

Review of the development of the extended question set on functioning:

Mitchell Loeb (U.S.A.)

National Center for Health Statistics/

Washington Group on Disability Statistics

Status...

With the adoption, in 2006, of the Short Set of 6 disability questions for censuses, the WG began to focus on extended sets of questions suitable for population surveys or as survey supplements.

Work began in 2008 in collaboration with the Budapest Initiative (BI) and UNESCAP.

The approach...

... was to first review extant disability questions from other surveys 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).

To that end, a “Matrix” was created as a framework to guide the development of the extended question sets.

Washington Group/Budapest Initiative/UNESCAP Question Development

| Row | Questionnaire Topic/Type | Basic Activity Domains | | | | | | | | | Complex Activity Domains | | | | |
|-----|------------------------------------------------------|----------------------------------------------------------------------------|---------|----------|---------------|-----------------------|------------|------------------------|--------|--------------------|--------------------------|----------|---------------------------|-----------------------|--------------------------|
| | | Vision | Hearing | Mobility | Communication | Cognition/remembering | Upper Body | Learning/understanding | Affect | Pain | Fatigue | ADL/IADL | Getting Along with People | Major Life Activities | Participation in Society |
| 1 | Capacity Short Set Single Questions (1) | | | | | | d | a | | | | d | | | |
| 2 | Extended Set Multiple Questions (1) | | | | | c | c | | e | e | c | b | | | |
| 3 | Performance Use of Assistive Devices Micro-E (2) | | | | Sign language | | | | | | | | | | |
| 4 | Functioning with Assistance, Micro-E | | | | | | | | e | | | | | | |
| 5 | Age at Onset | | | | | | | | | | | | | | |
| 6 | Cause | Questions cognitively tested but not included on ESCAP field test | | | | | | | | | | | | | |
| 7 | Duration | | | | | | | | | | | | | | |
| 8 | Impact (limit ability to carry out daily activities) | | | | | | | | | | | ? | ? | ? | |
| 9 | Meso-Environment (3) | Question Set currently under development | | | | | | | | | | | | | |
| 10 | Macro-Environment (4) | To be obtained through other sources, not personal survey data collections | | | | | | | | | | | | | |
| | ICF Chapter Reference - Activities/Participation | ICF-1 | ICF-1 | ICF-4 | ICF-3 | ICF-1,2 | ICF-4 | ICF-1 | ICF-2 | (5) See Note below | ICF-5,6 | ICF-7 | ICF-8 | ICF-9 | |

Domains (columns)

Basic Activity Domains

- Vision
- Hearing
- Mobility
- Cognition/remembering
- Upper body
- Learning/ understanding
- Affect
- Pain
- Fatigue

Domains (columns)

Complex Activity Domains

- ADL/IADL
- Getting along with people
- Life activities
- Participation in Society

Questionnaire Topic/Type (rows)

Capacity:

- ▶ Short set questions
- ▶ Extended set – multiple questions

Performance

- ▶ Use of assistive devices (micro-environment)
- ▶ Functioning with assistance
- ▶ Age at onset, Cause, Duration
- ▶ Impact
- ▶ Meso-environment
- ▶ Macro-environment

| Row | Questionnaire Topic/Type | Basic activity domain |
|--------------------|-----------------------------------------|-----------------------|
| | | Mobility |
| Capacity | Short Set Single Questions | |
| | Extended Set Multiple Questions | |
| Performance | Use of Assistive Devices | |
| | Functioning with Assistance, Micro-E | |
| 5 | Age at Onset | |
| 6 | Cause | |
| 7 | Duration | |
| 8 | Impact | |
| 9 | Meso-Environment | |
| 10 | Macro-Environment | |
| | ICF Chapter Reference - | ICF-4 |

| Row | Questionnaire Topic/Type | Basic activity domain |
|-------------|-----------------------------------------|-----------------------|
| | | Mobility |
| Capacity | Short Set Single Questions | |
| | Extended Set Multiple Questions | |
| Performance | Use of Assistive Devices | |
| | Functioning with Assistance, Micro-E | |
| 5 | Age at Onset | |
| 6 | Cause | |
| 7 | Duration | |
| 8 | Impact | |
| 9 | Meso-Environment | |
| 10 | Macro-Environment | |
| | ICF Chapter Reference - | ICF-4 |

Additional domain specific Extended questions

Age at onset

How old were you when the difficulty walking or climbing began?

Impact

How much does your difficulty walking or climbing limit your ability to carry out daily activities?

1. Working to support you or your family?
2. Working outside the home to earn an income?
3. Going to school or achieving your education goals?
4. Participating in leisure or social activities?
5. Getting out with friends or family?
6. Doing household chores such as cooking and cleaning?
7. Using transportation to get to places you want to go?
8. Participating in religious activities?
9. Participating in community gatherings?

| Row | Questionnaire Topic/Type | Basic activity domain |
|-------------|-----------------------------------------|-----------------------|
| | | Mobility |
| Capacity | Short Set Single Questions | |
| | Extended Set Multiple Questions | |
| Performance | Use of Assistive Devices | |
| | Functioning with Assistance, Micro-E | |
| 5 | Age at Onset | |
| 6 | Cause | |
| 7 | Duration | |
| 8 | Impact | |
| 9 | Meso-Environment | |
| 10 | Macro-Environment | |
| | ICF Chapter Reference - | ICF-4 |

3/18/2013

WG-12 Bangkok, Thailand

| | Basic activity domains |
|-----------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Question topic | Mobility |
| Short set | Do you have difficulty walking or climbing steps? |
| | Do you have difficulty moving around inside your home? |
| Functioning without assistance | <ol style="list-style-type: none"> 1. Do you have difficulty walking 100 (meters/yards) on level ground, that would be about the length of one (1) football field or one (1) city block? 2. Do you have difficulty walking half a km/ a third of a mile on level ground, that would be the length of five (5) football fields or five (5) city blocks? 3. Do you have difficulty walking up or down 12 steps? |
| Probe | How much difficulty would you have going up or down those steps without using a handrail? |
| Use of AD/Micro-Environment | <ol style="list-style-type: none"> 1. Do you use any equipment or receive help for getting around? 2. Do you use any of the following? Cane or walking stick? Walker? Zimmer frame? Crutches? Wheelchair? Prothesis(es)? Someone's assistance? Other? |
| Functioning with Assistance 3/18/2013 | <ol style="list-style-type: none"> 1. Do you have difficulty walking 100 (meters/yards) on level ground, that would be about the length of one (1) football field or one (1) city block, when using your aid? 2. Do you have difficulty walking half a km/ a third of a mile on level ground, that would be the length of 5 football fields or 5 city blocks, when using your aid? 3. Do you have difficulty walking up or down 12 steps, even when using your aid? |

WG Extended Set Testing History

2008 (July): a joint Budapest Initiative/ WG meeting held in Washington, D.C., to discuss extended question set development;

✓ the development of a cognitive test protocol;

2009 (February): ESCAP/WG training, held in Bangkok, to train six ESCAP countries (Cambodia, Kazakhstan, Maldives, Mongolia, 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 (continued)

WG Extended Set Testing History

2009 (May): Washington Group Extended Set Analysis Workshop, held in Washington, D.C.

✓ the development of a field test protocol and field testing in the same six ESCAP countries; and

2009 (October): presentation of results from cognitive testing and preliminary field test results to the ninth meeting of the Washington Group in Dar es Salaam.

WG Extended Set Testing History

Coordinated data collection and joint analysis with Q-Notes

2010 Granada Group: European Cognitive Testing of Extended Set in US (English/Spanish), Spain, Germany, Switzerland, Italy, France, Portugal

2010: Training & Cognitive Testing of Extended Set in Oman.

2010/2011: ESCAP Round II Cognitive Testing in Sri Lanka, Cambodia, Philippines, Maldives, Mongolia, Kazakhstan

WG Extended Set Testing History

2010 (November): Finalization of an extended set of questions on functioning agreed upon at the 10th Meeting of the WG in Luxembourg.

2010: Extended set (functioning) added to the US National Health Interview Survey (Final version of this set appended to the NHIS in 2011).

2011 (January): The proposed extended question set on functioning (BI version) presented to Eurostat for inclusion in the European Health Interview Survey (EHIS).