

...from Census to Survey:

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

NCHS USA

Washington Group on Disability Statistics

Potential sources of disability data

- ✓ National censuses
 - Specialized surveys
 - Health or disability surveys
 - Other population surveys
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...from Census questions to Survey modules

- A 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
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Washington Group/Budapest Initiative/UNESCAP Activities and Workplan

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)						d	a	X	X	X	d	X	X	X
	Extended Set Multiple Questions (1)					c			c	c	c	b	X	X	X
Performance	Use of Assistive Devices Micro-E (2)									X	X		X	X	
	Functioning with Assistance, Micro-E (2)									X	X		X	X	
5	Age at Onset												X	X	X
6	Cause												X	X	X
7	Duration												X	X	X
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 Note below		ICF-5,6	ICF-7	ICF-8	ICF-9

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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; †Same as ADL

Question Sets: Rows

- Multiple questions/functioning without assistance (Capacity – Row 2). Domains added: **mobility**, **cognition**, **upper body**, **affect pain** & **fatigue**
 - Use of technical and personal assistance (Performance – Row 3). Domains added: **vision**, **hearing**, **mobility**, **communication** & **affect**
 - Multiple questions/functioning with assistance (Performance – Row 4). Domains added: **vision**, **hearing**, **mobility** & **affect**
 - Age at onset (Row 5), Impact (Row 8) added
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Measures of Capacity

- Ask for difficulty functioning in basic actions or complex activities 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.
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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 actions 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
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Still to do:

- Develop/agree upon a question set for the meso-environment
 - Agree upon an approach to measuring/capturing complex activity limitations and impact
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