

WG 8th meeting Manila, 29 – 31 October 2008

Session 2: Background and guiding principles – extended sets

1. Introduction of background and purpose of the extended sets

Please refer to the documents presented at the 7th Meeting of the WG in Dublin (Sept 2007) for background on the proposals.

This section will reiterate the purpose of the extended sets and present the structure of the proposed sets.

The Purpose of the extended sets is to measure equalisation of opportunities which is the same as that of the Short Set for Censuses. The extended sets are to be used in surveys where there is more space to ask more questions in order to identify the target population as for the Short Set (i.e. people at risk of experiencing discrimination and disadvantage in life opportunities because of limitations in one or more basic activity domains).

When measuring disability it is important to include the following steps:

1. **Identify the population at risk**: This is done by both the Short Set in Censuses and the extended sets proposed below in surveys. The identification becomes a demographic variable just as sex, age and geographic area are currently used. The demographic variable can be used to measure disability with varying degree of detail.¹
2. **Describe the experience of disability** by the population identified as being at risk. This information is obtained by analysing the employment and education status, social inclusion, access to basic and other services, poverty, disadvantage, discrimination, etc., and the effect of different levels of environmental factors (assistive devices and personal assistants, physical and built environment, social support and attitudes, services, systems and policies) by disability status using the demographic variable (+ other variables such as age of onset, etc.).

The questions posed to measure these other aspects are either.....

- those used by the country for employment, education, etc. and not specifically part of the extended sets

OR

- those developed specifically as part of the extended sets to ensure that aspects relevant to people with disabilities are covered (e.g. use of transport) and that the response options reflect their experiences as well (e.g. ‘Why are you not working?’ – to include ‘Attitudes of employers’ together with other response options).

¹ The creation of this variable as a binary or other variable is a separate issue to be discussed in a session on methodology in future WG meetings. Furthermore, the extent to which the identification of the population at risk is comprehensive or complete is also a separate issue to be discussed.

The use of the demographic variable allows for a comparison of the experience of 'disabled' vs 'non-disabled'.

2. Matrix : Structure for moving forward

The Matrix was originally designed as a means to place the work of the WG in a larger context or perspective and was developed after the 7th WG meeting in September 2007. The matrix was used to guide the work of the Extended Sets Workgroup between the 7th and 8th meetings. In addition it provides a means of illustrating the commonalities between the WG and other initiatives that are in the process of questionnaire development.

It has now been put to use as a tool for the development of the extended question sets, providing a framework on which these sets can be built. The matrix is attached together with these documents and will be presented in more detail at the 8th WG meeting.

3. The proposed sets

The proposed sets presented here (and the actual questions in the separate document) are an outcome of the meeting held in July 2008 in Washington where a number of people from the WG Extended Sets workgroup and the Budapest Initiative attended.² The basis for the selection was made on what evidence was available from people's experiences, a review of existing ICF based surveys over the last few years, a review of results from cognitive testing undertaken for the WG Short Set and the Budapest Initiative, and deliberations during the meeting.

These sets are presented for discussion and are most certainly not final as yet. The sets will be revised based on the discussions at the 8th meeting followed by a series of cognitive and field testing at an international level. Only after that is all completed will we be nearer to the final extended sets.

In addition, the development of questions for the complex domains of civic and social participation, employment, education, and environmental factors have not been completed as yet and are aspects to work on in the next year.

a) Structure of sets (not including the Short Set): (see questions in the separate document accompanying this one). Both these sets serve to identify the population at risk.

- Expanded Short Set: this comprises the Short Set 6 questions plus single questions in two domains: learning and upper body mobility.
- Extended set: this set comprises multiple questions on the domains included in the Expanded Short Set plus additional ones (e.g. affect, pain and fatigue). It also includes aspects of the immediate (micro) environment such as use of assistive

² The following people participated in the discussions from 8 – 10 July 2008: Ken Black (ABS); Dan Mont (WB); Margie Schneider (HSRC, SA); Susan Stobert (STATCAN); Michael Wolfson (STATCAN); from NCHS: Barbara Altman, Cordell Golden, Mitch Loeb, Jennifer Madans, Kristen Miller, Julie Weeks
On conference call 10 July:
Lucien Agafitei (Eurostat), Linda Hooper (BI/UNECE), Howard Meltzer, (BI/WG, University of Leicester)

devices and medication. The use of multiple questions allows further domains to be added such as affect, pain and fatigue.

b) Cautions related to sets and questions to be discussed:

Question development:

- It has not always been possible to find information on how questions were developed nor information on how well they work or not. The WG members should provide any additional information they have to complete the picture on the questions that have been proposed or provide alternative questions based on your experiences.
- Different response sets have been proposed. These will be discussed in the 8th meeting and depending on the outcomes of those discussions the different options will be tested in the cognitive and field tests.
- The pain, affect and fatigue questions need much discussion to ensure we have the correct approach that will work across different countries. WG members' experiences in using such questions are sought both in writing before the meeting if you are not attending or during the discussions if you are attending.

General issues:

- Should we develop more detailed questions on ADLs to accommodate specifically the elderly population and possibly people with intellectual impairments and psychiatric illness? These would include more detailed questions on self care and could also include taking care of domestic activities (e.g. finding a place to live, taking care of others, doing domestic chores).
- Issues of translation – we will be discussing this in some detail at the 8th meeting to determine the potential problems with the current proposed questions.
- The link of both 'extended sets' with the Short Set needs to be considered. Should the Short Set (or Expanded Short Set) be included into the Extended Set?
- Do our 'identifying' Qs identify the full population of interest? E.g. are Qs on basic activities enough or do we need Qs on more complex domains? How many people who have limitations in complex activities DO NOT have limitations in basic activities as covered in the extended sets?