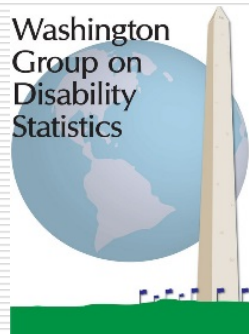


Disability Measurement and the Washington Group



Mitchell Loeb

National Center for Health Statistics, USA
and

Washington Group on Disability Statistics

Why Collect Data on Disability?

UN Convention on the Rights of Persons with Disability [UN CRPD]

Goal: Full participation of persons with disabilities

Role of Data: The information ... shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations ... to identify and address the barriers faced by persons with disabilities in exercising their rights.

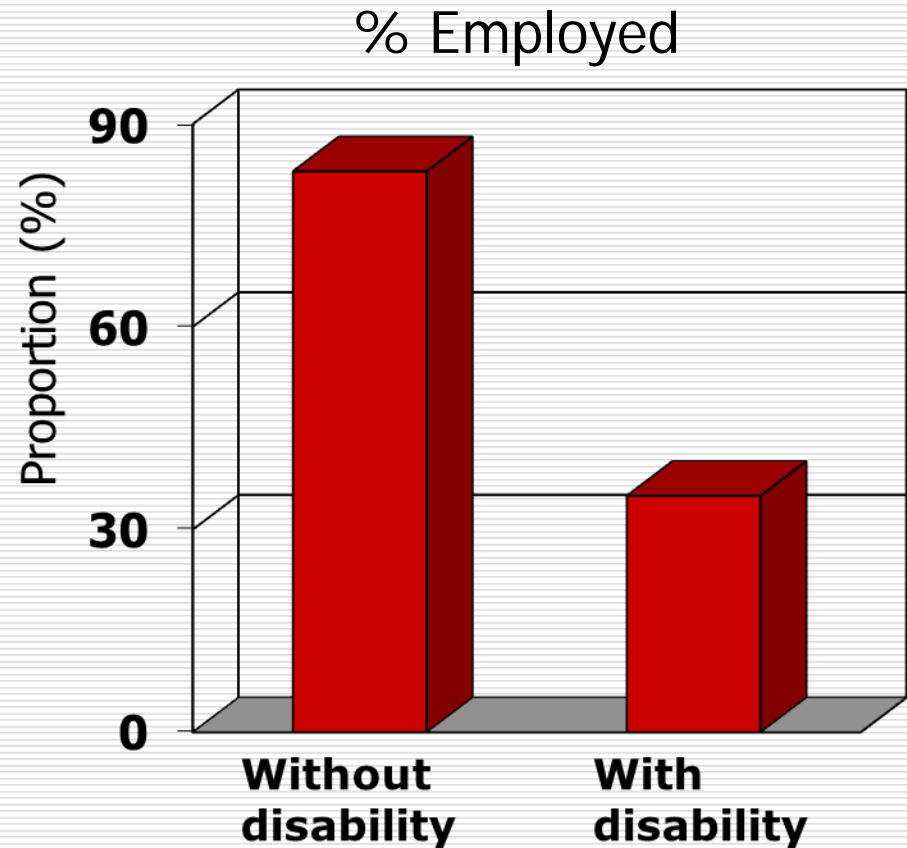
2030 Agenda on Sustainable Development: SDGs

Goal: No one left behind

Role of Data: Disaggregation of indicators

Have we met the UNCRPD and SDG Objectives?

- If bars are at equal height we have
- If bars are not at equal height we have not



How we ask questions matters!

Problematic Questions

Questions used to identify persons with disabilities on a past Census:

- | | |
|---------------------------------|--------|
| 1. Are you disabled in any way? | Yes/No |
| 2. What is your disability? | |
| Blind | Yes/No |
| Deaf / dumb | Yes/No |
| Crippled | Yes/No |
| Mentally retarded | Yes/No |

Disability prevalence = 0.9%

A medical model approach based on identifying and measuring **impairments** and affected by **stigma**.

Global Disability Prevalence Rates*

High-income countries			Low/Mid-income countries		
	Year	%		Year	%
Canada	1991	14.7			
Germany	1992	8.4	Kenya	1989	0.7
Italy	1994	5.0	Namibia	1991	3.1
Netherlands	1986	11.6	Nigeria	1991	0.5
Norway	1995	17.8	Senegal	1988	1.1
Sweden	1988	12.1	South Africa	1980	0.5
Spain	1986	15.0	Malawi	1983	2.9
UK	1991	12.2	Zambia	1990	0.9
USA	1994	15.0	Zimbabwe	1997	1.9

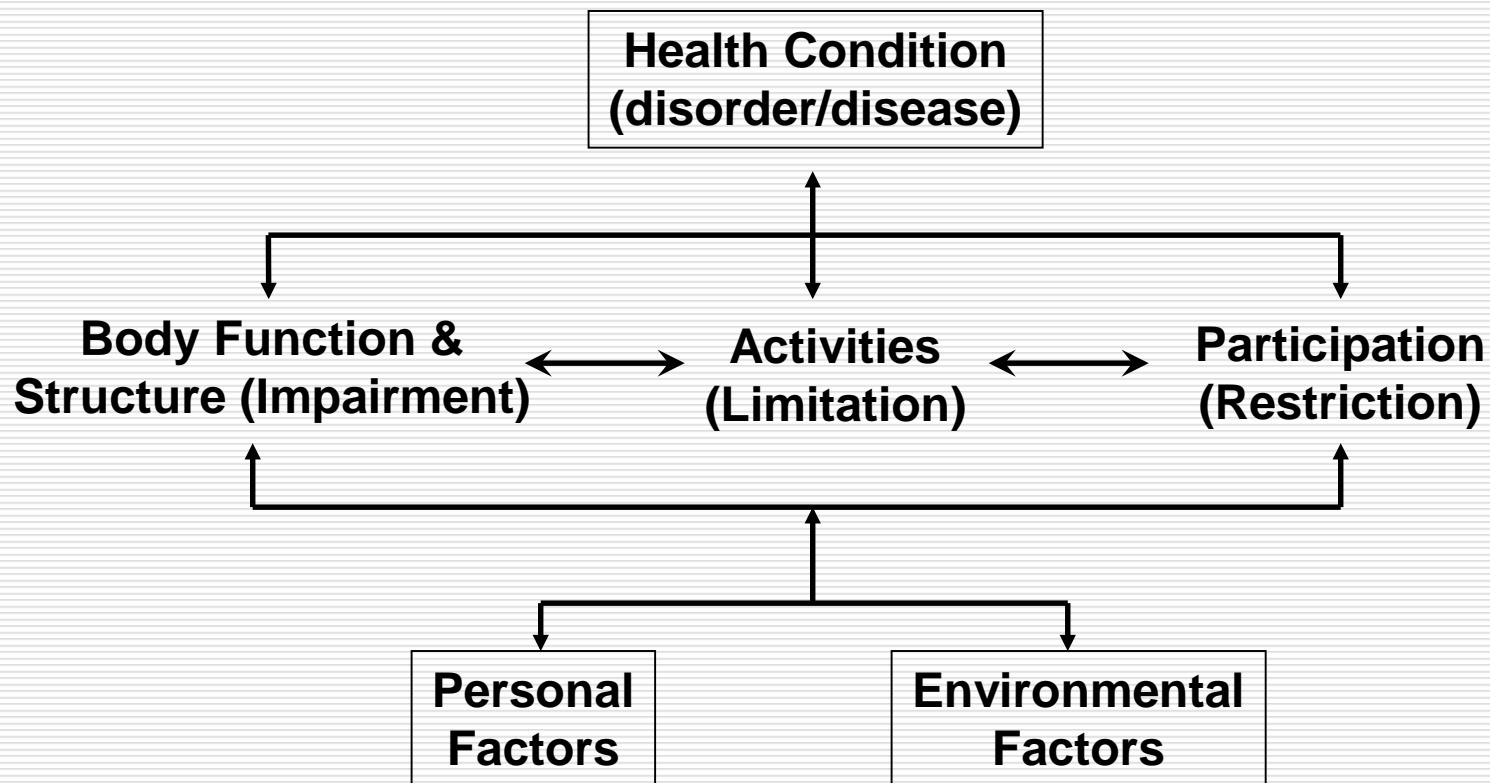
How has our Understanding of Disability Changed since the 1990s?

- Shift from a **medical model**/impairment approach → to a **social model**/human rights approach that focuses on participation and equalization of opportunities
- Focus of disability shifts from “fixing” a person with an impairment → to “fixing” the environment, focusing on accommodation and universal design

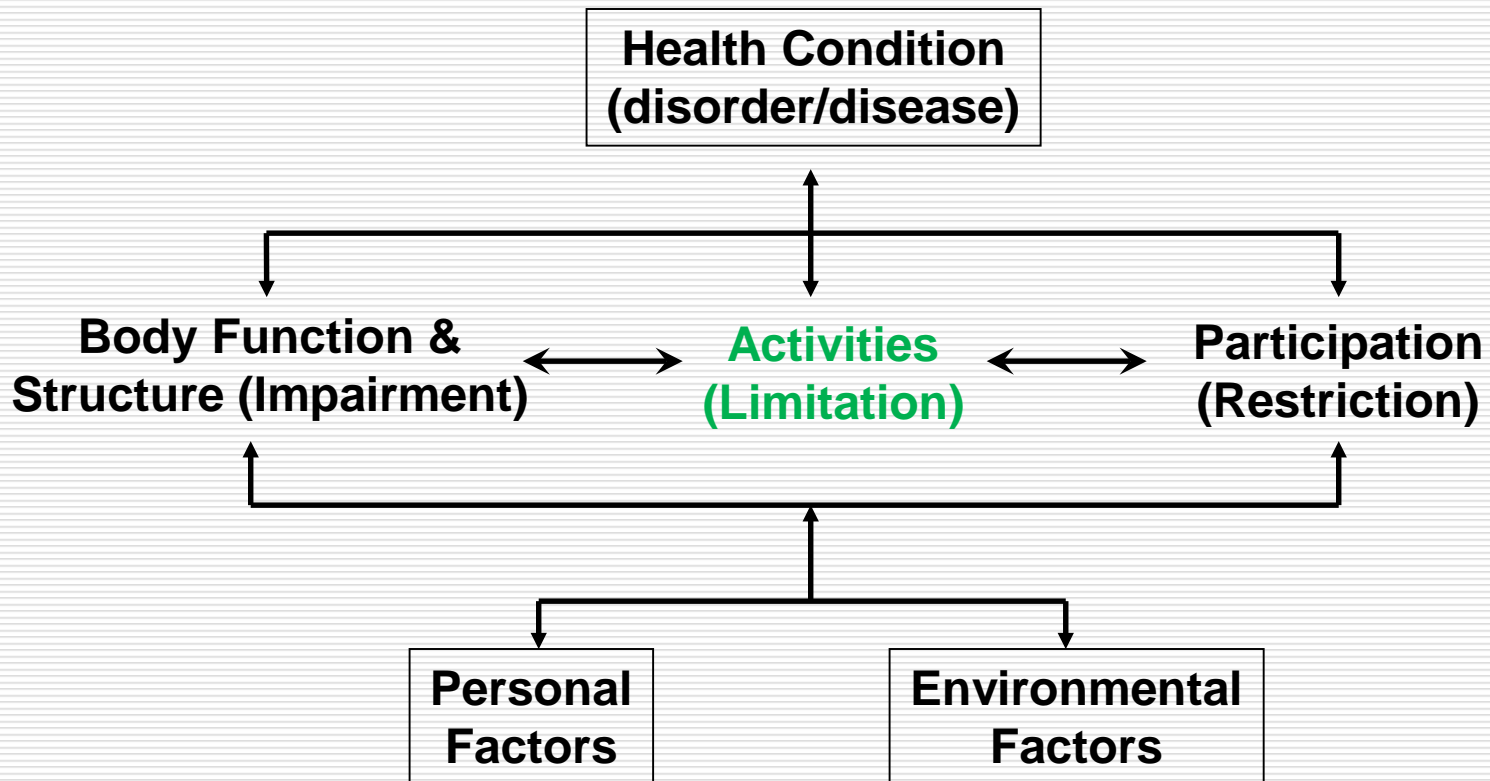
Where are we today?

- Disability conceptualized as the outcome of the interaction between a person's functional limitation (difficulties doing basic activities) and an unaccommodating environment that results in the inability to fully participate in society.
 - Not a medical diagnosis or condition
 - Not an impairment

The ICF Model - 2001



The ICF Model - 2001



'Disability' may be a complicated construct...

Disability is complex:

- incorporates a variety of different components: body functions & structure, limitations in activities (capacity) and restrictions in participation (performance), and
- includes characteristics of both the person and their environment.

The language of disability is *not* specific.

And finally, in some cultures, stigma is associated with disability – creating additional challenges to measurement and ultimately inclusion.

...but the questions used to capture 'disability' need not be complicated!

The WG defined an approach to measuring disability based on identifying those who:

- because of **difficulties** doing certain **universal, basic actions**,
- are at greater **risk** than the general population
- for **limitations in participation**.

So, the Challenge...

How to measure the broad experience of disability through:

- a limited number of questions,
- in a consistent manner,
- and in a cross-culturally comparable way?

WG Short Set on Functioning (WG-SS)

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

Defining a disability continuum and a disability dichotomy

The WG questions fulfil two specific data needs:
to describe disability data as a continuum of functioning from no difficulty to some difficulty, a lot of difficulty and unable to do at all, and

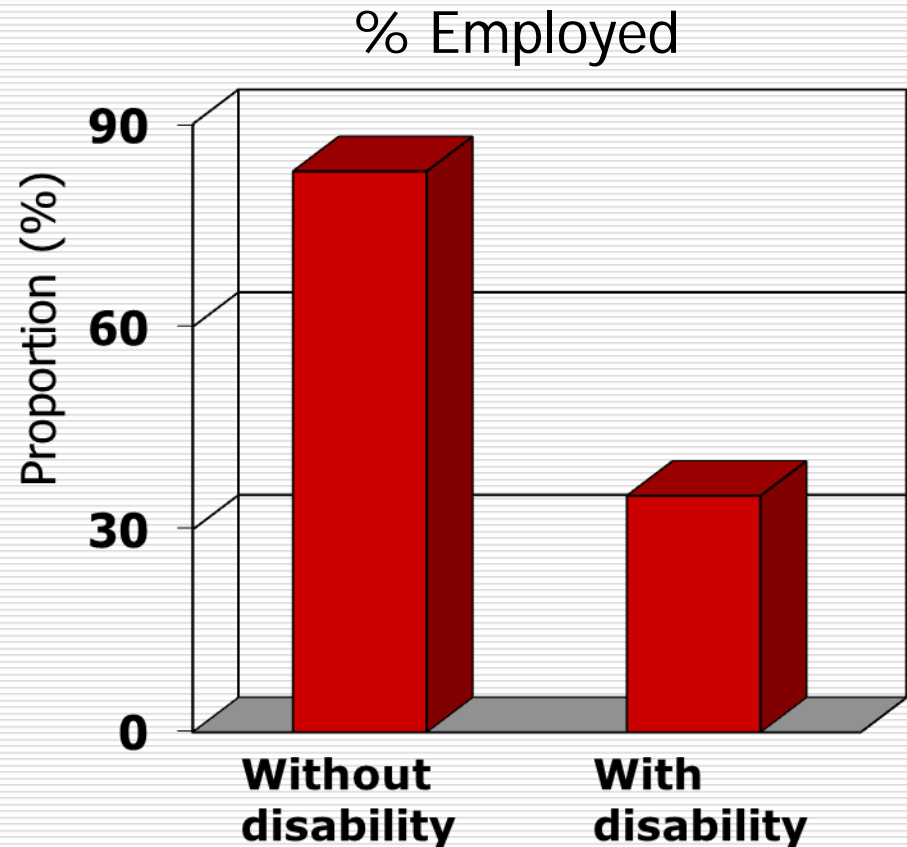
to define a cut-off (or a set of cut-offs) that can be agreed upon internationally in order to disaggregate other information (e.g. access to education, employment) by disability status

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' or 'unable to do at all'	1872	9.5
at least 1 Domain is 'unable to do at all'	465	2.2

Disaggregation by disability status

- Seeks to identify all those at greater risk than the general population for limitations in participation.
- Disability used as a **disaggregation variable**.



Disaggregation in U.S. NHIS Data

NHIS 2013, 18-64 years of age
Weighted %

Disability Status:
WG Short Set
*Cut-off = a lot of
difficulty*
in at least 1 domain

Indicator	Without Disability	With Disability
Employment Status Last Week = Working	73.5	30.8
Current Every Day Smoker	14.5	27.8
Health Insurance Coverage (yes)	79.5	81.0

WG Short Set Objectives

- Identify persons with similar types and degree of limitations in basic actions regardless of nationality or culture;
- Represent commonly occurring limitations in domains that can be captured in the census context; and
- Represent the majority (*but not all*) persons with limitations in basic actions.

Intended Use of the Data

- Compare levels of participation in employment, education, or family life for those *with* disability versus those *without* disability to see if persons with disability have achieved social inclusion.
- Monitor effectiveness of programs and policies to promote full participation.
- Monitor prevalence trends for persons with limitations in specific basic action domains.

Advantages

- Functional approach
- Tested successfully in many countries (low, middle, and high income)
- Designed to be internationally comparable
- Identifies most people with disabilities
- Can easily be added to existing censuses and surveys or to project based data
- Approximately 1.25 minutes to administer.

Limitations of WG-SS

- Not appropriate for children under age 5, and misses some children with developmental issues age 5-18
- Misses those with psychosocial issues that do not affect communication, cognition or self-care
- Does not capture age of onset
- Does not directly capture environmental barriers
- Does not address functioning with and without assistive devices

Issues of Translation

Adopting Existing Tools: Translation

Proper translation ensures:

- Cultural appropriateness
- Question constructs are adequately captured

Proper translation into the primary language(s) of the country:

- Reduces differences in question interpretation
- Increases reliability and validity of data collected

Adopting Existing Tools: Translation

Methods of translation:

- Literal: word-for-word
(forward/back translation)
- Non-literal: concept based
(team translation)
- Computer based: **No!**

Adopting Existing Tools: Translation

Translators require:

- Very good knowledge of the *source language*
- An excellent command of the *target language*
- Familiarity with the *subject matter* and the *intent* of the questions
- A sense of when to translate *literally* and when to *translate* conceptually

A competent translator is not only bilingual but bicultural.

Adopting Existing Tools: Translation

Questions AND answer categories need to be carefully translated.

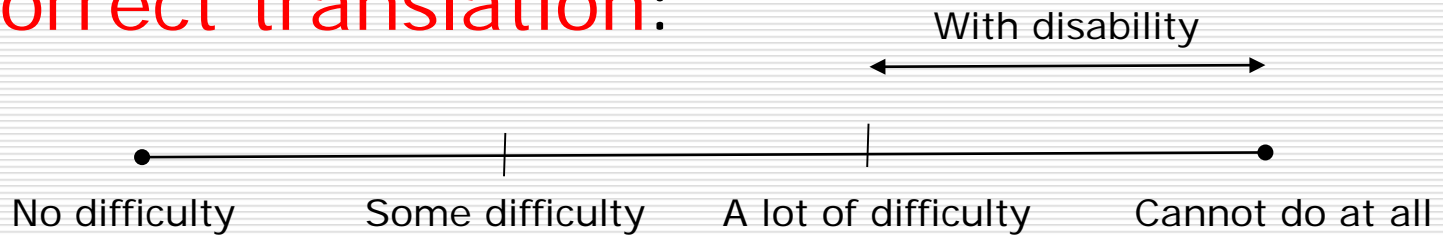
Translated questions should be **cognitively tested** prior to use in the field in order to ensure comparability to the source language [similar constructs are measured] and to fix any problems that arise with the translated versions.

Example: Response options

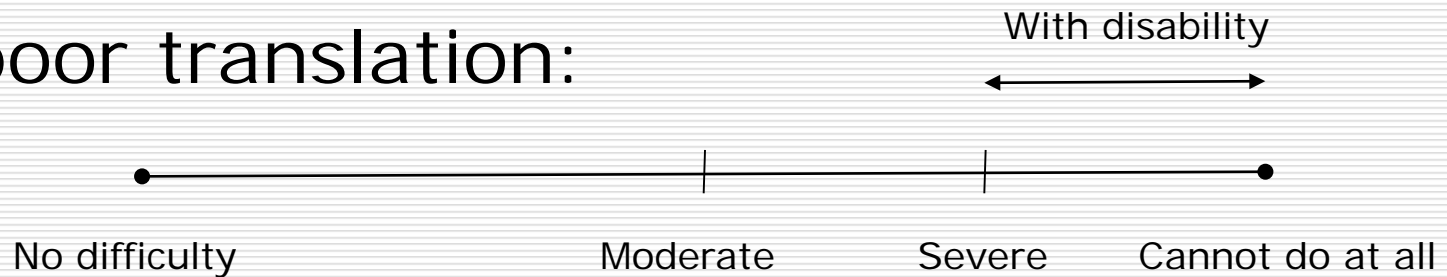
- The 4 response options describe a continuum of difficulty.
- The endpoints *no difficulty* and *cannot do at all* anchor the continuum and are probably easier to translate.
- The spread of the continuum is further defined through categories *some difficulty* and *a lot of difficulty*.
- It will be important for the translators to select descriptors of difficulty that approximate 3 equal levels of severity so as to capture the maximum amount of variation in functioning.

Visualizations of translations:

A correct translation:



A poor translation:



Mainstreaming Disability Statistics

The Path to Disaggregation

- Identify which data collection systems will be used for monitoring population-based SDG indicators.
- Include one of the Washington Group question sets in each of these data collection systems.
- Once the questions become integrated into core statistical systems:
 - Core information on disability becomes available for use by all government agencies and civil society; and
 - Disaggregating outcomes (education, employment etc.) by disability status becomes routine and sustainable.

Standardized Approach to Monitoring

- By standardizing disability data collection instruments it will be possible to provide comparable data cross-nationally for populations living in a variety of cultures;
- Data can be used to assess a country's compliance with development goals and the UN Convention on the Rights of Persons with Disabilities and, over time, improvement in meeting these goals.

SDG 8:

Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all

Employment Status disaggregated by Disability Status & Sex [15-64 years]

Country	Employment status % working			
	Males		Females	
	Without disability %	With disability %	Without disability %	With disability %
Afghanistan	82.7	71.5	60.4	42.5
Canada	78.4	51.6	72.6	49.1
Israel [20-64 years of age]	85.4	50.6	72.2	39.8
Mexico	82.8	63.7	48.4	39.8
New Zealand	82.4	41.5	72.3	37.2
Palestine	81.3	76.1	82.7	80.6
Trinidad & Tobago	69.4	18.1	49.7	13.0
Turkey	67.6	45.5	26.5	19.4
USA [18-64 years of age]	79.5	34.8	67.9	27.1
Yemen	84.3	62.5	75.4	82.0

Filling the Gaps: Other WG Tools

1. WG Extended Set on Functioning (WG-ES) (*adopted 2010*)
 - includes questions on upper body functioning and affect (anxiety and depression)
 - Collects some data on the use of assistive devices
2. UNICEF/WG Children questions (*adopted 2016*)
 - appropriate for children age 2-4 and 5-17
 - gets at full range of childhood disability
3. Environment
 - UNICEF/WG Inclusive Educational module (*final cognitive testing*)
 - ILO/WG Disability Module for Labor Force Surveys – (*adopted 2019*)
4. WG Work Group on Psychosocial Functioning and Mental Health (*under development*)

WG Extended Set on Functioning

Development and Proposed Guidelines for
Analysis

WG Extended Set:

- is comprised of about 35 questions relating to 11 different core domains of functioning.
 - 25 of the questions refer specifically to difficulty functioning
 - 10 questions relate to use of assistive technology or functioning with assistance
- As with the WG-SS, the selected domains
 - were selected based on their universality and commonality across cultures and countries at various stages of economic development,
 - and 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.

WG-ES composed of:

WG-SS: Vision, Hearing, Mobility, Cognition, Self-care, Communication (6 questions)

- Hearing Indicator (2 questions)
- Mobility Indicator (3 questions)
- Cognition Indicator (3 questions)
- Upper body Indicator (2 questions)

- Pain Indicator (2 questions)
- Fatigue Indicator (3 questions)
- Anxiety Indicator (2 questions)
- Depression Indicator (2 questions)

Going from SS to Extended set

What are the challenges going from a single question per domain to multiple questions per domain?

1. The need to create domain specific indicators for domains with more than one question.
2. The need to be able to combine multiple indicators to form a continuum of functional difficulty.
3. The need to determine the 'added value' of multiple questions and the additional domains.

Vision: Short/Extended set questions

1. Do you have difficulty seeing, even when wearing glasses? (SS)
2. Do you have difficulty clearly seeing someone's face across a room, even when wearing glasses?
3. Do you have difficulty clearly seeing a picture on a coin, even when wearing glasses?

Initial analyses using extended set questions (difficulty with near and far vision) did not create a continuum of functioning, so the questions were not included in the Extended set.

Do you have difficulty seeing, even when wearing glasses? **SS**

	Unweighted Frequency	Weighted Percent
No difficulty	13690	82.9
Some difficulty	2708	15.1
A lot of difficulty	333	1.8
Cannot do	36	0.2
Total	16767	100.0

Hearing: Short/Extended set questions

1. Do you have difficulty hearing, even when using a hearing aid? (SS)
2. Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when wearing your hearing aid(s)]?
3. Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when wearing your hearing aid(s)]?

Analyses were conducted on Q2 and Q3.

Do you have difficulty hearing, even when using a hearing aid? **SS**

	Unweighted Frequency	Weighted Percent
No difficulty	13680	82.8
Some difficulty	2753	15.4
A lot of difficulty	310	1.7
Cannot do	23	0.1
Total	16766	100.0

Difficulty hearing in a noisy room *by* quiet room

Quiet room	Noisy room				Total
	No difficulty	Some difficulty	A lot of difficulty	Cannot do	
No difficulty	11603	3373	253	8	15237
Some difficulty	94	809	388	24	1315
A lot of difficulty	0	8	138	16	162
Cannot do	0	0	0	23	23
Total	11697	4190	779	71	16737

Hearing Indicator

	Unweighted Frequency	Weighted Percent
1: low difficulty	14976	90.6
2	1156	6.2
3	404	2.2
4: high difficulty	201	1.0
Total	16737	100.0

Upper body: Short/Extended set questions

1. Do you have difficulty with self-care, such as washing all over or dressing? **SS**
2. Do you have difficulty raising a 2 liter bottle of water or soda from waist to eye level?
3. Do you have difficulty using your hands and fingers, such as picking up small objects, for example, a button or pencil, or opening or closing containers or bottles?

Note: Q2 & Q3 are used for the upper body indicator. Q1 remains the self-care indicator.

Do you have difficulty with self-care, such as washing all over or dressing? **SS**

	Unweighted Frequency	Weighted Percent
No difficulty	16029	96.2
Some difficulty	544	2.9
A lot of difficulty	114	0.6
Cannot do	68	0.3
Total	16755	100.0

Difficulty lifting 2 liter bottle *by* difficulty using hands/fingers

Amount of difficulty using hands/fingers	Amount of difficulty raising 2 liter bottle				Total
	No difficulty	Some difficulty	A lot of difficulty	Cannot do	
No difficulty	14786	309	58	44	15197
Some difficulty	782	355	51	40	1228
A lot of difficulty	98	73	51	33	255
Cannot do	9	5	7	49	70
Total	15675	742	167	166	16750

Upper body Indicator

	Unweighted Frequency	Weighted Percent
1: low difficulty	14786	89.5
2	1446	7.8
3	331	1.7
4: high difficulty	187	0.9
Total	16750	100.0

Employment status last week by upper body indicator

Weighted Column %	Upper Body Indicator				
	1	2	3	4	Total
Employment status					
not working	26.7	53.6	79.9	93.4	29.3
working	73.3	46.4	20.1	6.6	70.7

Source: NHIS 2013; n=12987; ages 18-64

Anxiety: Extended set questions

1. How often do you feel worried, nervous or anxious? (Frequency)
2. Thinking about the last time you felt worried, nervous or anxious, how would you describe the level of these feelings? (Intensity)
3. Do you take medication for these feelings?

Challenge to combining the questions into a single anxiety indicator

- Medication variable: what did taking medication for anxiety mean? Should everyone reporting medication use be considered anxious?
- Medication is an accommodation. (Prevalence of taking medication is 9.2%)
- What kind of medication are they taking?
- Are people reporting their anxiety with or without medication?

Anxiety: Frequency by Intensity

How often feel worried/nervous/anxious:

Level of feeling last time: <i>Intensity</i>	<i>Frequency</i>					Total
	Daily	Weekly	Monthly	A few times a year	Never	
Not asked	0	0	0	0	6638	6638
A little	489	887	897	3417	44	5734
In between	589	725	535	1221	16	3086
A lot	548	256	123	248	13	1188
Total	1626	1868	1555	4886	6711	16646

Anxiety Indicator

	Unweighted Frequency	Weighted Percent
1: low level	11597	70.2
2	3656	22.1
3	845	4.9
4: high level	548	2.9
Total	16646	100.0

Employment status last week by Anxiety indicator

Weighted Column %	Anxiety Indicator				
	1	2	3	4	Total
Employment status					
not working	26.0	30.8	47.7	59.4	29.3
working	74.0	69.2	52.3	40.6	70.7

K6 score by Anxiety indicator

Weighted Column %	Anxiety Indicator				
	1	2	3	4	Total
K6 score					
0-12	99.1	96.0	76.9	41.9	95.7
13-24	0.9	4.0	23.1	58.1	4.3

WG Extended set: Pain, Fatigue, Anxiety, Depression (PFAD)

		# of ?s	%
1	Pain, Fatigue, Anxiety, Depression (3/4)	9	24.9
2	Pain, Fatigue, Anxiety, Depression (4)	9	8.5
3	Pain, Fatigue (4)	5	6.5
4	Anxiety, Depression (4)	4	3.4

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5
2	SS plus <u>Hearing-indicator</u> , <u>Mobility-indicator</u> , <u>Cognition-indicator</u>	14	12.7

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5
2	SS plus <u>Hearing-indicator</u> , <u>Mobility-indicator</u> , <u>Cognition-indicator</u>	14	12.7
3	plus <u>Upper Body-indicator</u>	16	13.2

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5
2	SS plus <u>Hearing-indicator</u> , <u>Mobility-indicator</u> , <u>Cognition-indicator</u>	14	12.7
3	plus <u>Upper Body-indicator</u>	16	13.2
4	plus PFAD (4)	25	17.2

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5
2	SS plus <u>Hearing-indicator</u> , <u>Mobility-indicator</u> , <u>Cognition-indicator</u>	14	12.7
3	plus <u>Upper Body-indicator</u>	16	13.2
4	plus PFAD (4)	25	17.2
5	plus AD (4)	20	14.8

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5
2	SS plus <u>Upper Body-indicator</u>	8	10.0

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5
2	SS plus <u>Upper Body-indicator</u>	8	10.0
3	SS plus <u>Upper Body-indicator</u> plus PFAD (4)	17	14.7

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5
2	SS plus <u>Upper Body-indicator</u>	8	10.0
3	SS plus <u>Upper Body-indicator</u> plus PFAD (4)	17	14.7
4	SS plus <u>Upper Body-indicator</u> plus AD (4)	12	11.9

Defining the population with disability for disaggregation

		%
1	Short Set (SS)	9.5
2	Short Set plus Upper Body-indicator plus Anxiety and Depression at level 4	11.9

Defining the population with disability for disaggregation

			Employment Status Last Week: % working	
		Prevalence	Without disability	With disability
1	Short Set (SS)	6.6	73.5	30.8
2	Short Set plus Upper Body-indicator plus Anxiety and Depression at level 4	9.3	74.3	36.0

WG Extended set: Defining the population with disability

		# of ?s	%
1	Short Set (SS)	6	9.5
2	SS plus <u>Hearing-indicator</u> , <u>Mobility-indicator</u> , <u>Cognition-indicator</u> , <u>Upper Body-indicator</u> plus PFAD (4)	25	17.2
3	SS plus <u>Hearing-indicator</u> , <u>Mobility-indicator</u> , <u>Cognition-indicator</u> , <u>Upper Body-indicator</u> plus AD (4)	20	14.8
4	SS plus <u>Upper Body-indicator</u> + AD (4) Short Set Enhanced	12	11.9

Disability Identifiers – WG-ES

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.

WG-ES Syntax: SPSS / SAS / CPro

- SPSS: Implementation document 6a
- SAS: Implementation document 6b
<http://www.washingtongroup-disability.com/publications/implementing/>
- CPro (available upon request)

For more information about the WG visit our website:

<http://www.washingtongroup-disability.com/>

Questions:

WG_Secretariat@cdc.gov

