

...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

Basic Activity Domains

Complex Activity Domains

Questionnaire
Topic/Type

Vision

Hearing

Mobility

Communi-
cation

Cognition/
remembering

New
Domains

ADL/
IADL

Getting
Along with
People

Life
Activities

Participation
in Society

Short Set
Single ?s

Functioning
without
Assistance

Use of AD/
Micro-E

Functioning
with
Assistance

Age at Onset

Cause

Duration

Impact

Meso-
Environment

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

Complex Activity Domains

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Short Set
Single ?s

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without
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Upper body, Learning, Affect, Pain, Fatigue

Use of AD/
Micro-E

Technical & personal assistance: wheel chair, eye glasses, personal attendant

Functioning
with
Assistance

?

Age at Onset

Cause

Duration

Impact

Meso-
Environment

Environment beyond the person: home accommodations, transportation, service provision, attitudes of others

Macro-
Environment

Affects the entire country: policies & legislation, societal attitudes & practices

Basic Activity Domains

- ✓ Vision
 - ✓ Hearing
 - ✓ Mobility
 - ✓ Communication
 - ✓ Cognition
- Upper body
 - Learning
 - Affect
 - Pain
 - 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

1. Do you have difficulty walking 500 (100) meters on level ground – without using your aids?
2. Do you have difficulty waling up and down a flight of stairs/12 steps/a small hill – without using your aids?

Use of AD/Micro-Environment

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

1. Do you have difficulty walking 500 (100) meters on level ground – even when using your aids?
2. Do you have difficulty waling 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