

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
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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?

...from Census to Survey:

a framework for the development of extended question sets for use on surveys

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Potential sources of disability data

- ✓ National censuses
- Specialized surveys
 - Health or disability surveys
 - Other population surveys
- Administrative data
 - Registries
 - Medical and/or insurance records

...from Census questions to Survey modules

- A new set of 6 questions on disability for use on national Censuses has been developed, tested and adopted by the Washington Group on Disability Statistics
- The next step is to look beyond Censuses and focus on surveys
- Determine how the Short Set of 6 questions can be expanded and further developed for use in disability modules in larger surveys or disability surveys

R O W	Questionnaire Topic/Type	Basic Activity Domains						Complex Activity Domains					
		Vision	Hearing	Mobility	Communication	Cognition/ remembering	New Domains	ADL/ IADL	Getting Along with People	Life Activities	Participation in Society		
Capacity	Short Set Single ?s	Shaded	Shaded	Shaded	Shaded	Shaded	Shaded	Shaded	Shaded	Shaded	Shaded	Shaded	Shaded
	Functioning without Assistance												
Performance	Use of ADL/ Micro-E												
	Functioning with Assistance												
5	Age at Onset												
6	Cause												
7	Duration												
8	Impact												
9	Meso-Environment												
10	Macro-Environment												

Upper body, Learning, Affect, Pain, Fatigue

Development along two axes

- The Short Set focuses on 6 basic activity domains: vision, hearing, walking, cognition, self care and communication
- There is a need to:
 - expand upon the set of basic domains
 - to include more basic activity domains not included among the original 6, and add complex activity domains
 - expand upon the number of questions per domain
 - use of assistive devices-technical/personal assistance
 - levels of functioning with and without assistance
 - age at onset, cause , duration, etc.
 - address environmental factors

Basic Activity Domains

- ✓ Vision
 - Upper body
 - ✓ Hearing
 - Learning
 - ✓ Mobility
 - Affect
 - ✓ Communication
 - Pain
 - ✓ Cognition
 - Fatigue
-
- ✓ Indicates part of WG short set

Complex activity domains

- ADL and IADL
 - ✓ Bathing, dressing, toileting
 - Household activities / shopping
- Getting along with people/social relations
 - Making friends / maintaining friendships
 - Interacting with strangers / persons in authority
- Life activities
 - Going to school / getting and keeping a job
- Participation in society
 - Social / Religious / Civic activities
- ✓ Indicates part of WG short set

Question Sets: Rows

- ✓ Short set:
- ✓ Capacity Row 1:
 - ✓ six single questions
 - ✓ functioning without assistance*

- Expanded short set:
- Capacity Row 1:
 - eight single questions (upper body and learning added)
 - functioning without assistance*

*with the exception of vision and hearing

Question Sets: Rows

- Extended Set A
- Capacity Row 2:
Multiple questions/functioning without assistance
- Performance Rows 3-4:
Use of technical and personal assistance
Multiple questions/functioning with assistance
- Extended Set B / Rows 5-8:
Age at onset, Cause, Duration, Impact
- Extended Set C / Row 9:
Meso-environment: beyond the person (may or may not be domain specific)

Measures of Capacity

- Ask for difficulty functioning in basic or complex activities (ADL) without the use of assistive devices or the help of others.
- With the exception of:
 - Vision: Do you have difficulty seeing, even if wearing glasses?
 - Hearing: Do you have difficulty hearing, even if using a hearing aid?
 - since limitations in these domains can often be overcome with the use of glasses or hearing aids.

Measures of Performance

- Ask for use of assistive devices: technical or personal assistance, e.g. wheelchair or personal assistant
- Ask for difficulty functioning in basic activities with the use of assistive devices or the help of others, i.e. in their current environment
- Measure functioning with all available accommodation – direct measure of the interaction of individual characteristics and the micro-environment

	Basic activity domains
Question topic	Mobility
Short set	Do you have difficulty walking or climbing steps?
Functioning without assistance	<ol style="list-style-type: none"> 1. Do you have difficulty walking 500 (100) meters on level ground – without using your aids? 2. Do you have difficulty walking up and down a flight of stairs/12 steps/a small hill – without using your aids?
Use of AD/Micro-Environment	<ol style="list-style-type: none"> 1. Do you use any aids or equipment or receive help for walking or moving around? 2. Which aid(s) do you use? E.g. a cane, walker or wheelchair, crutches?
Functioning with Assistance	<ol style="list-style-type: none"> 1. Do you have difficulty walking 500 (100) meters on level ground – even when using your aids? 2. Do you have difficulty walking up and down a flight of stairs/12 steps/a small hill – even when using your aids?
Age at onset	How old were you when you first started having difficulty walking or climbing steps?
Cause	What condition or health problem is the reason for you difficulty walking and/or climbing steps?
Duration	How long have you had your current level of difficulty walking and/or climbing steps?
Impact	How does your difficulty affect your ability to work, attend school, etc?
Meso-Environment	Is the availability/accessibility of transportation a problem for you?

Still to do:

- Develop an extended question set for Block 2: age of onset, cause, duration, and impact
 - Agree on an approach to measurement of impact
- Develop/agree upon a question set for the meso-environment
- Agree upon an approach to measuring/capturing complex activity limitations

The Matrix: as a framework for the development of the Extended Set(s)

The Matrix (refer to attached Excel document, Framework Blocks and Work plan) was originally designed as means to place the work of the WG in a larger context or perspective – both in terms of the development of extended question sets; and as a means of illustrating the commonalities among 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 can be subdivided into 4 blocks:

1. Basic activity domains (columns) by Capacity and Performance (rows)
2. Complex activity domains (columns) by Capacity and Performance (rows)
3. All domains by Age at onset, Cause, Duration and Impact
4. Environmental factors (meso and macro).

The extended sets that will be presented fall under **Block 1**. Under **Block 2**, a single ADL question is included among the WG short set – but the development of extended questions under this domain, and the other domains included under Complex activities were determined to be beyond the scope of the Workgroup – and were in many cases often included in other sections of survey questionnaires. (Exceptions are self care and domestic activities and maybe that is something to be developed as well for a further extended set)

The items in **Block 3 - Age at onset, Cause and Duration** – might refer to the level of functional difficulty or the underlying (health) condition. Deliberations at the July meeting determined that these aspects of functioning should be measured with reference to the experience of difficulty in functioning under the domain and not the underlying (health) condition.

Questions would therefore be framed:

1. **Age at onset:** How old were you when you first starting having difficulty [*in this domain*]?
2. **Cause:** What condition or health problem is the reason for your difficulty [*with this domain*]?
3. **Duration:** How long have you had your current level of difficulty [*in this domain*]?

With respect to the measurement of **Impact** (green row) and three options were considered:

1. whether this was better captured as a Row item under specific domains. For example, “How does your difficulty walking affect your ability to: work & maintain a job, or get an education or make friends...?” – meaning impact of functional difficulty on education, employment, social activities etc.

2. whether it could be captured through measurements of outcome (columns as in Block 2). For example, as the impact of basic activity difficulties on complex activities and participation. “Considering the difficulties indicated under basic activities, how much difficulty do you have in participating in *life activities*?”
3. whether it could be derived through the analysis of existing data – as the impact of Assistive devices or other Environmental factors on functioning. This would involve asking questions about employment, education and social participation without asking about impact but measuring the impact through analysis with the responses on basic activities and to the questions about use of assistive devices and personal assistance and on other environmental factors.

In the first option, direct questions about impact are asked according to the domain- it is domain specific. In the second option, impact is treated as a more general outcome. In the third option, impact is not explicitly mentioned but is derived through data analyses.

Again, our discussions in July concluded that, as a question set, **Impact** would be best handled through the analysis of functional difficulties and outcome measures taking into account use of assistive devices, meso-environmental barriers – and also through qualitative case studies, that is, option 3 above.

Block 4 includes aspects of the meso- and macro-environment.

The **meso-environment** (blue, Row 9) comprises the environment beyond the person (e.g. services & service provision, transportation, infrastructure, accessibility, attitudes of others and feelings of stigmatization).

Meso-environmental factors have been conceptualized as NON-domain specific; the questions asked in general rather than for each domain. It may, however, be appropriate for some of these meso-environment factors to be examined within the specific domain.

Questions on service provision and use will necessarily be country specific (i.e. not cross-nationally comparable, but perhaps regionally) as service provision will vary in nature and extent across countries.

This is an area for which we do not have any set questions. There are some surveys that are starting to use questions on the meso-environment. The data from these surveys should be analyzed to determine if the questions used could be included in some extended sets.

Note: people’s experience of discrimination and feelings of stigma are considered here as **meso-environmental** factors and these can be collected in surveys.

Macro-environmental (yellow Row 10) factors include national policies, legislation and general societal attitudes and practices. These are better collected through other sources and were not suited to the format of population-based surveys or other personal survey data collections.

Further notes on the table are worth highlighting here:

1. **Note a** – Row 1 – indicates that two separate single questions on **Learning** would be developed: one for children and one for adults.
2. **Note b** – under **ADL**, it was thought that extended questions could be developed for ADL for special populations (e.g. the elderly) but that for general populations they were not required as prevalence estimates are usually very low and a person identified on this domain are usually also identified on more basic domains. It remained unclear whether extended questions should be developed to capture difficulty functioning (in terms of ADL) with assistance – hence the question mark (?). (Note: OECD is keen on the use of ADL questions as an indicator of health/social need.)
3. **Note c** – at this point the choice of questions and the exact wording of questions are yet to be decided; however, it was thought that extended questions on **Cognition** (including use of assistive devices) were needed.
4. **Note d** – it may be necessary to re-order the pattern of questions, compared to other domains, in order to capture performance: use of assistive devices and functioning with assistance (refer to: Proposed sets for measuring disability)

Row	Questionnaire Topic/Type	Basic Activity Domains							Complex Activity Domains						
		Vision (1)	Hearing (1)	Mobility	Communication	Cognition/remembering	Upper Body	Learning/understanding	Affect	Pain	Fatigue	ADL/IADL	Getting Along with People	Life Activities	Participation in Society
Capacity	Short Set Single Questions (1)														
	Extended Set Multiple Questions (1)														
Performance	Use of Assistive Devices Micro-E (2)				d										
	Functioning with Assistance, Micro-E (2)				d										
5	Age at Onset														
6	Cause														
7	Duration														
8	Impact														
To be captured through analysis of outcome measures and qualitative case studies															
9	Meso-Environment (3)														
10	Macro-Environment (4)														
	ICF Chapter Reference - Activities/Participation	ICF-1	ICF-1	ICF-4	ICF-3	ICF-1.2	ICF-4	ICF-1	ICF-2	ICF-7	ICF-8	ICF-9			

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. As such, Extended Set multiple questions are captured under Performance (Row 4).

NB - SEVERITY is captured in response categories

(2) Micro environment - technical and personal assistance that follows the person wherever they go (e.g. wheelchair, eye glasses, personal attendant). [CF 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). [CF Environment Chapters 2 & 4]

Meso environmental questions may also be non-domain specific.

(4) Macro environment - that which affects a whole country, such as policies and legislation, general societal attitudes and practices. [CF Environment Chapter 5]

Macro-environmental questions are NOT domain specific.

(5) Pain and Fatigue are not obvious *functional* domains (nor are they in the ICF) however they are included here as domains

a - one question for children / one question for adults

b - available for special populations

c - choice of questions and wording to be decided

d - possible re-ordering of these questions may be necessary to capture performance: use of assistive devices and functioning with assistance