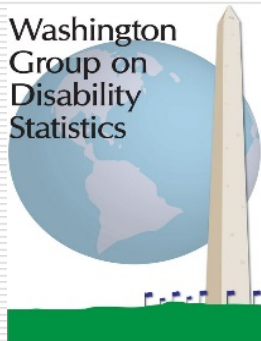


Overview of Data Collection Tools developed by the WG



Mitchell Loeb

National Center for Health Statistics, USA and
Washington Group on Disability Statistics

WG Short Set

WG Data Collection Tools: Short Set (WG-SS)

Question set that focus on measuring difficulty functioning in universal, basic activities:

- Short set on functioning adopted in 2006
 - Domains of functioning:
Seeing, Hearing, Mobility, Cognition, Self-care, Communication
 - Response categories:
No difficulty; Some difficulty; A lot of difficulty; Cannot do at all

WG Data Collection Tools: Short Set

Because of a Health problem:

- 1) Do you have difficulty **seeing** even if wearing glasses?
- 2) Do you have difficulty **hearing** even if using a hearing aid?
- 3) Do you have difficulty **walking** or **climbing** stairs?
- 4) Do you have difficulty **remembering** or **concentrating**?
- 5) Do you have difficulty with (**self-care** such as) washing all over or dressing?
- 6) Using your usual language, do you have difficulty **communicating** (for example understanding or being understood by others)?

Response categories:

No difficulty; Some difficulty; A lot of difficulty; Cannot do at all

Creation of Disability Identifiers

SPSS syntax was developed to provide guidelines for the disaggregation of outcome indicators (like access to education or employment) by disability status.

The WG-SS allows for the determination of multiple disability identifiers based on the choice of the severity threshold or cut-off.

One of these is recommended by the WG for the international reporting of disability statistics.

Disability Identifiers

DISABILITY1: the level of inclusion is at least one domain is coded *some difficulty* or *a lot of difficulty* or *cannot do at all*.

DISABILITY2: the level of inclusion is at least 2 domains are coded *some difficulty* or any 1 domain is coded *a lot of difficulty* or *cannot do at all*.

DISABILITY3: the level of inclusion is any 1 domain is coded *a lot of difficulty* or *cannot do at all*.

This is the cut-off recommended by the WG.

DISABILITY4: the level of inclusion is any one domain is coded *cannot do at all*.

Disability prevalence USA

Person with disability has:	n	%
at least 1 Domain is 'some difficulty'	7511	41.9
at least 2 Domains are 'some difficulty'	3672	19.6
at least 1 Domain is 'a lot of difficulty'	1872	9.5
at least 1 Domain is 'unable to do it'	465	2.2

WG Extended Set on Functioning

WG Data Collection Tools: Extended Sets for Adults (WG-ES-F)

Extended set on functioning for adults adopted 2010

- is comprised of about 35 questions relating to 11 core domains of functioning that were selected based on their universality and commonality across cultures and countries at various stages of economic development.
- As with the WG-SS, the domains are intended to identify those at a greater risk than the general population of experiencing restrictions in participation in an unaccommodating environment.

WG Extended Set:

- includes domains of functioning that were not in the Short Set (upper body functioning, affect, pain, and fatigue)
- includes additional information on the domains already covered by the short set;
- includes information on the use and impact of assistive devices, thereby beginning to establish a link between functioning and the environment.

The Short Set is embedded in the Extended Set.

Creation of Disability Identifiers

As with the WG-SS, analysis of the WG-ES can also produce multiple disability identifiers based on the choice of the severity threshold or cut-off.

The SPSS syntax developed, however, allows for the determination of disability identifiers using different combinations of WG-ES domains, each using the recommended cut-off for international comparisons.

Disability Identifiers

WG-SS: Short Set: six questions, six domains.

WG-ES1: Complete Extended Set: 25 questions, 11 domains

WG-ES2: Modified Extended Set (WG-ES1 MINUS Pain and Fatigue): 20 questions, 9 domains

WG-ES3: Short Set Enhanced (WG-SS PLUS Upper body, Anxiety and Depression): 12 questions, 9 domains.

Disability prevalence USA

Disability identifier based on:		n	%
WG-SS	6 questions	1872	9.5
WG-ES1	11 domains / 25 questions	3503	17.7
WG-ES2	9 domains / 20 questions	3104	15.4
WG-ES3	9 domains / 12 questions	2384	11.9

WG/UNICEF Child Functioning Module (CFM)

Challenge:

Why is measuring disability among children different from adults?

- Children are in a process of development and transition
 - not all of the 6 WG short set domains are applicable to young children
 - nor do they cover the full range of domains of particular interest in child development
- Child development does not follow a fixed schedule
 - there is natural variation in the attainment of functional skills
- Disability measurement often takes place through the filter of a parent or other adult.

Objectives

- Purpose
 - To to identify the sub-population of children (aged 2-17 years) with functional difficulties. These difficulties may place children at risk of experiencing limited participation in a non-accommodating environment.
- Aim
 - To provide cross-nationally comparable data
 - To be used as part of national population surveys or in addition to specific surveys (e.g., health, education, etc.)

Selected domains

1. Seeing*
2. Hearing*
3. Mobility**
4. Self-care (5-17)*
5. Dexterity (2-4)
6. Communication*
7. Learning (and Remembering 5-17)*
8. Emotions (5-17)**
9. Behaviour
10. Attention (5-17)
11. Coping with change (5-17)
12. Relationships (5-17)
13. Playing (2-4)

Disability Identifiers

Three levels of difficulty defined:

	Children age 2-4	Children age 5-17
Level 1: Mild to Severe	<ul style="list-style-type: none">At least 1 domain is some difficulty, a lot of difficulty or cannot do at all exceptControlling behavior: coded more or a lot more	<ul style="list-style-type: none">At least 1 domain is some difficulty, a lot of difficulty or cannot do at all exceptAnxiety and Depression: coded weekly or daily
Level 2: Moderate to Severe	<ul style="list-style-type: none">At least 1 domain is a lot of difficulty or cannot do at all exceptControlling behavior: coded more or a lot more	<ul style="list-style-type: none">At least 1 domain is a lot of difficulty or cannot do at all exceptAnxiety and Depression: coded daily
Level 3: Severe	<ul style="list-style-type: none">At least 1 domain is cannot do at all exceptControlling behavior: coded a lot more	<ul style="list-style-type: none">At least 1 domain is cannot do at all exceptAnxiety and Depression: coded daily

Field testing: Initial Results

Disability Prevalence Rate by Different Cut-offs		
	Samoa	Serbia
Level 1: Mild difficulty		
Age 2-4	15.5	9.4
Age 5-17	9.0	25.0
All Ages	10.4	22.7
Level 2: Moderate difficulty		
Age 2-4	2.9	3.8
Age 5-17	4.3	3.5
All Ages	4.0	3.5
Level 3: Severe difficulty		
Age 2-4	0.8	0.0
Age 5-17	2.4	2.2
All Ages	1.9	1.9
Number aged 2-4	2135	219
Number aged 5-17	7422	1250

Status and Next steps

- WG/UNICEF CFM adopted December 2016
- Release of interviewer guidelines and manual for implementation – 2017/2018
- Series of journal articles (submitted):
 - The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys.
 - I: Background
 - II: Question Development and Pretesting
 - III: Field testing

Analytic and Data reporting Guidelines

Analytic guidelines

- SPSS syntax for Data disaggregation
 - Other data analyses?
 - Number of domains included in disability identifier
 - Overall 'burden' of difficulties
-

Data Reporting Guidelines

- Table shells
 - Prevalence
 - Prevalence by age, gender, urban/rural
 - Domain specific prevalence
 - Prevalence by outcome: education/ employment
 - Development of a short report outline
-

Population with and without disabilities by age and sex

Geographical division, sex and age (in years)	Total	With disabilities	Without disabilities	Not stated
Total country/Urban/Rural Both sexes All ages Under 1 year 1-4 5-9 10-14 15-19 ... 95-99 100 years and over Not stated Male (age groups as above) Female (age groups as above)				

Population 5 years of age and over, by disability status, educational attainment, age and sex

Disability status, sex and age (in years)	Educational attainment					
	No schooling	Primary school	Middle school	Secondary school	Post-secondary education	Not classified/unknown
Both sexes/ Males/Females Without disabilities All ages 5-9 ... 95-99 100+ Not stated With disabilities (age groups as above)						

WG tools under development

WG Data Collection Tools: Participation

Question sets that focus on the environment and participation:

WG/UNICEF Module on Inclusive Education

- under development / at the stage of cognitive testing
- begins to address the association between environmental barriers and school participation for children with and without disabilities

Disability module for inclusion on labor force surveys

- under development in collaboration with ILO
- at the stage of cognitive testing

WG Data Collection Tools: Participation

Module on environment & participation

- under consideration
- measuring the environment indirectly through participation in selected activities: family, social and civic domains

WG Data Collection Tools: Administrative data

Development of Disability Module suitable for use on Administrative Records

- For discussion