Review of the development the extended question set on functioning:

An update on revisions since the 10th meeting, and a discussion of next steps

Jennifer H. Madans

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 Activities and Workplan

		Basic Activity Domains								Complex Activity Domains					
Row	Questionnaire Topic/Type	Vision (1)	Hearing (1)	Mobility	Communi- cation	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)						d	a	\times	\times		d		\times	
acity	Extended Set Multiple Questions (1)					c			c	c	c	h	\times	\times	
Perfor	Use of Assistive Devices Micro-E (2)									\times		b	\times	\times	
Performance	Functioning with Assistance, Micro-E (2)									\times					
5	Age at Onset														
6	Cause													\times	
7	Duration													\times	
8	Impact												?	?	?->
9	Meso-Environment (3)														
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 N	ote below	ICF-5,6	ICF-7	ICF-8	4 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

			Basic activity domain	
	Row	Questionnaire Topic/Type	Mobility	
	Capacity	Short Set Single Questions		
	ıcity	Extended Set Multiple Questions		
	Perfo	Use of Assistive Devices		
	Performanc	Functioning with Assistance, Micro-E		
	5	Age at Onset		
	6	Cause		
	7	Duration		
	8	Impact		
	9	Meso-Environment		
	10	Macro-Environment		
4/10/2012		ICF Chapter Reference -	ICF-4	8

		Questionnaire	Basic activity domain	
	Row		Mobility	
	Capacity	Short Set Single Questions Extended Set		
	ity	Multiple Questions		
	Performano	Use of Assistive Devices Functioning with		
	lanc	Assistance, Micro-E		
	5	Age at Onset		
	6	Cause		
	7	Duration		
	8	Impact (
	9	Meso-Environment		
	10	Macro-Environment		
4/10/2012		ICF Chapter Reference -	ICF-4	9

Additional domain specific Extended questions

Age at onset

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

Impact $\begin{bmatrix} 1\\2\\3\\4 \end{bmatrix}$

carry out daily activities?

1. Working to support you or your family?

How much does your difficulty walking or climbing limit your ability to

- 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?

		Questionnaire	Basic activity domain	
	Row	Topic/Type	Mobility	
	Capacity	Short Set Single Questions Extended Set Multiple Question		
	Performanc	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		
4/10/2012		ICF Chapter Reference -	ICF-4	11

	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	 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? 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? 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	 Do you use any equipment or receive help for getting around? 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	 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? 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. 						

ground, that would be the length of 5 football fields of 5 city blocks, when using your aid? 4/10/2012 3. Do you have difficulty walking up or down 12 steps, even when using your aid?

- 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)

- 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.

- 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

- 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).

Next Steps:

Cognitive and field testing of eventual new extended sets on environmental factors and child disability.