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: https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Questions/new_WG_Implementation_Document__2_-_The_Washington_Group_Short_Set_on_Functioning__1_.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 (WG-ES).

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-M1was 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 (WG-ES) 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: 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 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) can be found at this link: https://www.washingtongroup-disability.com/question-sets/wg-extended-set-on-functioning-wg-es/ and results of the WG/BI/UNESCAP testing of the extended set of questions are available here.

References:

[1] Miller K, Mont D, Maitland A, Altman B, Madans J. Results of a Cross-National Structured Cognitive Interviewing Protocol to Test Measures of Disability. Quality and Quantity, 2011; **45(4)**:801-15.

APPENDIX 1: Matrix

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	Communi-cation	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			
2		Extended Set Multiple Questions (1)					a	a		c	a/c	a				
3	Performance	Use of Assistive Devices Micro-E (2)				Sign language										
4		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													

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

Matrix 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 WITH 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).

(3) Module on Child Functioning and Disability developed as a WG/UNICEF collaboration currently undergoing cognitive testing

(4) Meso environment - the environment beyond the person (e.g. transportation infrastructure, accessibility, service provision at local level, attitudes of others). 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. Macro-environmental questions are NOT domain specific.

(6) Affect includes aspects of psychological functioning: anxiety and depression

Short set questions

Extended set questions

Tested in WG/ESCAP project but not adopted

WG/UNICEF Module on Child Functioning and Disability currently being tested

a No questions on functioning with/without assistive devices

b Upper body short set question is the ADL short set question

c Respondents are instructed to answer according to whatever medication they 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/social/sports events