_1* How often [do/does] [you/he/she] feel worried, nervous or anxious? Would you say… [Read response categories]
   1. Daily
   2. Weekly
   3. Monthly
   4. A few times a year
   5. Never

ANX_2* [Do/Does] [you/he/she] take medication for these feelings?
   1. Yes
   2. No  (If “Never” to ANX_1 and “No” to ANX_2, skip to DEP_1.)

ANX_3* Thinking about the last time [you/he/she] felt worried, nervous or anxious, how would [you/he/she] describe the level of these feelings? Would [you/he/she] say… [Read response categories]
   1. A little
   2. A lot
   3. Somewhere in between a little and a lot

DEP_1* How often [do/does] [you/he/she] feel depressed? Would [you/he/she] say… [Read response categories]
   1. Daily
   2. Weekly
   3. Monthly
   4. A few times a year
   5. Never

DEP_2* [Do/Does] [you/he/she] take medication for depression?
   1. Yes
   2. No  (If “Never” to DEP_1 and “No” to DEP_2, skip to next section.)

DEP_3* Thinking about the last time [you/he/she] felt depressed, how depressed did [you/he/she] feel? Would you say… [Read response categories]
   1. A little
   2. A lot
   3. Somewhere in between a little and a lot
PAIN

Proxy respondents may be omitted from this section, at country’s discretion.

Interviewer: If respondent asks whether they are to answer about their pain when taking their medications, say: “Please answer according to whatever medication [you were/he was/she was] taking.”

PAIN_1* In the past 3 months, how often did [you/he/she] have pain? Would you say… [Read response categories]

1. Never (If “Never” to PAIN_1, skip to next section.)
2. Some days
3. Most days
4. Every day

PAIN_2* Thinking about the last time [you/he/she] had pain, how much pain did [you/he/she] have? Would you say… [Read response categories]

1. A little
2. A lot
3. Somewhere in between a little and a lot

FATIGUE

Proxy respondents may be omitted from this section, at country’s discretion.

TIRED_1* In the past 3 months, how often did [you/he/she] feel very tired or exhausted? Would you say… [Read response categories]

1. Never (If “Never” to TIRED_1, skip to next section.)
2. Some days
3. Most days
4. Every day

TIRED_2* Thinking about the last time [you/he/she] felt very tired or exhausted, how long did it last? Would you say… [Read response categories]

1. Some of the day
2. Most of the day
3. All of the day

TIRED_3* Thinking about the last time [you/he/she] felt this way, how would you describe the level of tiredness? Would you say… [Read response categories]

1. A little
2. A lot
3. Somewhere in between a little and a lot