Mainstreaming Disability Data: The Washington Group Short Set

Washington Group on Disability Statistics

Jennifer Madans, PhD National Center for Health Statistics, USA Washington Group on Disability Statistics

UNSD Expert Group Meeting on Guidelines and Principles for the Development of Disability Statistics July 2017

The Washington Group

- City Group established by UN Statistical Commission in 2001
- Countries have ownership
 - national statistical offices of 133 countries and territories, 7 international organizations, 6 organizations that represent persons with disabilities
 - Emphasis on evidence and transparency <u>extensive testing of data collection tools in</u> <u>multiple countries</u>

The State of Disability Data

- In the past, disability data were of poor quality and varied dramatically cross-nationally.
- The Washington Group on Disability Statistics has developed and tested a variety of tools for collecting reliable, meaningful, and internationally comparable data that have been used by a growing number of countries.
- These tools can be used to monitor the UN CRPD and disaggregate the SDGs if incorporated into national statistical systems.
- Resources and training opportunities exist to support the implementation of these questions.

The Social Model of Disability

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

Washington Group Approach

- Identifying people who, because of a health condition, have difficulties with basic, universal activities that make them at greater risk than the general population for limitations in participation in an unaccommodating environment.
- Builds on the ICF framework
 - Framework is complex and needs to be deconstructed for data colletion
 - ICF codes do not translate into data collection tools

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

Testing of the WG SS

- Cognitive testing of the short set questions was carried out in 2006 in fifteen countries: Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda, Vietnam
- This was followed by field testing in five countries:

Argentina, Brazil, Gambia, Paraguay, Vietnam

 Feedback from fielding the questions in numerous countries has been used to develop implementation guidelines

Since its adoption in 2006 the WG-SS

- has been used in censuses or surveys in over 78 countries
- has been recommended as the means for collecting disability data by the UNSD and the UN ECE for the <u>2020 round of censuses</u>.
- both the US AID and UNICEF have developed disability modules that include the WG SS for their <u>Demographic and Health Surveys</u> (DHS) and <u>Multiple Indicator Cluster Surveys</u> (MICS) respectively.

Since its adoption in 2006 the WG-SS

- has been promoted by <u>international aid</u> <u>programs</u>, (DFID/UK and DFAT/Australia), as the means to collect disability data in all programs and projects
- has been endorsed or adopted for use in projects by, among others:
 - <u>UN agencies</u>: such as UNHCHR, WFP, UNICEF, ILO, UNFPA, UNESCO, UNHCR, UNDP, UN Women, UN Special Rapporteur on Disability
 - <u>International NGOs</u>: such as IDA, IDCC, Handicap International, Sightsavers, CBM
 - <u>Academia</u>: such as LSHTM, Fordham University, UCL

What can the WG SS produce?

Domain specific outputs:

 a range of functioning based on graded responses on each of the 6 domains

Overall outputs:

 a set of disability scores (based on different cut-offs) suitable for disaggregation

Prevalence (weighted %) by domain and degree of difficulty

At least:		
Some difficulty	A lot of difficulty	Unable To do it
17.1	2.0	0.2
17.2	1.8	0.1
17.0	5.7	1.8
16.8	2.1	0.1
3.8	0.9	0.3
4.8	0.7	0.2
	difficulty 17.1 17.2 17.0 16.8 3.8 4.8	Some difficultyA lot of difficulty17.12.017.21.817.05.716.82.13.80.9

02/08/2017

Source: NHIS 2013; n=16777; ages 18+

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

Monitoring the UN CRPD and SDGs through data disaggregation

WG question sets are developed:

- to collect internationally comparable data based on the ICF model
- that fulfill the monitoring requirements established by the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals.

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

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
 - Information on disability becomes available for use by all government agencies and civil society
 - <u>Disaggregating outcomes (education, employment</u> <u>etc.) by disability status becomes routine and</u> <u>sustainable</u>

Guidelines and documentation: completed, in preparation, planned

- Conceptualization and Measurement of Disability
- WG question sets Implementation Guidelines
- WG Question by Question Specifications
- Translation Protocol
- Interviewer Guidelines
- Analytic Guidelines including SPSS syntax
- Regional guide to improve disability data collection and analysis in Arab speaking countries (with ESCWA)

Beyond the WGSS:

- Extended set on functioning for adults adopted 2010
- WG/UNICEF Module on Child Functioning adopted 2016:
 - includes questions for children 2-4 and 5-17 years
- WG/UNICEF Module on Inclusive Education
- WG/ILO Disability module for inclusion on labor force surveys
- Under Development
 - Module on environment
 - Module on civic participation

Endorsements

Disability Data Disaggregation: Joint Statement by the Disability Sector

- Fourth meeting of the IAEG-SDG's, Geneva, November 2016
- Fifth meeting of the IAEG-SDG's, Ottawa, March 2017

Global Action on Disability (GLAD) Network Meeting Communiqué

• 2-3 March 2017, Berlin, Germany

Endorsements

Statistical Commission: Report on the fortyeighth session, (7-10 March 2017)

Refer to page 46 paragraph (g) (under: 48/109 Social statistics)

'The Statistical Commission...supported the use of the short set of questions on disability status developed by the WG for the purposes of disaggregation for the SDGs.'

Endorsements

Transcript from the 10th session of the Conference of States Parties to the CRPD, 13 to 15 June 2017:

New Zealand:

- statement on behalf of Argentina, Australia, Austria, Brazil, Bulgaria, Canada, Costa Rica, Dominican Republic, Finland, Iceland, Jamaica, Jordan, Norway, Panama, Poland, Spain, Tunisia, Turkey, UK, USA, and New Zealand.
- strongly recommends that the <u>WG questions to be used as a</u> tool to disaggregate data by disability, particularly in <u>household surveys and national agendas</u>.
- urges the <u>UNSD to utilize the WG-SS and recommends this</u> <u>tool to NSOs and the IAEG-SDG</u>. Delays in doing so could have detrimental consequences to the implementation processes of the SDGs which will leave persons with disabilities uncounted and behind.

The Road Ahead

Capacity building through 2018

- regional workshops
- implementation and other technical workshops

Development of guidance documents

Implications for Revised Guidelines: 1

Since the previous guidelines were finalized (2001) the WG, with a large and diverse membership, has:

- developed a suite of data collection tools that are in wide use in a variety of settings and have been endorsed by the statistical community, UN agencies and civil society for SDG disaggregation,
- developed and is developing a range of guidelines and documents regarding the collection, analysis and dissemination of disability statistics,
- received funding (DFAT, Australia) to conduct regional workshops and provide technical assistance in implementing disability data collection.

Implications for Revised Guidelines: 2

- Monitoring the SDGs and the disaggregation of SDG indicators by disability status – in a consistent and reliable manner – is a major focus for the statistical community. This must be addressed in the revised guidelines.
- The guidelines should take advantage of the work that countries have done and incorporate the approaches and materials developed by the Washington Group on Disability Statistics.

For more information about the WG visit our new website: http://www.washingtongroup-disability.com/

Questions: <u>WG Secretariat@cdc.gov</u>

