

Report of the Washington Group (WG) on Disability Statistics including an Executive Summary of the 19th 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 (WG-SS) 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 that can 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 for adults (WG-ES); and, in collaboration with UNICEF, a Child Functioning Module (CFM). In addition, in collaboration with UNICEF, a module on inclusive education is currently being tested to identify barriers to school participation for all children; and in collaboration with the International Labour Organization (ILO) a module on inclusive employment is being developed that will assess potential barriers to employment. These extended sets of survey items are intended to be related to the short set of disability measures. The World Health Organization's (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 19 meetings.

Current country representatives include (from national statistical offices): Afghanistan, Albania, Algeria, Anguilla, Argentina, Armenia, Aruba, Australia, Austria, Azerbaijan, Bangladesh, Barbados, Belarus, Belgium, Benin, Bermuda, Bhutan, Bolivia, Bosnia and Herzegovina, Botswana, Brazil, Bulgaria, Burundi, Cambodia, Cameroon, Canada, Cape Verde, Central African Republic, Chad, Chile, China, Hong Kong Special Administrative Region of China, Macao Special Administrative Region of China, Colombia, Republic of Congo, Costa Rica, Croatia, Cuba, Curacao, Cyprus, Czech Republic, Democratic Republic of the Congo, Denmark, Djibouti, Dominican Republic, Ecuador, Egypt, El Salvador, Estonia, Eswatini, Ethiopia, Fiji, Finland, France, Gambia, Georgia, Germany, Ghana, Greece, Guatemala, Guinea, Honduras, Hungary, India, Indonesia, Iran, Iraq, Ireland, Israel, Italy, Ivory Coast, Jamaica, Japan, Jordan, Kazakhstan, Kenya, Kiribati, Korea, Kosovo, Kuwait, Kyrgyz Republic, Laos, Latvia, Lebanon, Lesotho, Liberia, Libya, Lithuania, Luxembourg, Malawi, Malaysia, Maldives, Mali, Malta, Mauritius, Mexico, Micronesia, Moldova, Mongolia, Montenegro, Monserrat, Morocco, Mozambique, Myanmar, Namibia, Nepal, Netherlands, New Zealand, Niger, Norway, Oman, Pakistan, Palestine, Panama, Papua New Guinea, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Romania, Russia, Rwanda, St. Lucia, St. Maarten, Samoa, Saudi Arabia, Senegal, Serbia, Sierra Leone, Singapore, Slovak Republic, Slovenia, Somalia, South Africa, South Sudan, Spain, Sri Lanka, Sudan, Sweden, Syria, Tanzania, Thailand, Togo, Tonga, Trinidad and Tobago, Tunisia, Turkey, Tuvalu, Uganda, Ukraine, United Arab Emirates, United Kingdom, United States of America, Uruguay, Vanuatu, Venezuela, Viet Nam, Yemen, Zambia, and Zimbabwe. In the past, Antigua and Barbuda, Bahamas, Comoros, Nigeria, and the Turks and Caicos Islands have also participated.

Current non-government organizations include: Australian Department of Foreign Affairs and Trade (DFAT), European Disability Forum, Eurostat, Humanity & Inclusion (HI: formerly Handicap International), Higher Council for Affairs of Persons with Disabilities, Inter-American Institute on Disability, International Labour Organization (ILO), Organization for Economic Cooperation and Development (OECD), National Disability Authority-Ireland, Inter-American Development Bank (IADB), International Development Project, Japan International Cooperation Agency (JICA), Rehabilitation International (RI), United Kingdom Department for International Development (DFID), United Nations Children's Fund (UNICEF), United Nations Economic and Social Commission for Asia and the Pacific (UN ESCAP), United Nations Economic and Social Commission for Western Asia (UN ESCWA), United Nations Economic Commission of Europe (UNECE), United Nations Statistics Division (UNSD), World Bank, and World Health Organization (WHO).

Governmental Organizations of Persons with Disabilities: 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, and Disabled Organization for Legal Affairs and Social Economic Development (DOLASED) in Tanzania.

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 ascertain the single "true" disabled population. Different purposes 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 work group was designated to generate a draft set of questions related to this purpose. In addition, two other work groups 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 work group 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 work group 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 work group and the data analysis work group merged to continue the detailed analysis of

the pre-test data. The work group on extended measures was charged with drafting a position paper on the first extended set.

Seventh meeting: Dublin, 19-21 September 2007

The work group 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 work group on data analysis and methodological issues provided further analyses of the pre-test data presented at the 6^{th} meeting. A large part of the 7th 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 work group 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/s was to be done in collaboration with the Budapest Initiative, Eurostat, and UN ESCAP. Methodological issues were raised during the 8th 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 9th 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 10th meeting of the Washington Group on Disability Statistics (WG) 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 disability questions 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 Washington Group began to monitor the use the WG Short Set in national data collections (censuses and surveys). Preliminary analyses of data provided by countries using the WG Short Set and of the WG extended set of questions on functioning using data obtained from the US National Health Interview Survey (NHIS) were presented. The children's workgroup presented on the development of the extended set for children including a conceptual framework. A formal collaboration was arranged between the Washington Group 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) and from a mixed-method approach to assess validity and cross-subgroup comparability of the WG extended set using data from the 2010-11 NHIS 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) and analyses using data from the 2010 and 2011 US NHIS addressing how best to combine information from several questions per domain on the WG extended set on functioning and develop standards for determination of cut-points were presented. The WG/UNICEF workgroup on the development of specific question modules designed to measure disability among children presented the results of cognitive testing that was completed in Oman, Belize, India, Montenegro and USA and the revised Module on Child Functioning and Disability. The presentation on whether and how issues related to mental health could be incorporated into the work of the WG resulted in the creation of a workgroup to further address this. Interest was also expressed in having the WG look into the use of data registers in the compilation of disability statistics.

Fourteenth meeting: Buenos Aires, 8-10 October 2014

Final results from the analysis of data provided by countries using the WG short set showed that 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%. 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 using the WG extended set of questions on functioning were presented. A small workgroup was formed to finalize the analysis. The WG/UNICEF workgroup on disability among children and inclusive education and the workgroup on mental health presented the work accomplished in the previous. Two representatives from the Saudi Disability Registry Group (SDRG) presented on their experience developing a national

disability registry. The delegates agreed that the workgroup should continue its efforts and provide a status update at the next meeting.

Fifteenth meeting: Copenhagen, Denmark 27-29 October 2015

Proposed guidelines for analyzing data obtained from the WG Extended Set of disability questions on Functioning were discussed. A small workgroup will finalize the analysis for the outstanding domains and present results at the next meeting.

Status reports were provided by the workgroups focusing on methodological issues concerning surveys: child disability, mental health, disability module for labor force surveys, and environmental factors & participation. The child disability workgroup presented findings from preliminary analyses of data collected in a Samoan Demographic and Health Survey. The workgroup also presented results from the cognitive tests of the module on inclusive education carried out in the United States. A review of the development of a proposed disability module intended for use in labor force surveys was provided. The workgroup investigating the development of measures specific to mental health presented the work accomplished in the previous year. The meeting also included a review of recent international activities in disability statistics including the use of outcome indicators for monitoring the UN CRPD and SDGs.

Sixteenth meeting: Pretoria, South Africa 7-9 December 2016

The guidelines for analyzing data obtained using the WG Extended Set of disability questions on Functioning were finalized and approved by the delegates in attendance. The final version of the WG/UNICEF Child Functioning Module (CFM) was presented and formally adopted. Discussions included additional work in the development of the modules on barriers and facilitators to school participation (for children) and to employment (for adults). There was additional discussion of issues pertaining to measuring mental health. The next steps and future plans for the workgroups addressing these topics were discussed. The meeting also included special sessions devoted to the use of WG tools for disaggregation of the Sustainable Development Goals by disability status, and Disability Measurement in Africa.

Seventeenth meeting: Sydney, Australia 31 October – 2 November 2017

An overview of the recently revised WG website was provided at the meeting. The sessions also included a review of the best practices when implementing the WG data collection tools. Guidelines for analyzing data obtained using the WG Extended Set of disability questions on Functioning were presented and approved. The guidelines including SPSS and SAS syntax are available on the WG website. Discussions included the further development of modules on barriers and facilitators to school participation (children) and to employment (adults) as well as issues pertaining to measuring psychosocial functioning. The meeting also included special sessions devoted to regional capacity building to improve the collection and analysis of disability statistics, disability in Australia and New Zealand and measuring Disability in Asia and the Pacific region.

Eighteenth meeting: Rome, Italy 7 -9 November 2018

The World Bank representative highlighted the World Bank's commitment to disability inclusive development and outlined their plans to incorporate the WG Short Set into their Living Standards Measurement Study (LSMS). The representative from Eurostat outlined Eurostat's plans to modernize the European Social Surveys, which included integrating a subset of the WG-SS into the European

Union Statistics on Income and Living Conditions (EU-SILC) and a subset of the WG/UNICEF CFM into the European Health Interview Survey (EHIS).

A review of the revised WG website was provided, followed by an extensive discussion of potential refinements to make the website more user-friendly and the content easier to navigate. The best approaches for developing official translations of the questions sets and the supporting documents and the possibility of developing a standard template for disseminating data collected using the WG tools were also discussed.

Status updates were provided by the respective workgroups. The analysis workgroup reported on determining mutually exclusive severity categories and measurement of disability across multiple domains at different cut-offs. The workgroup focusing on child functioning outlined plans for further testing of the WG/UNICEF Inclusive Education Module in countries with an identifiable population of 'out of school' children. The workgroup on mental health and psychosocial functioning presented results from a scoping literature review on activity limitations, participation restrictions and environmental barriers commonly associated with common and severe mental disorders were also presented. The workgroup proposed a draft module based on the results of the scoping review for future cognitive testing. Preliminary results from cognitive tests in Mongolia were presented by the workgroup focusing on the development of a disability module for use in labor force surveys. Endorsement of the final module is expected at the next annual meeting (WG-19). The administrative workgroup discussed the challenges with using administrative data for measuring disability prevalence and the associated WG blog. In addition, an example of the use of the WG questions in administrative programs that collect information relevant to disability issues (e.g., education management information systems) was presented. The content of the blog and presentation will be expanded into a full article for journal submission or posted on the WG website.

Report of the Nineteenth meeting: 25 - 27 September 2019 in Buenos Aires, Argentina (WG-19):

WG-19 was hosted by the National Institute of Statistics and Census (INDEC) of Argentina.

The meeting was attended by 82 persons:

- 57 representing national statistical authorities from 24 countries (Argentina-29, Barbados, Bermuda, Belarus-2, Bhutan, Bolivia, Brazil, Cambodia-2, Costa Rica, Denmark, Ecuador, El Salvador, Fiji, Hong Kong, Italy-2, Kenya-2, Mongolia, Paraguay, Peru, Philippines-2, Russia, South Africa, Thailand, Zambia);
- 4 representatives from universities or national institutes of public health or other national research bodies or ministries (China, South Africa, United Kingdom-2);
- 4 representatives from the US National Center for Health Statistics (WG Secretariat);
- 10 representatives from non-government organizations and organizations representing persons with disabilities (Agencia Nacional de Discapacidad (Argentina)-3, Asociación Azul, Center for Inclusive Policy, Consejo Nacional de Coordinacion de Politicas Sociales (Argentina), European Disability Forum, Humanity & Inclusion, National Council on Disability (Dominican Republic), Sightsavers);
- 5 representatives from international organizations (Australian Department of Foreign Affairs and Trade (DFAT), UK Department for International Development (DFID), Economic Commission for Latin America and the Caribbean (ECLAC), International Labour Organization (ILO), Organization of American States (OAS)); and
- 2 distinguished alum former WG representatives active in disability statistics (Brazil, Peru)

Objectives for WG-19 were to:

- Seek consensus on Analysis Workgroup work-plan: creating a Disability Severity Indicator;
- Seek consensus on Data Dissemination templates;
- Discuss next steps in finalizing the Inclusive Education Module and further work on the Child Functioning Module Teacher's Version (CFM-TV);
- Endorse the use of the WG-SS and disability modules in ongoing Labor Force Surveys;
- Agree on next steps in finalizing translations;
- Agree on next steps in the development of measures of psychosocial functioning;
- Seek consensus on how/whether to move forward with use of administrative systems for disability data collection;
- Seek consensus on how/whether to move forward in other areas of the environment and participation; and
- Discuss the way forward: regional implementation workshops and regional capacity building/ collaborations

Pre-meeting Sessions

The formal WG meeting was preceded by two pre-meeting sessions held on 24 September. The first session was attended by a representative from ECLAC and WG representatives from Latin American and Caribbean countries. Building on growing country-specific interest in utilizing the WG tools, the WG has begun to lay the groundwork for the establishment of regional entities that would collaborate on implementation activities and share best practices for the collection of disability data at the regional level. To date, regional group leaders and membership have been identified for Arabic-speaking countries, French-speaking Western African countries, Eastern and Southern African countries, Russian-speaking and Commonwealth of Independent States countries, Southern Asian countries, and countries in the Pacific region. This session focused on the establishing similar regional entities for Latin American and Caribbean countries. ECLAC and the WG country representatives from Brazil and Argentina will take on leading roles in this group.

This second pre-meeting session was open to all meeting attendees and included a brief orientation on the WG, including background on the history and the development of the WG's data collection tools. The session also covered topics related to the implementation of the WG questions and the analysis of the resulting data. Participants were provided the opportunity to share their experiences using the WG questions and seek guidance on specific implementation issues.

Workgroup Updates

Psychosocial Functioning / Mental Health

This workgroup, co-chaired by representatives from South Africa and Italy, provided a review of the work that has been completed to date. Preliminary results from cognitive tests of the draft module conducted in South Africa were presented. The module was developed based on the assessment of the performance of the WG questions on depression and anxiety and the scoping literature review on activity limitations, participation restrictions and environmental barriers commonly associated with common and severe mental disorders. Based on the results of the tests in South Africa, the workgroup plans to revise the cognitive testing protocol and test alternative questions. The workgroup is seeking additional members and countries for further cognitive testing. A training workshop on cognitive testing will be arranged for countries interested in participating. Countries representatives should contact the WG Secretariat to express interest.

Child Disability and Inclusive Education

The WG and UNICEF have collaborated to develop several resources intended to assist users with the implementation of the WG/UNICEF Child Functioning Module (CFM) and analysis of the data collected. The CFM has been officially translated into nine languages (Arabic, Chinese, French, Khmer, Portuguese (standard and Brazilian), Russian, Spanish, and Vietnamese), in addition to English. Supporting documentation, including a concept note, tabulation plans, narrative and syntaxes (SPSS and Stata), templates for reporting, guidelines for interviewers (available in English, French and Spanish), and training materials are also available. The official translations of the CFM and all of the supporting documentation are available on UNICEF's website: https://data.unicef.org/topic/child-disability/module-on-child-functioning/ In addition, training videos on disability measurement are also available on UNICEF's website: https://data.unicef.org/resources/child-disability-training-videos/ The CFM is

included in UNICEF's current Multiple Indicator Cluster Survey (MICS6), with approximately 70 countries in various stages of implementation.

An update on the WG collaboration with UNICEF on the development of a module designed to measure facilitators and barriers to school participation was presented. Cognitive testing of the UNICEF/WG Module on Inclusive Education had been carried out in the United States (35 interviews), India (40 interviews), Jamaica (40 interviews), Cambodia (69 interviews), and Kazakhstan (60 interviews). Results from the cognitive tests were used to inform revisions to the module. A revised module is being developed. Further testing is still needed in countries with an identifiable population of 'out of school' children. Countries interested in cognitive testing should contact the WG Secretariat.

Work to validate selected domains (vision, hearing and mobility) from the CFM in Fijian schools through Fiji's Education Management Information System (EMIS), was presented at previous WG meetings by a representative from Nossal Institute for Global Health at the University of Melbourne. Building on this work and in response to requests for a shortened version of the CFM that could be administered to teachers and school administrators, the workgroup began to explore the development of the Child Functioning Module – Teacher's Version (CFM-TV). A draft of the CFM-TV was presented at the meeting. A representative from Humanity & Inclusion (HI) presented preliminary results from testing of the draft CFM-TV in Senegal. The testing was part of a multi-country inclusive education project with the goal of promoting equitable access to education for children with disabilities. Results from the initial test were favorable. The workgroup, along with HI, plans to continue to work on the CFM-TV for eventual incorporation into EMIS.

Labor Force Surveys

A representative from ILO provided background on ILO's statistical activities and policy needs for data on labor force indicators. These needs have led to ILO's ongoing collaboration with the WG on the development of a disability module intended for use in labor force surveys. This workgroup, co-chaired by ILO and the Secretariat has developed a module for use in labor force surveys. The module includes five sections: disability identification (based on the WG-SS and two optional affect (anxiety and depression) questions); barriers to employment; accommodations necessary for employment; attitudes; and social protection. The module has undergone cognitive testing in the US and India. Final results from field testing in Mongolia were presented. At the conclusion of the presentation, WG/ILO Disability Module for Labor Force Surveys was endorsed by the meeting attendees.

Analysis and Dissemination

An update on the work to address the determination of mutually exclusive severity categories such as mild, moderate and severe disability using the WG-SS was presented using data from the US National Health Interview Survey (NHIS). The workgroup, chaired by the Secretariat, is planning to solicit additional countries to replicate result presented. WG members interested in joining the workgroup or replicating the results using their country data should contact the WG Secretariat.

A member of the Secretariat also presented examples of templates for standard tables for the reporting of results using the WG questions. A template for preparing a standard report was also presented during the session. The templates were populated using data from the US NHIS. The presentation was followed by a discussion of possible modifications to be made to the tables and reports. The delegates also discussed the best approach for collecting the data from countries and disseminating the completed tables and reports. The workgroup will continue its efforts develop standard templates for disseminating

data collected using the WG questions. WG members who would like to provide input on the format for templates should contact the WG Secretariat.

Administrative Data

The session opened with a presentation by a representative from the Center for Inclusive Policy focusing on the use of administrative data for inclusive policies. The presentation outlined some of the advantages and disadvantages with using administrative data for policy development. Work previously done with Fiji's Education Management Information System, the disability determination program in Vietnam and Sightsavers' service referral program were highlighted as successful examples. The presenter concluded that data on disability in administrative programs can be useful for examining how programs are reaching the target population, determining unmet needs, evaluating impact of outreach programs and process evaluation. However, administrative is not appropriate for measuring prevalence/patterns of prevalence and evaluating outcomes of programs.

The session also included a presentation by the WG representative from Statistics South Africa providing an overview on a project intended to improve the quality of disability statistics in South Africa. The goal of the project is to investigate the feasibility of harmonizing disability definitions and classifications across the three data source categories (questionnaire surveys, administrative data sets with no or limited information based on medical diagnoses, and administrative data sets based on medical diagnoses). The outcomes of the research will be used to operationalize the disability definition from the White Paper on the Rights of Persons with Disabilities (WPRPDs) across statistical data systems in South Africa.

Environment and Participation

At previous meetings, interest was expressed in establishing a workgroup to focus on the built environment and participation. However, no one volunteered to take on an active role in leading the workgroup and very little interest was expressed by the WG membership. WG-19 included a discussion on whether this activity should be included in the WG's future workplan. The delegates agreed the WG Secretariat should send another request for participation the WG membership. If insufficient interest is expressed, the activity will be removed from the workplan.

Translation of the WG Questions and Documents

The WG Secretariat led a discussion of the best approaches for developing official translations of the questions sets and the supporting documents. The session included a case study focusing on the adjudication of three versions of the Spanish translation of the WG-SS. The three translations of the questions and response categories were reviewed by WG representatives from Latin American countries and Spain. There was no consensus on a single translation or appropriate wording for all questions and response categories. However, the reviewers agreed that one version of the translation that was generally acceptable and this version could be provided on the WG website along with a list of acceptable country and region-specific modifications. The delegates agreed that it would be beneficial to conduct a similar adjudication exercise with the translations for other languages with representative from countries where those languages are spoken.

WG Website Redesign

The session also included a review of recent updates to the WG website as part of the WG's ongoing efforts to make the website more user-friendly and the content easier to navigate. A website developer has been employed to improve the appearance and utility of the website and provide guidance on best practices for content presentation. A short video was shown highlighting the proposed enhancements to the website. The presentation and video were followed by an extensive discussion of potential refinements. The delegates agreed that a review committee should be formed to provide feedback on the new revisions that would be made.

WG's Efforts to Support Regional Capacity Building

The session opened with an introduction from a representative from DFAT emphasizing DFAT's commitment to disability-inclusive development. The DFAT representative also provided a brief overview of DFAT's collaboration with the WG to improve international disability statistics. This was followed by an update from the chair of the WG's steering committee on the WG's current and future plans related to this initiative.

Over the past 4 years, with DFAT's support, the WG has been able to continue its capacity building and outreach efforts by hosting or participating in several webinars, training and implementation workshops to meet the varied needs of data producers and users. Recently, the WG has begun to shift focus from providing national support, to building capacity regionally. Building on growing country-specific interest in utilizing the WG tools, the WG has begun to establish regional entities that would collaborate on implementation activities and share best practices for the collection of disability data at the regional level. To date, several regional groups have been established (see *Pre-Meeting Sessions* above).

The Pacific Group on Disability Statistics (for countries in Polynesia, Melanesia, and Micronesia) has been selected as the pilot group to demonstrate how an on-going regional consortium of national statistical offices, working in consultation with civil society and advocacy groups, can be established as a viable and sustainable support mechanism for the on-going and accurate use of the WG methodology. The initial workplan for the group includes securing membership from countries in the region and developing scope of work and terms of reference.

In addition to assisting with the establishment of the Pacific Group on Disability Statistics, the DFAT funding with be used to continue to support WG's efforts to enhance the functionality of the WG website and provide trainings and ongoing technical consultation related to the use of the WG tools.

Disability Measurement in the 2020 Round of Population Censuses in Latin America and the Caribbean

In a session organized by INDEC, representatives from Costa Rica, Ecuador, and Argentina provided presentations covering the following topics:

- 1) Disability Measurement in Costa Rica, towards 2021 Census
- 2) 2020 Census in Ecuador and Disability
- 3) 2018 National Study on the Profile of People with Disabilities in Argentina
- 4) Challenges in the Disability Measurement towards 2020 Census Round in Argentina

The presentations were followed by a discussion of common challenges faced by countries collecting disability data in the region and potential ways to overcome some of the challenges.

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 58 countries. To date, 98 countries have indicated that the WG-SS (or some variant) was included in a previous or most recent census, national surveys, disability modules or pretests. In addition, 42 countries have indicated that WG-SS will be used in the 2020 census round or an upcoming survey between 2019 and 2029. To date, 25 countries have indicated that the WG-ES (or a subset) has been used as a module on a national survey or as part of a disability survey and 16 countries reported us of the WG/UNICEF CFM. The session also included presentations by representatives from Kenya and Belarus on the use of the WG questions in their respective countries. A representative from Peking University also provided an overview of disability statistical surveys and policies in China.

Copies of the presentations from each of the sessions are available on the WG's website: <u>http://www.washingtongroup-disability.com</u>

Key Agreements of WG-19 and Next Steps:

The WG agreed to its work plan for 2020. 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 work groups include:

- 1) Workgroup on Analysis:
 - a) Continue work to develop a disability severity indicator
 - b) Continue work to develop standard templates for disseminating data collected using the WG questions
- 2) Workgroup on Child Functioning:
 - a) Continue cognitive testing of the out-of-school portion of the Module on Inclusive Education
 - b) Continue work on the CFM-TV for eventual incorporation into EMIS
- 3) Workgroup on Psychosocial Functioning/Mental Health:
 - a) Finalize scoping review of literature
 - b) Finalize cognitive testing protocol
 - c) Expand the cognitive testing of proposed questions
- 4) Workgroup on Administrative Data:
 - a) Continue work on incorporating WG tools into administrative systems (*pending sufficient interest and participation from the WG membership*)
- 5) Workgroup on Environment and Participation:
 - a) Reestablish the workgroup (*pending sufficient interest and participation from the WG membership*)
- 6) Continue work on redesigned website
- 7) Continue work to develop translations of WG questions and documents
- 8) Continue work to establish regional entities to collaborate on implementation activities and share best practices for the collection of disability data at the regional level

Governance issues

Due to the COVID-19 pandemic, a virtual annual meeting will be held 22-24 September 2020.

The next in-person meeting is tentatively scheduled for late 2020/early 2021 and will be hosted by the Kenya National Bureau of Statistics at a date to be announced.

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 (<u>http://www.washingtongroup-disability.com</u>/).

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