

# **Report of the Washington Group (WG) on Disability Statistics: Executive Summary of the 15<sup>th</sup> Annual Meeting**

## **Purpose**

The main objective of the WG is the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys. The aim is to provide basic necessary information on disability which is comparable throughout the world. For the primary purpose of informing policy on equalization of opportunities, the WG has developed, tested internationally, and adopted a short set of disability measures suitable for use in censuses, sample-based national surveys, or other statistical formats.

A second priority is to recommend one or more extended sets of survey items to measure disability to be used as components of population surveys or as supplements to specialty surveys. To that end, the WG has developed, tested and adopted an extended set of questions on functioning; and, in collaboration with UNICEF, is working on survey modules that address child functioning and disability as well as inclusive education. These extended sets of survey items are intended to be related to the short set of disability measures. The World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) has been used as the basic framework for the development of all questions sets. The disability measures recommended by the WG, both short and extended, are accompanied by descriptions of their technical properties, and methodological guidance is given on their implementation and their applicability to population subgroups. The WG disseminates its work products globally through the world-wide web and scientific publications.

## **Year organized**

2001

## **Participants**

Representatives of national statistical offices, international organizations, and non-government organizations including international disability organizations have participated in the last 15 meetings.

There are currently representatives from national statistical authorities in 133 countries and territories: Afghanistan, Albania, Argentina, Armenia, Aruba, Australia, Austria, Azerbaijan, Bangladesh, Barbados, Belarus, Belgium, Bermuda, Bolivia, Botswana, Brazil, Bulgaria, Burundi, Cambodia, Canada, Chad, Chile, China, Hong Kong Special Administrative Region of China, Macao Special Administrative Region of China, Colombia, Costa Rica, Croatia, Cuba, Curacao, Cyprus, Czech Republic, Democratic Republic of the Congo, Denmark, Dominican Republic, Egypt, Estonia, Fiji, Finland, France, Gambia, Georgia, Germany, Ghana, Greece, Guatemala, Hungary, India, Indonesia, Iran, Iraq, Ireland, Israel, Italy, Ivory Coast, Jamaica, Japan, Jordan, Kazakhstan, Kenya, Korea, Kosovo, Kuwait, Kyrgyz Republic, Laos, Latvia, Lebanon, Lesotho, Lithuania, Luxembourg, Malawi, Maldives, Malta, Mauritius, Mexico, Micronesia, Moldova, Mongolia, Montenegro, Monserrat, Morocco, Mozambique, Netherlands, New Zealand, Norway, Oman, Pakistan, Palestine, Panama, Papua New Guinea, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Romania, Rwanda, Saint Lucia, Saint Maarten, Samoa, Saudi Arabia, Serbia, Sierra Leone,

Singapore, Slovak Republic, Slovenia, Somalia, South Africa, Spain, Sri Lanka, Sudan, Sweden, Syria, Tanzania, Thailand, Togo, Tonga, Trinidad and Tobago, Tunisia, Turkey, Tuvalu, Uganda, United Arab Emirates, United Kingdom of Great Britain and Northern Ireland, United States of America, Uruguay, Vanuatu, Venezuela, Viet Nam, Yemen, Zambia, and Zimbabwe. In the past, Antigua and Barbuda, Bahamas, Comoros, Ecuador, Nigeria, and the Turks and Caicos Islands have also participated.

Past and present representatives of international organizations representing persons with disabilities (DPO) include the European Disability Forum, Handicap International, Rehabilitation International, the Inter-American Institute on Disability, the African Rehabilitation Institute, the International Federation for Spina Bifida and Hydrocephalus and the International Disability Alliance (IDA) and Sightsavers. Past and present representatives of national DPOs include the National Disability Authority in Ireland, Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência (CORDE) in Brazil, Secretaria Nacional para la Integración de las personas con Discapacidad (SENADIS) in Panama, Disabled Organization for Legal Affairs and Social Economic Development (DOLASED) in Tanzania, Association Pro Personas Con Paralisis del Parque in Mexico, the Puerto Rico Council on Developmental Disabilities, the Office of the Ombudsman for People with Disabilities in Puerto Rico, the National Institute on Disability and Rehabilitation Research in the United States of America, the National Union of Persons with Disabilities of Uganda (NUDIPU), Age Concern Bermuda, Bermuda Resources for the Advancement of Children with Special Needs, Bermuda Autism Support & Education, Bermuda Government - Community Rehabilitation Occupational and Physiotherapy Services, Bermuda Government - National Office for Seniors and the Physically Challenged, Bermuda Government - Human Rights Commission, Bermuda Government - Department of National Drug Control, Bermuda Society for the Blind, Bermuda Hospitals Board, ADAPT (formerly The Spastics Society of India), and the Higher Council for Affairs of Persons with Disabilities (HCD) in Jordan.

Other international organizations that have previously participated or currently participate in the Washington Group include Eurostat, the European Union Agency for Fundamental Rights (FRA), Partnership Health EU, the International Labor Organization (ILO), the Organization for Economic Cooperation and Development (OECD), the Inter-American Development Bank, the International Development Project, the World Bank, the World Health Organization (WHO), World Health Organization Family of International Classifications (WHO-FIC) Collaborating Center, the United Nations Children's Fund (UNICEF), the United Nations Economic and Social Commission for Asia and the Pacific (UN ESCAP), the United Nations Economic and Social Commission for Western Asia (UN ESCWA), the United Nations Economic Commission for Europe (UNECE), the United Nations Statistics Division (UNSD), the United Nations Department of Economic and Social Affairs (UNDESA), the Japan International Cooperation Agency (JICA), the United Kingdom Department for International Development (DFID) and the Australian Department of Foreign Affairs and Trade (DFAT).

## **Past meetings/major outcomes**

*First meeting:* Washington, D.C., 18-20 February 2002

Agreement was reached on the following: 1) it is important and possible to craft a short set/s of internationally comparable disability measures; 2) short and long set(s) of measures that are inter-related are needed; 3) the ICF model will be used as a framework in developing disability measures; and 4) census questions are the first priority.

*Second meeting:* Ottawa, 9-10 January 2003

A link was established between the purpose/s of a short measure on disability and aspects of measurement. A conceptual matrix was developed linking the purpose of a short disability measure with conceptual definitions and question characteristics. An empirical matrix was developed evaluating the characteristics of short set(s) of disability measures currently in use according to the dimensions of the conceptual matrix. Both matrices helped the WG to identify gaps in disability measurement.

*Third meeting:* Brussels, 19-20 February 2004

Since disability is multidimensional, it is not possible to identify the single “true” disabled population. Different purposes for data collection are related to different dimensions of disability or different conceptual components of disability models. Equalization of opportunities was selected as the purpose for which an internationally comparable short disability measure would be developed. A workgroup was designated to generate a draft set of questions related to this purpose. In addition, two other workgroups were formed to propose methods for implementing the short set and to propose an approach for developing extended measurement sets related to the short set. Finally, a plan for WG governance was adopted.

*Fourth meeting:* Bangkok, 29 September - 1 October 2004

Agreement was reached on the following: Conceptual agreement on a draft set of questions for the general disability measure, but wording revisions were required prior to pre-testing; a new workgroup operating in conjunction with a consultant to develop six implementation protocols for pre-testing the short set of disability measures was formed; agreement to start development of the first extended measurement set was reached; and a new workgroup on methodological issues was formed.

*Fifth meeting:* Rio de Janeiro, 21-23 September 2005

Revisions were suggested for the short measurement set, the accompanying rationale, and the implementation protocols. A new workgroup was formed to plan and implement analyses of the WG pre-tests. All results pertaining to the six WG questions will be considered by the new workgroup including the WG sponsored pre-tests, the WHO/ESCAP test, and other testing activities.

*Sixth meeting:* Kampala, 10-13 October 2006

Based on the outcomes of the pre-tests, the WG endorsed the six question set for use in censuses. The set comprises questions on four core functional domains (seeing, hearing, walking, and cognition) as well as two additional domains desired by member countries (self-care and communication). The methodological workgroup and the data analysis workgroup merged to continue the detailed analysis of the pre-test data. The workgroup on extended measures was charged with drafting a position paper on the first extended set.

*Seventh meeting:* Dublin, 19-21 September 2007

The workgroup on the short set addressed the use of the short set as a screener and presented an alternative (optional) question on upper body function. The combined workgroup on data analysis and methodological issues provided further analyses of the pre-test data presented at the 6<sup>th</sup> meeting. A large part of the 7<sup>th</sup> meeting was dedicated to a discussion of work being done on the extended set of disability questions for surveys and survey modules. The extended set workgroup would coordinate its work with the work of the Budapest Initiative, Eurostat, and UN ESCAP.

*Eighth meeting:* Manila, 29-31 October 2008

Work on the extended set continued by expanding upon the set of domains already covered in the short set, and adding supplementary questions within domains (cause, age at onset, duration). Development of the extended set was to be done in collaboration with the Budapest Initiative, Eurostat, and UN ESCAP. Methodological issues were raised during the 8<sup>th</sup> meeting concerning the development of questions for children and institutionalized populations and the use of proxy respondents. WG representatives from Canada and France volunteered to look at the work being done in the areas of children and institutionalized populations.

*Ninth meeting:* Dar es Salaam, 7-9 October 2009

The primary focus of the 9<sup>th</sup> meeting was the presentation and discussion of results from the cognitive tests and preliminary field tests results in South-East Asia. Preliminary results from the field tests in two of the participating UN ESCAP countries (Maldives and Sri Lanka) were presented. The overall conclusion was that further analysis of the field test data was required before a final decision could be made regarding the extended set of questions. It was concluded that it was beyond the scope of the WG to address the issue of dealing with institutionalized populations at that time. Two workgroups were constituted to look more closely at the measurement of child disability and the development of a set of questions on environmental factors as they relate to the measurement of disability. It was strongly recommended by the delegates, particularly those from African countries, that projects similar to the one funded by UN ESCAP in the Asia and Pacific region, also be established in other regions.

*Tenth meeting:* Luxembourg, 3-5 November 2010

The 10<sup>th</sup> meeting was held in conjunction with the Budapest Initiative Task Force on Measuring Health Status (BI). The primary focus of the meeting was to review results obtained from the 2010 round of cognitive and field testing of the extended set of questions on functioning that took place in

Europe (Granada Group) and South-East Asia (UN ESCAP). In collaboration with the BI, a final version of a question set on health state (a subset of the extended set on functioning) was submitted to Eurostat for inclusion on the European Health Interview Survey (EHIS). It was determined that the workgroups were ready to begin developing question sets designed to measure disability for children and environmental factors.

*Eleventh meeting:* Southampton, 14-16 November 2011

The WG began to monitor the use the short set in national data collections (censuses and surveys). Preliminary analyses of data provided by countries using the short set questions were presented. It was agreed to prepare reports for publication on the use of the WG short set (and other measures of disability) and the impact of wording changes to the standard set. Preliminary findings from analyses of the WG extended set of questions on functioning using data obtained from the US National Health Interview Survey (NHIS) were also presented at the meeting.

The children's workgroup presented a well-received proposal for the development of the extended set for children including a conceptual framework and examples of how the framework could be operationalized. A formal collaboration was arranged between the WG and UNICEF to work on the development of specific question modules designed to measure disability among children. The workgroup investigating environmental factors also presented their work consisting of a conceptual framework and related questions sets.

*Twelfth meeting:* Bangkok, 23-25 October 2012

Results from further analysis of data provided by countries using the WG short set in recent national data collections (censuses and surveys) were presented. Using data from the 2010/11 NHIS, results using a mixed-method approach to assess validity and cross-subgroup comparability of the WG extended set of questions on functioning (ES-F) were presented. The workgroup investigating environmental factors and participation provide an update on their work including a review of the conceptual framework and related questions sets.

The workgroup (in collaboration with UNICEF) on the development of specific question modules designed to measure disability among children presented a review of the conceptual framework for question development and a proposed set of questions.

*Thirteenth meeting:* Amman, 29-31 October 2013

Results from the continued analysis of data provided by countries using the WG short set in recent national data collections (censuses and surveys) were presented. Using data from the 2010 and 2011 NHIS, results from further analysis of the WG extended set of questions on functioning (ES-F) were presented. Analyses addressed how best to combine information from several questions per domain and develop standards for determination of cut-points.

The workgroup on the development of question modules designed to measure disability among children presented the work accomplished in the previous year as part of its collaboration with UNICEF. Results of cognitive testing that was completed in Oman, Belize, India, Montenegro and

USA; and a revised Module on Child Functioning and Disability based on these findings were presented.

The representative from UNICEF presented for review work that has begun on measuring facilitators and barriers to school participation and a work plan for the development of guidelines and accompanying documentation for the modules developed in collaboration with the WG.

There was a presentation on whether and how issues related to mental health could be incorporated into the work of the WG. A proposal was made to create a workgroup to further address this issue. Interest was expressed in having the WG look into the use of data registers in the compilation of disability statistics. A call was made to see if there is interest in setting up a workgroup on this topic.

*Fourteenth meeting: Buenos Aires, 8-10 October 2014*

Final results from the analysis of data provided by countries using the WG short set in recent national data collections (censuses and surveys) were presented. Although countries continue to report disparate disability prevalence rates; with some exceptions, those that use the WG as intended, using a cut-off of least one domain that is coded as a lot of difficulty or cannot do it at all, have reported disability prevalence rates that are comparable – in the range 7 – 10%.

Further analyses of the WG extended set of questions on functioning (ES-F) were presented using 2010 and 2011 NHIS data. Algorithms for combining multiple domain questions into single domain indicators of disability and developing standards for determination of cut-points were presented. A small workgroup was formed to finalize the analysis for the outstanding domains.

The workgroup on the development of question modules designed to measure disability among children presented the work accomplished in the previous year as part of its collaboration with UNICEF.

Recent work on measuring facilitators and barriers to school participation was also presented. Work to develop a survey module for cognitive and field testing will begin in 2015

The workgroup investigating the development of measures specific to mental health presented a review of a background document that had been drafted describing the global impact of mental health disorders; a brief review of the measures that are commonly used; and some examples of countries that collected data on mental health. The delegates agreed that the workgroup should continue its review of existing measures before attempting to develop new measures and provide a status update at the next WG meeting.

In response to the call sent following the thirteenth meeting, a representative from the Aruba Central Bureau of Statistics expressed interest in setting up a workgroup to explore the use of data registers in the compilation of disability statistics. Two representatives from the Saudi Disability Registry Group (SDRG) presented on their experience in attempt to develop a national disability registry in Saudi Arabia. The delegates agreed that the workgroup should continue its efforts and provide a status update at the next meeting.

## **Report of the Fifteenth meeting: 27-29 October 2015 in Copenhagen, Denmark**

The 15<sup>th</sup> meeting was hosted by Statistics Denmark. The meeting was attended by 72 persons;

- 32 representing national statistical authorities from 23 countries (Albania, Australia, Austria, Botswana, Brazil, Canada, China – Hong Kong SAR, Denmark-7, Hungary-2, Ireland, Italy-2, Kenya, Kosovo, Latvia, Mexico, Mongolia, Oman, Palestine, Romania, South Africa, Spain, Sweden, Uganda-2 );
- 15 representatives from universities or national institutes of public health or other national research bodies or ministries (Brazil-2, Denmark,-3 Finland, France, Ireland, Morocco, South Africa, Turkey-2, United Kingdom-3);
- 4 representatives from the US National Center for Health Statistics (WG Secretariat);
- 13 representatives from organizations representing persons with disabilities (Danish Institute for Human Rights-2, Disabled People’s Organization Denmark-3, Handicap International-2, Higher Council for Affairs of Persons with Disability (Jordan), International Disability Alliance, National Rehabilitation Center for Persons with Disabilities (Japan), Sightsavers-2, Swedish Institute for Participation); and
- 8 representatives from international organizations (DFAT, DFID, Eurostat, ILO, JICA, UN DESA/UN Secretariat of the CRPD, WHO-FIC Collaborating Center - Netherlands)

Objectives for the 15<sup>th</sup> WG meeting were to:

- Provide an update on the analysis of the WG short and extended sets of questions and approve guidelines for analyzing data obtained from the WG extended set on functioning
- Present additional work on the UNICEF/WG Module on Child Functioning
- Review progress in the development of module on inclusive education
- Present work on the development of disability modules on labor force surveys
- Review progress in developing an extended set of questions on environmental factors and participation
- Present progress in work on measures specific to mental health
- Review recent international activities in disability statistics, including the use of outcome indicators for monitoring the UN Convention on the Rights of Persons with Disabilities (CRPD) and attainment of the Post 2015 Sustainable Development Goals (SDGs)
- Approve work plan

### WG Short Set and Extended Set on Functioning

The extended set of disability questions on functioning (ES-F) were added to the US National Health Interview Survey (NHIS) beginning in 2010. During the past year, analyses of individual domains were finalized using data from the 2010 and 2013 NHIS. A review of the algorithms developed for combining multiple domain questions into single domain indicators of disability and the standards for determination of cut-points were presented. The presentation was followed by a discussion of the proposed algorithms and cut-points for each domain. The delegates agreed on the completed domains and identified certain domains that required some slight modifications or further analysis. A small workgroup will finalize the analysis for the outstanding domains. All analyses will be

compiled and presented in a document describing the properties of individual domains of functioning. The document will also include examples of various cut-points that can be used to estimate disability prevalence rates and provide a recommendation for the cut-point to use for internationally comparable reporting.

### Methodological Issues

#### Child Functioning (formerly: Child Functioning and Disability)

The workgroup on the development of specific question modules designed to measure functioning and disability among children presented the work accomplished in the previous year as part of its collaboration with UNICEF. A review of past and recent work on the development of the module was presented. The Module on Child Functioning was included as part of a Demographic and Health Survey in Samoa. Findings from preliminary analyses of the Samoan data were presented. Further analysis of the Samoan data and data collected from additional field testing of the module will be used to inform the development of guidelines for producing statistics on children with disabilities. The workgroup has also been working with UNICEF to develop a user's manual to accompany the Module on Child Functioning. The manual will provide background information on the development of the module, as well as technical information that will be useful for the module's implementation. Both the manual and the guidelines for analysis are expected to be finalized in 2016. The session also included a presentation by a representative from the London School of Hygiene and Tropical Medicine showing results using a pre-final version of the Module on Child Functioning in Cameroon, India and Fiji.

#### Inclusive Education

The WG has also collaborated with UNICEF on the development of a module designed to measure facilitators and barriers to school participation. An update on the work accomplished in the past year, including the presentation of sample questions from the current version of the module were presented. Cognitive testing of the UNICEF/WG Module on Inclusive Education was carried out in the United States by the Question Design Research Laboratory (QDRL) at the National Center for Health Statistics (NCHS) in 2015. Results from the cognitive tests will be used to inform revisions to the module. Additional cognitive testing and field testing of the revised module are scheduled to take place in 2016. The final module is expected to be ready by the next WG meeting.

#### Labor Force Surveys

The WG has recently began a collaboration with the International Labor Organization (ILO) and University College of London on the development of a disability module intended for use in labor force surveys. A representative from ILO provided a presentation describing the current practices used for collecting information on disability in labor force surveys and explaining the need for the development of a module to collect information on the barriers people with disabilities face in the labor market. The session also included a presentation by a representative from the Leonard Cheshire Disability and Inclusive Development Centre at University College of London. The



presentation included a review of the development of proposed module and provided examples of some of the questions that have been drafted. The module will include sections on barriers to participation in the labor force, workplace accommodations, social attitudes and social protection. The QDRL at NCHS is scheduled to conduct cognitive testing of the module in the United States in 2016. Revisions will be made based on the cognitive test results; followed by cognitive and field testing in additional countries.

## Mental Health

The workgroup investigating the development of measures specific to mental health, currently led by the representative from South Africa, presented the work accomplished in the previous year. The presentation included a review of some of the issues related to developing measures specific to mental health including: a brief description of the global impact of mental, neurological and substance abuse disorders; definitions of two general classifications of mental disorders (severe and common); and citing some examples of existing measures used to collect data on mental health. The presentation also included review of the proposed next steps for the workgroup. A systematic review of existing questions on activity limitations, participation restrictions and environmental barriers commonly associated with common and severe mental disorders is planned. The workgroup will also examine the existing WG questions to determine the extent to which they address the measurement of activity limitations and participation restrictions commonly associated with severe and common mental disorders. A status update will be provided at the next WG meeting. The workgroup has been operating with contributions from a small number of members and the representative from South Africa serving as the interim chair. At the conclusion of the session, a call was made for the participation of additional members and a volunteer to co-chair the workgroup. A representative from the Italian National Institute of Statistics (ISTAT) agreed to co-chair the workgroup along with the representation from South Africa.

## Environmental Factors and Participation

Following the ninth WG meeting in Dar es Salaam, a workgroup was formed to look more closely at the development of a set of questions on environmental factors as they relate to the measurement of disability. An evaluation of the available approaches and questions were presented at subsequent meetings. Work on the development of questions on environmental factors and participation was revisited at the meeting in Copenhagen. A presentation was provided by a representative from the WG Secretariat on behalf of the workgroup chair. The presentation included a review of the purpose for developing the question set as well as an overview of two approaches that can be used to capture information about the environment: 1) directly - measuring the environment independently of the person; and 2) indirectly - measuring the environment through the person's participation in selected activities. The major challenges associated with each approach and sample questions were also provided. The presentation was followed by a discussion of the next steps for the workgroup. The delegates in attendance were asked to provide feedback on the approach the workgroup should follow, the specific-activity domains to be covered and the types of questions that should be included. The delegates agreed that the workgroup should follow the strategies adopted by the workgroups developing questions on inclusive education and labor force participation. It was agreed to proceed with measuring the environment indirectly through the person's participation in selected

activities. The workgroup was asked to write up the proposal and draft a set of questions for one domain to illustrate the approach for discussion at the next meeting.

### Frameworks for Indicators to Address Monitoring Disparities by Disability Status

The meeting in Copenhagen included a session focusing on the development of outcome indicators that can be used to measure the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) and attainment of the Post 2015 Sustainable Development Goals (SDGs). The session opened with a discussion led by the chair of the WG Steering Committee on the use of the WG short set questions in population censuses and surveys for the purpose of data disaggregation by disability status. A representative from the Danish Institute for Human Rights provided a presentation on their work with the Danish Social Research Institute to develop a set of 10 statistical outcome indicators (Gold Indicators) that correspond with 10 key elements from the UN CRPD. The goal of the project is to develop a tool that can be used to monitor the implementation of the UN CRPD in Denmark and also inspire organizations in other countries to take on similar initiatives.

The session also included a presentation describing the implementation of the Incheon Strategy in UN Economic and Social Commission for Asia and the Pacific (ESCAP) countries. The Incheon Strategy was launched in November 2012 and is based on 10 goals designed to help realize the CRPD. Within the 10 goals, there are 27 targets and 62 indicators to guide and monitor the implementation of the strategy. ESCAP countries are scheduled to provide status reports based on their implementation of the strategy at a regional meeting in 2017.

A presentation was provided by two representatives from Sightsavers based on their work on a disability disaggregation pilot project. The objectives of the project are to determine whether people with disabilities are accessing the services provided by Sightsavers; compile data that can be used to inform their programs; and work towards making Sightsavers projects more inclusive of people with disabilities. The project consists of two pilots: an Eye Health Project in Bhopal, India and a Neglected Tropical Disease (NTD) Project in Tanzania. The WG short set questions have been used in both pilots. Some preliminary results from analysis of the data collected in both pilots were presented. Further analyses of the data are planned and a new pilot on Mass Drug Administration for neglected tropical diseases is scheduled to take place in Ghana in 2016.

A presentation on disability indicators for the SDGs was provided by a representative from UN DESA/UN Secretariat of the CRPD. The UN Secretariat of the CRPD has been working to assist the Inter-agency and Expert Group (IAEG) on SDGs by compiling feedback from the different partners on relevant disability indicators for the SDGs. In collaboration with ILO, International Telecommunication Union (ITU), UNFPA, UN-Habitat, UNICEF, WHO, UN Special Rapporteur on the Rights of Persons with Disabilities, Disabled People's International, International Disability Alliance (IDA) and International Disability and Development Consortium (IDDC), a technical note on disability indicators for the SDGs was submitted to IAEG-SDGs in August 2015. The technical note recommended that disaggregation by disability should be carried out wherever possible and highlighted the key targets for disability indicators. A list of target areas that do not mention disability, but could benefit from disaggregation by disability status were also listed. The technical note will continue to be revised as new information is received from the partners.

At the conclusion of the session it was agreed that the chair of the WG Steering Committee would send a note to the co-chairs of the IAEG on SDGs informing them of the WG's work and encouraging the recommendation of the WG short set questions as a tool for disaggregation of the SDG indicators by disability status.

### Country Activities

The WG continues to monitor the collection of disability data internationally, and annually requests detailed information from member countries covering survey periodicity, sample size and frame, mode of data collection, language(s) used, and exact question wording along with response options. Annual reports were completed by 57 countries. To date, 41 countries have indicated that the WG short set (or some variant) was included in their most recent census and 54 countries have indicated that the short set has been pre-tested or added to a national survey. Countries were also asked whether the WG short set were included on a national survey that also collects information on school attendance, employment status and information and communications technology (ICT). This information will be used to respond to future data requests. The format of the country report form was updated in 2015 to obtain information on the use of the extended set of questions on functioning. Responses were received from 5 countries indicating that the extended set (or a subset) have added to a national survey.

Individual country activities were presented by representatives from Brazil, Denmark and Morocco. These covered, respectively, a comparison of results from the 2000 and 2010 Populations Censuses in Brazil, practical experiences from the Danish disability registry and results from the 2004 and 2014 Censuses and 2014 National Survey on Disability in Morocco.

### Collaborative Activities

A representative from the Australian Department of Foreign Affairs and Trade (DFAT) provided an overview of DFAT's collaborations with the WG, University College London, UNICEF, UN Statistics Division (UNSD) and the Australian Bureau of Statistics (ABS). DFAT has provided funding to the WG to improve the collection and analysis of disability statistics globally by strengthening the WG's capacity to broadly disseminate and provide technical assistance to support the consistent implementation of the WG's existing data collection tools; and engage in new work on measures of participation and functional limitations related to mental health. University College London will assist the WG by providing administrative and technical support for this collaboration. DFAT is also partnering with UNICEF and the WG to improve the availability, quality and use of data on children with disabilities. The funding provided by DFAT will support UNICEF's and the WG's efforts to develop the Module on Child Functioning and Disability and Module on Inclusive Education. The aim is to develop modules that will improve the data collection on children with disabilities in UNICEF's Multiple Indicator Cluster Survey (MICS) and that can be inserted into existing national data collections to provide internationally comparable data on children with disabilities. DFAT is working with the UNSD to enhance the capacity of national statistical offices to produce and disseminate quality statistics on disability for evidence-based policy making and monitoring. UNSD is planning to make an inventory of existing disability measurements and produce technical guidelines based on best practices. The funding provided to UNSD by DFAT will

also be used for the capacity building of national statistical systems to efficiently collect and generate disability statistics that can be used to formulate, implement and monitor disability inclusive development policies and programs. DFAT is also endorsing the use of the WG short set questions through the Pacific statistics strengthening program. The program aims to provide technical assistance to Pacific island countries and territories to improve their collection, analysis and dissemination of economic and social statistics. A recommendation at the recent 2020 census planning workshop to use of the WG short set questions in 2020 Pacific census.

A representative from ABS provided an overview of their collaboration with DFAT to assess the impact of transitioning from the disability questions currently used in Australia's national data collections to implementing the WG short set questions. A subset of respondents from the 2015 Australian Survey of Disability Ageing and Carers (SDAC) will be asked to complete a Supplementary Disability Survey, which will include the WG short set questions. Analysis will be conducted to compare the responses obtained using the WG questions and disability questions from the 2015 SDAC. ABS hopes to be able to present results from their analysis at the next WG meeting. ABS will also be working with DFAT to provide technical assistance to strengthen the capacity among other national statistics offices within the Pacific region.

An overview of the United Kingdom's 'Leave No One Behind' promise was presented by a representative from the United Kingdom (UK) Department for International Development (DFID). The promise was launched by UK's Prime Minister at the 2015 United Nations General Assembly and is based on 8 principles with the aim of eradicating extreme poverty and leaving no one behind. Key elements to achieving the promise include strengthening data collection activities and disability inclusion. DFID has developed a Disability Framework with the goal of becoming an authority in disability data in order to support the UK's efforts to achieve the promise. The Framework was launched by DFID in December 2014 and a progress review is currently underway. A revised Framework is expected to be launched in December 2015. Elements of the current Framework include: advocating the use of the WG questions to obtain data on disability, producing guidance on disaggregation, and advocating for disaggregation in the SDGs.

An overview of the WG's collaboration with Handicap International (HI) was provided by two representatives from HI. The presentation included a few examples of projects conducted by HI that incorporate the use of disability data and the timeline of events leading to the eventual collaboration between HI and the WG. Currently, there are plans for the WG and HI to collaborate on three proposed projects. One project involves providing training and technical support for disability data collection activities for countries in East Africa and the Andean region. Another project includes the development of a data collection tool that can be used to support evacuation efforts in emergency situations, such as earthquakes, floods and other natural disasters. The third project is the development of an e-learning module on disability data collection to support the training and capacity building efforts.

A post-meeting session on the Global Network on Monitoring and Evaluation for Disability-inclusive Development (MEDD) was led by a representative from the UN DESA/UN Secretariat of the CRPD. The session included a short presentation followed by a discussion. The MEDD Global Network is an informal group of experts, researchers and practitioners in the areas of disability policy, data and statistics, monitoring and evaluation. The Network's aim is to support the production of a UN flagship report to compile and analyze national policies, programs, best practices

and available statistics related to persons with disabilities. The proposed timeline for completion of objectives related to the development of the report was included in the presentation. The report is planned for submission to the UN General Assembly in 2018. The Network also aims to measure the progress made in addressing the relevant internationally agreed development goals and the provisions of the CRPD. The Network's partners include the WG, UN Statistics Division, WHO, UNICEF and Sightsavers.

#### Key agreements of the 15<sup>th</sup> meeting and next steps:

The WG agreed to its work plan for 2016. Among other items, the plan delegates specific responsibilities to working groups that meet throughout the year (via email and telephone conferences). Next steps for the steering committee and workgroups include:

- 1) Work on the short set questions (WG SS) and extended sets of questions on functioning (WG ES-F):
  - a) Finalize analyses of WG ES-F data from the US NHIS
  - b) Finalize guidelines for analyzing data obtained from the WG ES-F
    - Provide examples using different cut-points for estimating disability prevalence rates
    - Provide a recommended cut-point to be used reporting internationally comparable disability prevalence rates
  - c) Focus on development of strategies for implementation and dissemination of data collected using the WG questions
- 2) Work on the UNICEF/WG Module on Child Functioning:
  - a) Continue field testing and use test results to inform additional changes to the module
  - b) Continue collaboration with UNICEF to finalize a manual for implementation of the module
  - c) Present a final version of the module and manual for implementation at the 16<sup>th</sup> meeting
- 3) Work on module measuring inclusive education:
  - a) Continue collaboration with UNICEF on the development of the module including cognitive and field testing
  - b) Continue collaboration with UNICEF on the development of a manual for implementation
  - c) Present a final version of the survey module and manual for implementation at the 16<sup>th</sup> meeting
- 4) Work on the development of extended sets of questions on environmental factors and participation
  - a) Draft a report describing the different approaches for question development, including the challenges and limitations
  - b) Provide example of questions for one domain following the approach adopted by the workgroups focusing on inclusive education and labor force participation
- 5) Work on other methodological areas:

- a) Continue work on disability module for use in labor force surveys
- b) Continue work on development of measures specific to mental health

#### Objectives for the 16<sup>th</sup> WG meeting:

- Present any updates to analyses of WG Short Question Set (WG SS) and Extended Question Set on Functioning (WG ES-F)
  - Present final guidelines for analyzing data obtained from the WG ES-F
- Present additional work on the UNICEF/WG Module on Child Functioning
  - Present results from analysis of field test data
  - Present manual for implementation of the module
  - Adopt final question module
- Review progress in development of the module on inclusive education
  - Present draft module
  - Present results from analysis of cognitive test data and proposed revisions based on the tests
- Present progress in work on disability module for use in labor force surveys
- Present progress in work on measures specific to mental health
- Review progress in developing the WG Extended Set of Questions on Environmental Factors and Participation (WG ES-E/P):
  - Present paper describing the different approaches and challenges
  - Provide example of questions for one domain following the approach adopted by the workgroups focusing on inclusive education and labor force participation
- Review recent international activities in disability statistics
- Approve work plan

#### Governance issues

The 16<sup>th</sup> WG meeting is tentatively scheduled to be held in Pretoria, South Africa.

In keeping with UN guidelines, issues of gender bias and other potential sources of bias will be a consideration of all WG work.

#### **Products:**

Proceedings from the meetings (presentations and papers), reports to the UN Statistical Commission, final meeting reports, and information on upcoming meetings can be accessed through the Washington Group website, currently hosted by the National Center for Health Statistics, U.S.A. ([http://www.cdc.gov/nchs/washington\\_group.htm](http://www.cdc.gov/nchs/washington_group.htm)).

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