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Items for information: Disability statistics

Background document
Available in English only

The Washington Group on Disability Statistics

Background Document



E/CN.3/2022/**

Item 4(b) of the provisional agenda

Disability Statistics: Joint report of the Secretary-General and the Washington Group on Disability Statistics

The Washington Group on Disability Statistics

Background Document

**53rd Session of the
United Nations Statistical Commission**

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Washington Group on Disability Statistics: History

In 2001, the International Seminar on the Measurement of Disability organized by the United Nations was held in New York. During this meeting, participants agreed that there was need for common definitions, concepts, standards and methodologies in the production of statistics about persons with disabilities. Furthermore, the need for a clearer understanding of disability was also recognized, including the numbers of individuals living with disability, their characteristics and their access to all mainstream policies, systems and services (e.g., education, health, employment, social protection, and transportation, *inter alia*).

As a result, the Washington Group on Disability Statistics (WG) was formed as a United Nations Statistical Commission City Group to address these urgent needs. The United States National Center for Health Statistics (NCHS) hosts the Washington Group Secretariat, and the group is governed by a Steering Committee currently comprised of representatives from the following National Statistical Offices: Argentina, Bermuda, Brazil, Congo-Brazzaville, Italy, Kenya, the Maldives, Nepal, Palestine, Samoa, and South Africa. The main purpose of the WG is the promotion and coordination of international cooperation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. Its major objective is to provide basic necessary information on disability that is comparable throughout the world. The WG meets annually with representatives of international statistical offices and non-governmental organizations. In the past two decades, over 165 countries have had representation within the WG. Member countries identified the need for a short set of questions for use in censuses and surveys as a priority so that the collection of disability data could be mainstreamed into national data collections. The UN CRPD (Convention of the Rights of Persons with Disabilities) and the 2030 Agenda for Sustainable Development and its Sustainable Development Goals call for the collection of disability data in order to assess progress towards the goals set forth in these frameworks.

Since its inception, the WG has received funding from various partners. The WG has received funding from the World Bank and collaborated with the Statistics Divisions of the Economic and Social Commission for Asia and the Pacific (ESCAP) and the United Nations Economic Commission for Western Africa (ESCWA). In addition, in 2015 the Washington Group received a grant from the Australian Department of Foreign Affairs and Trade (DFAT) to promote the inclusion of the WG question modules in all data systems and to facilitate UN Member States in the collection, analysis, reporting and wider dissemination of information on disability. More recently, in 2021, the Washington Group received funding from the Federal Ministry for Economic Cooperation and Development (BMZ) of Germany to support the work of two regional African Disability Statistics Groups.

Washington Group Tools

The WG question sets are designed to provide cross-nationally comparable data for populations living in a variety of cultures with varying economic resources. The WG tools (Appendix 1) have been implemented in a growing and significant number of countries' national data collections (censuses and surveys), and have been used by other actors in the field of disability, including NGOs, INGOs, DPOs, academia, and development agencies. A brief overview of WG question

sets that have been finalized and adopted follows. For detailed information on the rationale, development, testing and use of all WG tools please visit <https://www.washingtongroup-disability.com/about/the-washington-group-primer/>.

Washington Group Short Set on Functioning (WG-SS)

The WG-SS is a set of six questions designed to identify people with a disability, namely those at greater risk than the general population for participation restrictions due to the presence of difficulties in six core functional domains, if appropriate accommodations are not made. The questions ask whether people have difficulty performing basic universal activities (walking, seeing, hearing, cognition, self-care and communication) and are designed for use in censuses and general population surveys. However, the focus on functioning and the brevity of the tool also allows the WG-SS to be easily and rapidly added to a variety of data collection settings. The WG-SS was not designed to be used in isolation. Rather, it should be used in conjunction with other measurement tools, i.e., included within a larger survey or registration form to enable disaggregation of other measures such as employment status, educational attainment, etc. by disability status. Due to the complexity of disability, the questions were not designed to measure all aspects of difficulty in functioning that people may experience, but rather those domains of functioning that are likely to identify the majority of people at risk of participation restrictions.

Washington Group Extended Set on Functioning (WG-ES) and the WG-SS Enhanced

Because the WG-SS had to be appropriate for inclusion in censuses, it will identify most, but not all, people with disabilities (in particular missing some, though not all, people with psychosocial disabilities). When more information about disability is required, the Washington Group Extended Set on Functioning (WG-ES) should be used. In 2008, the WG, the Budapest Initiative and the Economic and Social Commission for Asia and the Pacific (UNESCAP) came together to work on what would become the WG-ES. The WG-ES captures more extensive information on functional status, includes domains that could not be included in the WG-SS (affect – anxiety and depression, and upper body functioning), obtains more information on some domains than are provided by the WG-SS and obtains information on the use of mobility assistive devices and their impact on functioning. The six WG-SS questions are embedded in the WG-ES.

Given the need for an intermediate-length question set, and in response to this need, the Short Set on Functioning - Enhanced (WG-SS Enhanced) was developed and validated. The WG-SS Enhanced uses the six WG-SS questions plus an additional six questions drawn from the Extended Set (four questions about psychosocial functioning and two questions on upper body functioning).

WG/UNICEF Child Functioning Module (CFM)

While the WG-SS can identify many children with functional difficulties, the WG determined that a special set devoted to measuring child functioning was needed to improve and expand upon that identification, and to address the aspects of child development not addressed in previous methods. Therefore, in partnership with UNICEF, the WG developed a set of survey questions for identifying children with disabilities. The Child Functioning Module (CFM), which was finalized in 2016, can be used as a component of national population surveys or as supplements to surveys

on specific topics of interest. The UNICEF-sponsored Multiple Indicator Cluster Surveys (MICS) include both the WG-SS for adults and the CFM for children, beginning with its sixth round of surveys. To date, the CFM has been included in the MICS in 63 countries and the recently released UNICEF *Global Report on Children with Disabilities* presents disability data using the CFM.

As with other WG question sets, disability is defined as difficulty undertaking basic activities. As such, the CFM draws upon the both the WG-SS and the WG-ES. The CFM was developed to produce internationally comparable data and was tested extensively both cognitively and in the field to achieve this goal. The CFM was designed to expand the functional domains relative to children and child development, in recognition that the distribution of types of functional limitations are different for children compared with adults. In adults, the major difficulties arise in mobility, sensory, and personal care – especially with advancing age. In children, the main disabilities are related to intellectual functioning, affect and behavior. The CFM has two versions: one for children age 2-4 years old and one for children age 5-17 years old. Both are designed for administration to mothers (or primary caregivers). In March 2017, a joint statement issued by multiple UN agencies, member states, organizations of persons with disabilities, and other stakeholders recommended the CFM as the appropriate tool for SDG data disaggregation for children.

WG/UNICEF Child Functioning Module-Teacher Version (CFM-TV)

In recognition that in some settings, particularly education settings, modifications to the CFM may be necessary, a version intended to be administered to teachers and school administrators has been created. This tool, the CFM-Teacher Version (CFM-TV), is still under development and further testing is needed. Testing has been temporarily paused due to COVID-19, but several testing projects are planned or underway resulting from the increased interest in exploring the use of the CFM-TV in a range of contexts, including in humanitarian crisis and emergency settings and administering the tool to children as well as teachers. The WG Secretariat has responded to a series of requests from partners for information and access to the tool. In response to these requests and the aforementioned increased interest, the WG Secretariat convened a meeting to promote an exchange of knowledge among partners on their experiences with the CFM-TV which provided valuable information and generated collaborations among the initiatives. Further information about this meeting and the resulting interest group is described below.

WG/UNICEF Inclusive Education Module (IEM)

Since 2012, the WG and UNICEF have been developing a set of questions on school participation and environmental factors affecting participation in school for all children. The intent is for the survey module to be used in conjunction with the CFM to identify both facilitators and barriers to school participation in order to inform policies to improve full inclusion in education for children with disabilities. The IEM contains four main sections, each related to potential environmental barriers to education: i) Parental Attitudes, including attitudes on inclusive education; ii) Accessibility, including to, and within, the physical school environment, access to information, communication, assistance and learning aids, and program accessibility; iii) Affordability, including tuition fees, costs associated with school attendance, the availability of types of assistance, and non-educational benefits; and iv) a section designed to gather information on out-

of-school children. To date, cognitive testing of the first three sections has been carried out in 5 countries (United States, India, Jamaica, Cambodia and Kazakhstan). Additional cognitive testing of the IEM, including the out-of-school component, has been delayed due to the COVID-19 pandemic but the plan is to resume testing in early 2022.

WG/ILO Labor Force Survey Disability Module (LFS-DM)

The WG/ILO Labor Force Survey Disability Module (LFS-DM) was developed, tested and adopted by the International Labour Organization (ILO) and the WG. The questions reflect advances in the conceptualization of disability and use the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) as a conceptual framework. The module was endorsed for use by the attendees at the 2019 annual WG meeting in Buenos Aires, Argentina. The LFS-DM was intended for inclusion in Labor Force Surveys and is also suitable for use in population-based surveys that collect data on employment. This module is designed specifically for the collection of information on the adult working-age population but may be used for workers of younger ages. The module includes five sections: (1) Disability Identification; (2) Barriers to Employment; (3) Accommodations Necessary for Employment; (4) Attitudes; and (5) Social Protection.

Annual Meetings

The WG meets annually. Since its inception, the group has convened 21 annual meetings and one mid-year meeting. In-person meetings have been organized in different regions of the world to facilitate participation of resource-poor countries. Over the years, funds have been available to support travel to annual meetings by the US National Center for Health Statistics (NCHS) and the Australian Department of Foreign Affairs and Trade (DFAT).

List of WG Meetings

| | | | |
|-------------------|---------|----------------------|---------|
| 1. Washington, DC | 02/2002 | 12. Thailand | 10/2012 |
| 2. Canada | 01/2003 | 13. Jordan | 10/2013 |
| 3. Belgium | 02/2004 | 14. Argentina | 10/2014 |
| 4. Thailand | 09/2004 | 15. Denmark | 10/2015 |
| 5. Brazil | 09/2005 | 16. South Africa | 12/2016 |
| 6. Uganda | 10/2006 | 17. Australia | 10/2017 |
| 7. Ireland | 09/2007 | 18. Italy | 11/2018 |
| 8. Philippines | 10/2008 | 19. Argentina | 09/2019 |
| 9. Tanzania | 10/2009 | 20. Virtual | 09/2020 |
| 10. Luxembourg | 11/2010 | 21. Virtual mid-year | 05/2021 |
| 11. Bermuda | 11/2011 | 22. Virtual | 11/2021 |

Summary of the 21st Annual Meeting of the Washington Group on Disability Statistics

Due to the COVID-19 pandemic, the in-person meeting scheduled to be hosted by the Kenya National Bureau of Statistics was postponed. In lieu of the in-person meeting, a shortened virtual meeting, organized by the WG Secretariat (WGS) and the Steering Committee, was held via Zoom

in November 2021. To account for regional time differences, the WG-21 was divided into two session tracks: one to accommodate participants from the Americas, Europe, Africa and the Middle East and another for participants from countries in the Asia and Pacific regions. Approximately 130 participants from over 60 countries representing national statistics offices, ministries of health, academia, international and non-government organizations, and organizations representing persons with disabilities attended the two session tracks combined. The meeting was conducted in English and included interpretation in French. During this meeting, accomplishments since the WG-20 were shared, and the chairs of the work and regional groups presented their progress and future plans. Participants also learned about the application of WG tools in humanitarian contexts, recent initiatives to include WG tools in administrative data collections, and experiences using the Child Functioning Module-Teacher Version. Partners from Save the Children, the UN Economic and Social Commission for Western Africa, and CMB shared information about recent publications and projects. During the WG-21, UNICEF also launched its Global Report on Children with Disabilities and Centre of Excellence on Data for Children with Disabilities.

In 2022, the Washington Group will continue its efforts to support the regional disability statistics groups to advance the work among countries that share a common language or culture and common disability data challenges. Additional next steps were identified during the 21st annual meeting, including: (a) testing of psychosocial functioning questions; (b) developing questions on accessible transportation; (c) finalizing an age-adjustment guidance document; (d) facilitating exchanges on experiences with the Child Functioning Module – Teacher Version and develop module evaluation guidance; (e) addressing the need for a focused disability survey; (f) addressing the use of its tools in humanitarian contexts and disasters; (g) advancing the plans of the regional disability statistics groups; (h) convening a mid-year 2022 meeting; and (i) exploring additional avenues of communication between the members.

Workgroups

The work plan of the WG is developed and carried out through dedicated workgroups. Six active workgroups are currently engaged in furthering the WG's work plan.

Administrative Data – Chaired by South Africa and the WG Secretariat, this workgroup focuses on the use of administrative systems for the collection of disability information. The group was constituted at the 17th meeting of the WG and has developed a work plan to assess the feasibility of collecting disability data through administrative sources. Workgroup plans include the development of a guidance note on disability data collection in administrative records.

Age-Adjustment – Following discussions held during the May 2021 mid-year meeting, the WG membership agreed to the creation of a workgroup on age-adjustment for the reporting of disability data in WG publications. The age-adjustment workgroup is comprised of representatives from INDEC Argentina, DANE Colombia, INEGI Mexico, Statistics New Zealand and the WG Secretariat. The group held its first meeting in September 2021 and it was decided that the group will prepare a guidance document on age adjustment in the context of disability data collection. An initial outline of this document is circulating among group members and one of the group members, the National Institute of Statistics and Geography (INEGI) of Mexico, has sent an input for consideration. The first draft of the report will be available in early 2022.

Analysis and Dissemination – Chaired by NCHS, this workgroup has addressed the development of analytic guidelines and computer syntax for the determination of a set of disability identifiers (based on different severity cutoffs and describing the continuum of disability) for each of the WG-SS, WG-ES and the CFM. Additional guidance documents have been developed on domain-specific disability indicators and future work will focus on proposing a common disability data reporting template. A template for WG member use has been drafted and will be completed when the age-adjustment workgroup’s report is completed.

Child Functioning – Chaired by the NCHS, and working jointly with UNICEF, this workgroup is focusing on the cognitive and field testing of the aforementioned Inclusive Education Module to be used in conjunction with the child functioning module that would address barriers and facilitators to education among all children.

Environment and Participation – Chaired by Kenya, this workgroup will develop a questionnaire to obtain data on environment and participation for persons with disabilities. The group has held one meeting, during which it was decided to advance towards developing questions that can be used to assess accessibility in transportation.

Mental Health and Psychosocial Functioning – Co-chaired by South Africa and Italy, this group is proceeding with cognitive testing of additional psychosocial questions to assess mental health functioning. Testing has been conducted in the U.S. and in South Africa and preparations are underway for testing to occur in Costa Rica in early 2022. Interviewer training will be conducted virtually which required that a new set of materials targeted to the requirements of virtual trainings be prepared, translated and finalized. This was accomplished with assistance provided by the NCHS Collaborating Center on Question Design and Research, the Secretaría Nacional para la Integración de las personas con Discapacidad (SENADIS) of Chile, and members of the WG Buenos Aires Regional Disability Statistics Group. Once fielded and evaluated, the testing protocols will be available for broad use.

Regional Disability Statistics Groups

The WG was established to address the need for cross-nationally comparable population-based measures of disability. In addition to its global work, several years ago the WG began to shift focus to building capacity regionally. To that end, the WG is promoting the establishment of Regional Disability Statistics Groups that would carry on the work of the WG at a regional level. The goal is to create a consortium of National Statistical Offices (NSOs) that, working in consultation with civil society and advocacy groups, can be established as a viable and sustainable support mechanism for the implementation of the WG tools and methodology – on a regional basis. To date, there are six active regional disability statistics groups that are self-governed and have developed their respective work plans: the Buenos Aires Group (Countries of Latin America), the Brazzaville Group (French-speaking African countries), the Casablanca Group (Arabic-speaking countries of the Middle East and Northern Africa), the Kathmandu Group (Countries of South Asia), the Pacific Group (small island States of the Pacific), and the South/East Africa Group (English-speaking African countries). As noted previously, the Brazzaville Group and the South/East Africa Group are receiving support from BMZ. All regional groups are preparing, or

have finalized, their Terms of Reference and work plans. The WG Secretariat will be working with other regions that have expressed interest in starting groups.

Guidelines and Documentation

The WG strives to make its products and documentation readily available to users on a public platform. To that end, the WG has developed a series of documents that are available online at: <http://www.washingtongroup-disability.com/publications/implementing/>. These documents include:

- A WG Primer (overview of the WG)
- Conceptualization and Measurement of Disability (outlining WG Tools)
- WG Question set Implementation Guidelines
- WG Question by Question Specifications
- Translation Protocol
- Interviewer Guidelines (under revision)
- Analytic Guidelines including SPSS, STATA, SAS, and CSPro syntaxes for creating disability indicators, disability severity indicators and domain-specific disability indicators.

WG Website

The WG has recently revised its website (<http://www.washingtongroup-disability.com>), making it more accessible and easier to navigate, as well as providing links to new and important information. In addition to the Implementation Guidelines mentioned above, the website hosts a series of Blogs on experiences using the WG tools (<http://www.washingtongroup-disability.com/washington-group-blog/>) and Frequently Asked Questions (FAQs) (<http://www.washingtongroup-disability.com/frequentlyasked-questions/>)

Recent Adoption and Endorsements of the WG-SS

Based on information provided by WG members to the WG Secretariat for the 2021 annual meeting, between 2009 and 2021, 111 countries had included the WG-SS in a census or survey. Thirty-four countries responded that they would use the WG-SS in a census or survey taking place in 2021 and 2022. In addition to their wide adoption in census and surveys, the tools developed by the WG have been championed by Organizations of Persons with Disabilities (OPDs) and the WG has supported various disability data initiatives by these groups, among them: Save the Children, Global Action on Disability (GLAD) Network, Humanity and Inclusion/Education Cannot Wait and the Nigerian National Association of the Deaf. The WG tools have likewise been endorsed by numerous bilateral international development agencies for gathering information on persons with disabilities in their sponsored projects and programmes. Some of these agencies include Department of Foreign Affairs and Trade (DFAT) of Australia, the Foreign, Commonwealth and Development Office (FCDO) of the UK, the Norwegian Agency for Development Cooperation (NORAD), the United States Agency for International Development (USAID), and the German Society for International Cooperation (GIZ).

In light of the importance placed on the 2030 Agenda for Sustainable Development and the identification and measurement of goals, targets and indicators to monitor sustainable development over the coming decade, the international community has focused on disability as one of several demographic characteristics for the disaggregation of SDG outcome indicators. The WG-SS has been recommended as the means to disaggregate SDG indicators by disability status:

1. Joint Statement by the Disability Sector:

- 4th Meeting of the IAEG-SDG's: Geneva, Nov 2016 (Appendix 2)
- 5th Meeting of the IAEG-SDG's: Ottawa, March 2017 (Appendix 3)

2. Global Action on Disability (GLAD) Network Meeting Communiqué: 2-3 March 2017, Berlin, Germany (Appendix 4)

3. UN Statistical Commission:

Report on the 48th session: United Nations, NYC, 7-10 March 2017

<https://unstats.un.org/unsd/statcom/48th-session/documents/Report-on-the-48th-session-of-the-statistical-commission-E.pdf>

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

The Statistical Commission:

(g) Welcomed the relaunch of the disability statistics programme by the Statistics Division, endorsed its work programme, requested that the work be expanded in the context of the monitoring of the Sustainable Development Goals in collaboration with relevant stakeholders in this field, requested the Statistics Division to take into account the existing measurement instruments, including those developed by the World Health Organization and the Washington Group on Disability Statistics, and supported the use of the short set of questions on disability status developed by the Washington Group for the purposes of disaggregation for the Goals.

4. Transcript from the 10th session of the Conference of States Parties to the CRPD United Nations: twenty-one signatories, NYC, 13 to 15 June 2017
<https://www.un.org/development/desa/disabilities/conference-of-states-parties-to-the-convention-on-the-rights-of-persons-with-disabilities-2/cosp10.html>

Excerpts from CART Transcripts 15 June: 3-6 pm (Appendix 5 – see intervention from New Zealand representative in text pages 22-23 in hyperlinked document above)

5. Joint statement by UNSD and WG: Towards Further Improvements in Disability Statistics (Appendix 6)

WG Accomplishments and Future Work Areas

Trainings, Technical Assistance and Collaborations

The WG Secretariat responds to a diverse set of requests for technical assistance and carries out trainings related to disability measurement and the use of its tools for a range of partners and interested entities. Requests are directed to the WG Secretariat directly or through the WG website and illustrate the reliance on the WG for information on the collection, availability and use of disability data. The WG has provided support to UN entities, Organizations of Persons with Disabilities (OPDs), National Statistical Offices (NSOs), and created spaces for the exchange of information among these and other partners. Some recent examples are highlighted below.

The WG has a long history of collaborating with UN entities to provide technical guidance, contribute inputs to documents, co-organize training sessions, and other activities. To date, collaborations have involved UNSD, WFP, UNICEF, UNFPA, UNPRPD, UNDP, OHCHR, UNESCO, UNHCR, and UN Regional Commissions. One example of a recent collaboration is a training provided by the WG in July 2021, in conjunction with UNFPA and UNDP, for the Namibia Statistics Agency on the implementation of the Washington Group Question Sets ahead of their census. An example of a collaboration with an OPD is the training workshop held in August 2021 at the request of the Disabled People's Organisation of Denmark with participation of OPDs from Ghana, Nepal and Rwanda. An example of collaboration with a wider range of partners occurred in September 2021 through a meeting convened by the WGS on experiences using the CFM-TV (more on this activity below).

The WG Secretariat has also provided technical assistance to seven NSOs and other public entities since 2020 (Gambia Bureau of Statistics; National Rehabilitation Center for Persons with Disabilities of Japan; Maldives National Bureau of Statistics; National Public Health Institute of Finland; National Institute of Statistics and Geography of Mexico; Statistics New Zealand; United States Agency for International Development). Finally, the WGS has responded to requests for information and translations of WG tools, presented at conferences and seminars, and contributed comments and inputs to partner consultations and documents, including those of the Global Action on Disability (GLAD) Network and the World Bank.

The WG Secretariat convened a meeting in September 2021 to promote an exchange of knowledge among partners regarding their experiences with the CFM-TV and plans for evaluations. The objectives of this meeting were to provide a space to share information, to establish connections among partners, and to explore future activities. Participants were invited to provide a brief intervention on their experiences and/or planned activities using the CFM-TV, followed by an open discussion of the presentations and a discussion of next steps. Invitations were extended to those who requested information and access to the CFM-TV from the WGS and the following entities participated in the meeting: Education Cannot Wait; Humanity and Inclusion; Save the Children International; Save the Children Norway; Sightsavers; UNICEF; USAID; and World Vision. During the meeting, participants requested that the WGS continue to convene meetings so that they can share progress on their respective projects and to develop a document that summarized the different planned evaluation strategies, as well as a statement of cross-cutting issues that would be addressed in evaluations of the CFM-TV. Participants suggested that the

group consider sharing experiences in some to-be-determined format during the Global Disability Summit. GLAD was also raised as possible dissemination entry-point.

Finally, the WGS has received numerous inquiries and requests for information and technical guidance on the use of the WG tools in the context of humanitarian crises and emergencies. In view of this, a session on this topic was included in its 21st Annual Meeting in November 2021, so that WG members could learn of the application of the WG tools in these settings. A representative from UNHCR presented on the work this entity is doing to advance disability data collection in humanitarian crises and emergencies, including modifications to their information systems and the inclusion of WG questions in their registrations. A partner from Education Cannot Wait (ECW) shared information about this entity and their work in providing education in emergency contexts and their efforts to ensure that learners with disabilities are considered in these settings. Going forward, the WG will determine its role in addressing the use of WG tools in humanitarian contexts and disasters including the development of a guidance document on use of WG tools in these contexts.

Conclusion

The work of the Washington Group, in terms of the development and testing of standardized data collection tools, accompanied by a range of documents that support the implementation of the tools and the interpretation of data, have improved the quality and availability of disability data. While NSOs remain the core constituents of the WG, the impact of the work has been felt more broadly as the tools have been supported, endorsed and used by UN agencies, NGOs, INGOs, OPDs, development ministries and academia.



Appendix 1

The Data Collection Tools Developed by the Washington Group on Disability Statistics and their Recommended Use



The Data Collection Tools Developed by the Washington Group on Disability Statistics and their Recommended Use

Introduction

The Washington Group on Disability Statistics (WG), a city group established under the United Nations Statistical Commission, was formed to address the urgent need for population-based measures of disability by promoting and coordinating international co-operation in the area of health statistics focusing on disability data collection tools suitable for censuses and national surveys. The major objective is to provide basic necessary information on disability that is comparable throughout the world. The WG has developed data collection tools for use in national censuses and surveys that produce internationally comparable data on disability.

Disability is a complex and dynamic process that presents considerable challenges for data collection. The definition of disability has changed over time and is currently conceptualized as the outcome of the interaction between a person with a functional limitation (difficulties doing basic functional activities) and an unaccommodating environment resulting in the inability to fully participate in society. Thus, to provide complete information on all aspects of disability would require extensive and detailed data collection on almost all aspects of life including body structure and function, individual functional abilities across the full range of activities, a full description of all aspects (physical, cultural, legal) of the environment in which a person lives, and levels of participation across the full range of social roles (e.g. work, school, social interaction, community engagement, civil participation). This is not practical and for many purposes is not necessary. Multiple tools can be used to address the different components of the disability framework.

The data collection tools developed by the WG are easily incorporated into ongoing national data collection systems, as well as topic-specific surveys, programmatic, and research data collections. The tools are designed to complement each other, making it possible to use information from different

This first in a series of **Washington Group Implementation Documents** covers the tools developed by the Washington Group to collect internationally comparable disability data on censuses and surveys. The WG-SS, WG-ES and CFM are included, as well as tools now in development. Use of the WG-SS for the purposes of disaggregation is also discussed.

Additional Implementation Documents cover: The Washington Group Short Set on Functioning; Translation of the Washington Group Tools; Question Specifications; Analytic Guidelines; and other tools developed by the WG and partners for the measurement of disability.

For more information, visit the Washington Group website:
<http://www.washingtongroup-disability.com/>.

sources together. When selecting a tool, it is critical to match the tool with the intended use of the data and the data collection method.

This overview describes the WG data collection tools - both those currently available and those under development – and how they relate to each other so that users can select the most appropriate tool for their needs. All tools have undergone extensive testing and the results of the tests are available on the WG website. The website also contains more detailed information on each tool and on the work of the WG.

THE WG SHORT SET ON FUNCTIONING

The first tool developed by the WG is the Short Set on Functioning (WG-SS). The tool, a set of six questions, was developed in response to the stated need of member countries for a short module that can be added to decennial censuses, which in many countries can be the sole or most reliable means of collecting population-based data. Because of the restrictions inherent in the census format, the module had to be short and parsimonious. While developed initially for censuses, the brevity of the module is also well suited for inclusion in surveys for the purpose of disaggregating outcome indicators by disability status.

The 3rd Revision of Principles and Recommendations for Population and Housing Censuses (United Nations Statistical Division, <https://unstats.un.org/unsd/demographic/sources/census/census3.htm>) contains recommendations pertaining specifically to the collection of disability data on censuses. Disability is categorized as a ‘core topic’ indicating that the majority of the regional recommendations in previous census decades have designated disability as a priority topic. Furthermore, suggested tabulations based on the recommendations for disability data collection using the WG-SS are provided. Similar recommendations for the 2020 Censuses of Population and Housing have been prepared by the Conference of European Statisticians in cooperation with the Statistical Office of the European Union.

To maximize international comparability, the WG-SS obtains information on difficulties a person may have in undertaking basic activities that apply to people in all cultures and societies and of all nationalities and so are universally applicable. Difficulties in these basic activities in a non-accommodating environment are associated with a higher risk of participation restrictions. When analyzed in conjunction with other information collected on censuses and surveys, it is possible to compare whether difficulties in basic activities are associated with participation restrictions or if the necessary accommodations have been made so that all persons can fully participate in society. This definition is in keeping with the United Nations Convention on the Rights of Persons with Disability (UNCRPD) and its goal of full and effective participation and inclusion in society (Article 3, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-3-general-principles.html>).

Given the need to keep the module short, a single question per functional domain is included. The final set of questions includes difficulties seeing, hearing, walking or climbing stairs, remembering or concentrating, self-care, and communication (expressive and receptive). Other functional domains were considered, but not included as some would require more than one question per domain and some domains, such as affect or pain, are not appropriate for a census. It is acknowledged, therefore, that the short set of six questions will not identify all persons with all types of difficulties in basic activities. However, evidence shows that using these questions covering major functional domains identifies the large majority of people with disabilities, and so is useful for making inferences about the characteristics

The Washington Group Data Collection Tools and their Recommended Use

of people with disabilities in the population and their outcomes that are critical for policy planning and evaluation. To identify those remaining, a more extensive set of questions is needed, for example the WG Extended Set on Functioning summarized below.

The WG-SS was not designed for use among children, and does not include key aspects of child development important for identifying disability in children. The Module on Child Functioning (described below) was designed specifically to meet the needs of identifying and measuring disability in children.

THE WG EXTENDED SET ON FUNCTIONING

Upon completion and adoption of the WG-SS, the WG embarked upon the development of an Extended Set on Functioning (WG-ES) that would allow for the collection of additional data on domains of functioning not included in the WG-SS; for example, affect (anxiety and depression), upper body functioning, and pain and fatigue. These were not included initially because a single question could not be crafted that captured the essence of functional difficulty in these domains. The WG-ES also collects more information for certain domains included in the WG-SS. This additional information allows for greater granularity along the continuum of functioning. For example, more detail on functional ability is obtained for hearing and mobility.

The WG-ES also begins to explore the connection between functioning and the environment through the inclusion of questions on the use of assistive devices and personal assistance in the mobility (walking) domain.

The WG-ES includes about 35 questions and is intended for population-based household surveys (demographic and health surveys-DHS, household income and expenditure surveys-HIES etc.) or as part of a larger disability survey. The questions are designed for the adult population 18 years and above.

It is important to note that the six Short Set on Functioning questions are embedded into the Extended Set on Functioning.

THE WG/UNICEF CHILD FUNCTIONING MODULE

As noted above the WG acknowledged early in its work that the WG-SS questions was not ideal for the child/adolescent population. To address the unique situation of children, the WG therefore embarked upon the development of a separate module that would specifically address child functioning. This work began in 2009 and United Nations Children's Fund (UNICEF) joined the collaboration in 2011.

The Child Functioning Module (CFM) follows the same principles as the earlier WG modules: to determine disability through a series of questions on difficulty in functional domains that would place a child at risk of participation restrictions in a non-accommodating environment. The CFM is comprised of two sub-modules: one for children 2-4 years of age and another for children 5-17 years of age. Domains of functioning for children 2-4 years of age include: seeing, hearing, mobility, fine motor, communication, cognition (learning), playing and controlling behavior. Domains of functioning for children 5-17 years of age include: seeing, hearing, mobility, self-care, communication, cognition (learning, remembering and concentrating), accepting change, controlling behavior, relationships and

The Washington Group Data Collection Tools and their Recommended Use

affect (anxiety and depression). The sensory questions allow for an introductory question on the use of glasses or hearing aids as is done for the WG-ES for adults.

Six of the domains mirror those included in the WG Short and Extended sets of questions, but the questions used in the child module are modified slightly to be suitable for use with this subpopulation.

The CFM is intended to be administered to the child's mother. In cases where the mother is not alive or not living in the same household, the primary caregiver is the recommended respondent for this module.

MODULES UNDER DEVELOPMENT

The WG is working with partners to develop two additional modules that focus on participation and the barriers and facilitators that affect level of participation. The WG and UNICEF are developing an inclusive education module that would be used in conjunction with the CFM. This module focuses on measuring barriers & facilitators to education for children with and without disabilities. Data are collected under three main domains related to the environment and within the context of school participation: attitudes, school environment (including getting to school, accessibility and affordability), and a set of questions designed for children currently out of school.

The WG is working with the International Labour Organization (ILO) to develop a module on employment. Questions for selected domains from the WG-ES are used in conjunction with the WG-SS and information on work related barriers and facilitators to address issues related to full participation in work.

SELECTION OF THE APPROPRIATE DATA COLLECTION TOOL

A data collection tool should be selected to meet the objectives of the data collection and the data collection platform to be used.

The **Short Set on Functioning** is recommended for data collections in

- (1) Censuses where space is very limited.
- (2) Targeted surveys where at least some information is obtained on all or multiple members of the household/family.
- (3) Broad based household surveys that cover a wide range of topics where information is obtained on all household/family members (e.g., living standard measurement surveys or household income and expenditure surveys)

The WG-SS tool is, as the title states, short (only six questions) and it is easy to administer. While self-response is preferred, the WG-SS can be administered to a household or family respondent following the usual practice of the data collection. When included in such surveys, the WG-SS should be used to disaggregate the information obtained on the survey's main focus by disability status in order to compare the outcomes for persons with and without disability. The WG-SS implementation guide provides detailed information on how to construct the disability indicator.

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The WG-SS is not recommended for reporting on disability in children, as information will be missed on key aspects of child development, including learning, interacting with peers, coping with change, and focusing attention.

In cases where the Child Functioning Module cannot be incorporated into ongoing data collections due to design requirements, such as in censuses which focus on the total population, but where the WG-SS is included, the WG-SS questions should only be administered for the population five years and older.

The WG-SS should not be used to collect data on children below the age of five. When the WG-SS is used for children aged five and older, it is important to emphasize that estimates of prevalence would be underestimated. Under these circumstances, the fact that estimates for children only apply to a subset of key functional domains for this age group would need to be clearly documented when reporting results. In addition, the wording of some of the WG-SS questions, such as on self-care, are not optimized for children. The questions in the CFM were intentionally modified in the domains covered by both question sets to address this limitation. Finally, the mother (or primary caregiver) is the best informant when obtaining information on children. For many surveys that will include the WG-SS, the mother is unlikely to be the survey respondent.

Taking into consideration the limitations outlined above, any analysis of the information obtained using the WG-SS specifically for children, including disaggregation, should refer to children having difficulties in only those six domains covered by the WG-SS. A more accurate definition of disability among children would require the full range of functional domains included in the CFM. This module should be used in data collections where children are a major focus or where key findings will be reported separately for children.

The **Extended Set on Functioning** is recommended for use in surveys in order to obtain information on domains covered by the WG-SS as well as those not covered. The WG-ES should be used in health surveys and surveys that focus specifically on disability but also should be included in surveys that focus on other topics where the survey design is such that:

- a) Extensive information is collected on selected adult family members.
- b) Information is collected from the respondent, and not a proxy, unless the respondent is unable to participate due to a health problem or functional limitation.

This module should not be used for children. Instead, the CFM should be used.

Including the WG-SS each year on ongoing surveys, and the WG-ES on a periodic basis, is one way to reduce burden but assure that information on all functional domains will be available.

When the WG-ES is used, estimates of disability prevalence will increase. This is because additional domains are included, as well as additional questions within the WG-SS domains. However, as the WG-SS is embedded in the WG-ES, it is possible to identify the additional people with disabilities identified by the WG-ES, and to make comparisons with results of other data sets that use only the WG-SS.

Depending on the focus of the survey, only selected domains from the WG-ES can be included however, the inclusion of all domains will provide a fuller description of functioning. The WG-ES implementation guide provides detailed information on how to construct the disability indicator.

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As in all data collection, the choice of respondent will impact the results. For disability among adults, a self-respondent is preferred. This may not always be possible, such as in cases when the WG-SS or WG-ES is added to existing surveys where the existing protocol for administering the survey is pre-determined and may not consist of self-response. Therefore, in any analysis the type of respondent should be noted.

The **Child Functioning Module** is recommended for use in surveys that either focus on children, or that contain modules that focus on one or all children in the household. The child functioning module should always be used in surveys that focus on education. The domains included in this module address the unique situation of children and are critical for understanding participation in educational activities which is children's primary activity and which will have major impacts on their lives as adults. Information obtained using only the WG-SS will not provide information on these key domains.

The WG tools were developed as interrelated components that would describe functioning in different population subgroups depending on the objectives and selected platform for data collection. The analysis guides for the three survey components will provide information on how to relate the information produced using the different tools on the same study population. The data collection tools were developed to meet user needs and reflect the need to balance requirements for a very short set of questions for some purposes against the need for more detail for other purposes and for specific age groups.

DISAGGREGATION BY DISABILITY STATUS

Disability is not inherently a dichotomous concept; it exists on a continuum. How that continuum is created and which cut point is chosen to define the population with disabilities will have a direct effect on the prevalence of disability and the characteristics of the population with disabilities. Which questions to include and where to define disability is a function of the data collection objective. When reporting information on disability, it is essential to also report on the questions used to define disability.

There are two necessary conditions that must be met in order to disaggregate data by disability. First, the indicator must already be collected and second, there must be a straightforward and simple way to identify persons with disabilities so that the indicator can be disaggregated by disability status.

The current Sustainable Development Goals (SDGs) framework addresses the first condition, as the agreed set of indicators will be used for monitoring and evaluating progress in the implementation of the SDG goals and targets. The second condition has also been met with the development of census and survey tools adopted by the WG and partners. WG tools can identify persons with disabilities for disaggregation purposes in an internationally comparable way.

Overall, there is broad international consensus that the WG-SS represents the international best practice for disaggregating data by disability. United Nations Statistical Division (UNSD) and the UN Economic Commission for Europe have recommended the WG Short Set on Functioning for use in the current round of population censuses

(see: <https://unstats.un.org/unsd/statcom/doc15/BG-Censuses.pdf>). A UN-sponsored Disability Data Expert Group has recommended them for use in disaggregating the SDGs and for monitoring the implementation of the UNUNCRPD. A Joint Statement provided by the Disability Sector (composed of UN Member States, UN Agencies, organizations of persons with disabilities, civil society and independent experts) to the Interagency Expert Group on SDGs (IAEG-SDGs) has recommended the

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

The Washington Group Data Collection Tools and their Recommended Use

WG Short Set on Functioning for the purposes of SDG data disaggregation for adults and the UNICEF/Washington Group CFM for disaggregation by disability among children in order to ensure international comparability and comparability over time (see: <http://www.internationaldisabilityalliance.org/data-joint-statement-march2017>). Countries in the Asia and Pacific Region, through the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), have recommended their use in producing the Incheon “Making the Right Real” Disability Strategy indicators. Bilateral agencies have also adopted tools developed by the WG. For example, both DFID (UK Department for International Development) and DFAT (Australian Department of Foreign Affairs and Trade) have determined that the questions be used for monitoring the effectiveness of their programs in reaching persons with disabilities.

How to use the Short Set on Functioning to Disaggregate Data by Disability Status

Collecting data using the WG-SS provides valuable insight into whether those identified with disabilities are benefitting from policies and programs designed to improve participation. The disaggregated data can be used to evaluate these programs and policies and determine whether the needs of all population sub-groups are being met. The questions can be asked at several points in time to see if progress has been made during an intervention period and to ascertain if people with disabilities are being included or left behind. The questions can be added to existing or planned large- or small-scale surveys or can be included into a program’s usual management/monitoring and data collection processes. For example, the questions could be used in an existing employment survey to disaggregate access to employment by disability status or can be asked as part of an intake form for those seeking general, non-disability specific services to see if the service is being accessed by persons with disability to the same extent as it is accessed by persons without disability. As a group, the WG-SS questions can be administered in just over one minute, which does not impose a significant administration burden on existing instruments.

Following standard best practices, any reporting of data collected using the WG-SS needs to articulate clearly how the questions were used, the age range of participants, and the cut-off point used to determine disability status.

For example, the table below shows employment status disaggregated by disability status using data from a national survey. Disability status is determined using the WG-SS. Four possible cut-offs are presented: the recommended cut-off, at least one domain with reported difficulty of a lot or cannot do, is highlighted in red. At the recommended cut-off, the estimates for those 18-64 years of age illustrate that those with a disability are much less likely to be working (30.8%) than are those without a disability (73.5%).

The table also clearly illustrates how different cut-offs elicit different results: higher prevalence and less disparity in employment when the cut-off includes those with minor difficulties; and lower prevalence and greatest disparity when the cut-off is more restrictive and includes only those with the most severe difficulties. If this survey was repeated in five years, it would be possible to determine if programs that were put in place to increase employment among those with a disability were having the desired effect by showing whether the employment rates for those with a disability were approaching the rates of those without.

Employment¹ disaggregated by disability status²: adults 18-64 years

| Person with disability has at least: | Overall prevalence | % working | |
|---------------------------------------|--------------------|--------------------|-----------------|
| | | Without disability | With disability |
| 1 Domain ‘some difficulty’ | 35.4 | 76.6 | 60.2 |
| 2 Domains ‘some difficulty’ | 14.9 | 74.6 | 48.5 |
| 1 Domain ‘a lot of difficulty’ | 6.6 | 73.5 | 30.8 |
| 1 Domain ‘unable to do it’ | 1.2 | 71.4 | 14.6 |

Data Source: U.S. National Health Interview Survey, 2013.

¹ NHIS question: What was your employment status last week?

² Disability status determined by use of the Washington Group short set of questions. The sub-population *with disability* includes everyone with at least one domain that is coded as *a lot of difficulty* or *cannot do it at all*.

Why is this important?

Understanding the exact nature of the barriers faced by persons with disabilities and determining the actions necessary to equalize participation requires the collection of extensive and detailed information. Disaggregating outcome indicators, such as the SDGs, or programmatic objectives, to determine if gaps exist between those with and without a disability is a necessary first step towards addressing disparities. Doing so only requires the addition of a small set of questions on already existing data instruments. The importance of disaggregation is illustrated by an example in the area of education. In recent years, the rate of primary education has increased significantly, in no small part from efforts to build more schools and train more teachers. A logical conclusion would be that to address those last few percent of children not in school, a country should simply build even more schools and train more teachers according to past models. But if the remaining out-of-school children are out of school for reasons associated with other characteristics – such as disability – then only doing what has been done in the past may not get a country that much closer to universal primary education. It may require different actions, like making schools, school materials and curricula more accessible. If school enrolment was not disaggregated by disability status, we would not know that children with disability were not attending school at the same rate as those without disability – and interventions would not be initiated to address this disparity.

For more information, please refer to the Washington Group website:

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

For content of Washington Group tools, please refer to:

<http://www.washingtongroup-disability.com/washington-group-question-sets/>



Appendix 2

Disability Data Disaggregation Joint Statement by the Disability Sector Fourth Meeting of the IAEG-SDG's Geneva, November 2016



“In committing to the realization of the 2030 Agenda for Sustainable Development, Member States recognized that the dignity of the individual is fundamental and that the Agenda’s Goals and targets should be met for all nations and people and for all segments of society. Furthermore, they endeavoured to reach first those who are furthest behind.”

- Sustainable Development Goals Report 2016

Disability Data Disaggregation Joint Statement by the Disability Sector

Fourth meeting of the IAEG-SDG’s

Geneva, November 2016

Persons with disabilities are among those furthest behind and accordingly the Sustainable Development Goals (SDGs) and their indicators clearly state that disaggregated data are needed and should be collected for the purpose of monitoring advancement in the implementation of the goals for this segment of the population.

We - UN agencies, organizations of persons with disabilities, civil society and independent experts - would like to call the attention of the IAEG-SDGs and the UN Statistics Division to the need for taking immediate action and clearly recommend national statistical offices to move forward with the disaggregation of data by disability.

To that end, we would like to state our unanimous position that there are appropriate and broadly tested methodologies in place to disaggregate data by disability:

First, to ensure international comparability and comparability over time for the purposes of SDG data disaggregation for adults, we recommend the use of the Washington Group short set of questions. For disaggregation by disability among children the recommended tool is the UNICEF/Washington Group module on Child Functioning. Both instruments can be easily and cost effectively inserted in all national data collection efforts.

We also recommend going beyond disaggregation. Additional information could and should be collected to give guidance to policy makers on how to achieve the SDGs and measure the impact of policies and programmes. For this purpose, the WHO has developed the Model Disability Survey and other UN agencies are also in the process of developing additional modules.

United Nations Development Programme • International Labour Organization
United Nations Children’s Fund (UNICEF) • World Health Organisation
Office of the High Commissioner for Human Rights • United Nations Population Fund
United Nations Special Rapporteur on the rights of persons with disabilities
United Nations Partnership to Promote the Rights of Persons with Disabilities
International Disability Alliance • International Disability and Development Consortium



Appendix 3

Disability Data Disaggregation Joint Statement by the Disability Sector Fifth Meeting of the IAEG-SDG's Ottawa, March 2017



Empowered lives.
Resilient nations.



International
Labour
Organization



***Disability Data Disaggregation
Joint Statement by the Disability Sector
Fifth meeting of the IAEG-SDG's
Ottawa, March 2017***

Persons with disabilities are among those furthest behind and accordingly the Sustainable Development Goals (SDGs) and their indicators clearly state that disaggregated data are needed and should be collected for the purpose of monitoring advancement in the implementation of the goals for this segment of the population.

We - UN Member States, UN Agencies, organizations of persons with disabilities, civil society and independent experts - would like to call the attention of the IAEG-SDGs and the UN Statistics Division to the need for taking immediate action and clearly recommend national statistical offices to move forward with the disaggregation of data by disability.

To that end, we would like to state our unanimous position that there are appropriate and broadly tested methodologies in place to disaggregate data by disability. In order to ensure international comparability and comparability over time for the purposes of SDG data disaggregation for adults, **we recommend the use of the short set of questions developed by the Washington Group. For disaggregation by disability among children the recommended tool is the UNICEF/Washington Group module on Child Functioning. Both instruments can be easily and cost effectively inserted in all national data collection efforts.**

This joint statement has been endorsed by: the UK Department for International Development (DFID, UK); the Department for Foreign Affairs and Trade (DFAT, Australia); United Nations Development Program; the International Labour Organisation; the United Nations Special Rapporteur on the Rights of Persons with Disabilities; United Nations Women; the United Nations Human Rights Office of the High Commissioner; United Nations International Children's Emergency Fund (UNICEF); the International Disability Alliance (IDA, with eight global and six regional Members); and the International Disability and Development Consortium (IDDC, with 26 full members).



Appendix 4

Global Action Network on Disability (GLAD) Meeting Communique 2-3 March 2017 Berlin, Germany



Global Action on Disability (GLAD) Network Meeting Communiqué¹

2-3 March 2017, Berlin, Germany

The Global Action on Disability (GLAD) Network met in Berlin on 2-3 March 2017, for the first time since its launch on 3 December 2015. The Australian Department of Foreign Affairs and Trade (DFAT) and the International Disability Alliance (IDA) co-chaired the meeting. The meeting was hosted by the Federal Ministry for Economic Cooperation and Development of Germany (BMZ). Representatives from 32 organisations (see attached) met to identify key actions to advance disability inclusive education, social protection and humanitarian action in developing countries. Representatives also agreed to work together to prioritise the collection and analysis of data to guarantee that people with disabilities are not left behind in development and humanitarian efforts.

Ms Annette Seidel, Head of Division 302 (Human Rights, Gender Equality, Inclusion of Persons with Disabilities) of BMZ, opened the meeting, highlighting GLAD's uniqueness in facilitating learning opportunities by uniting a broad range of stakeholders within one network of like-minded people. Ms Dinah Radtke, Vice-Chair of Disabled Peoples International (DPI), emphasized the importance of supporting the inclusion and capacity building of disabled people's organisations (DPOs) in developing countries. The Australian Minister for International Development and the Pacific, [Senator the Hon Concetta Fierravanti-Wells](#), reaffirmed Australia's commitment to disability rights and disability inclusive development. The Minister also emphasised that working with, and learning from, people with disabilities themselves, is critical to understanding how best to address barriers to full participation. Colin Allen, Chair of IDA, reminded that the GLAD Network exists to motivate and inspire entities to further support the inclusion of persons with disabilities in their international development and humanitarian action efforts.

Carsten Schmitz-Hoffmann (Head of department of GIZ) underlined that GIZ is still facing challenges in systematically addressing inclusion in their development programmes; therefore, it is important to share knowledge in dialogue with network initiatives like GLAD to improve jointly promising approaches.

¹ Issued by the co-chairs in consultation with the participants.

Michael Krake, Head of Political Analysis and Strategic Planning Department (Federal Ministry for Economic Cooperation and Development), filled in for the parliamentary state secretary of Germany Thomas Silberhorn and underlined the importance of the disability marker and a gender balanced CRPD Committee.

GLAD welcomed the International Labor Organization (ILO) as a new Network member and noted that the Open Society Foundations was the newest member of the Steering Committee. The United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) would represent the United Nations agencies on the Steering Committee. GLAD also acknowledges the participation of interested organisations and observers at this Berlin meeting.

GLAD Updates

The Australian Minister for International Development and the Pacific chaired a session on the work undertaken since the 17 June 2016 Steering Committee meeting to facilitate greater cooperation and coordination by GLAD members.

DFAT presented the GLAD stakeholder mapping exercise commissioned by the GLAD Network to identify and understand the entities that are actively involved in contributing international resources to disability-inclusive development and humanitarian action, and the rationale behind these efforts. The first phase identified areas in which the Steering Committee members are investing their financial and political capital to support disability-inclusive development and humanitarian action. In particular, it identified that advocacy efforts focus on common work in inclusive education, promoting improved data on disability, and endorsement and implementation of the Charter on Inclusion of Persons with Disabilities in Humanitarian Action. Subsequent phases of the mapping exercise will expand the scope to include all GLAD members and, eventually, potential members. A working group, which is to be established, will refine the findings into a collaboration tool for the online knowledge-sharing platform, and guide subsequent phases of the project.

The Ministry for Foreign Affairs of Finland (FORMIN) presented on progress in developing an online knowledge-sharing platform. Following consideration of an options paper, the GLAD Network agreed on the guiding principles and functionality of the platform. FORMIN called for financial and in-kind contributions by multiple partners to enhance sustainability and create

a sense of shared responsibility and mutual accountability. A working group will explore options for, and lead on the development of, the platform.

The importance of both stakeholder mapping and an online knowledge-sharing platform for facilitating out of session communication, information sharing and collaboration was emphasised throughout the meeting.

Shared experiences monitoring and measuring progress on disability inclusion

Consistent with GLAD's goal of learning from each other by sharing knowledge and resources, the Australian Minister for International Development and the Pacific chaired a session on monitoring and measuring progress towards inclusive development and humanitarian action.

The International Disability and Development Consortium (IDDC) presented on the current momentum towards disability-disaggregated data and statistics, and highlighted the importance of consistent advocacy on methodology. The UK Department for International Development (DFID) introduced a proposal for an OECD DAC marker on disability inclusion. The GLAD Network welcomed the findings of the strategic evaluation of disability-inclusive development in the United Nations Development Programme (UNDP) and agreed that the next UNDP strategic plan should give greater prominence to disability. DFAT provided an overview of its ongoing strategic evaluation of disability-inclusive development, committing to sharing final findings at the next GLAD Network meeting. Preliminary findings indicate that while increased commitment from senior leadership is encouraging more inclusive programming, investment managers are missing or under-estimating opportunities to engage with persons with disabilities in program design and implementation. The BMZ committed to sharing the findings of an external evaluation of its Action Plan for the Inclusion of Persons with Disabilities, following its completion in May 2017.

Thematic Working Group Sessions

On 17 January 2017, the Steering Committee, noting their common focus on disability-inclusive programming and advocacy on humanitarian action, education and social protection, established three working groups to lead GLAD engagement on these priority issues. The working groups met for the first time in Berlin and, in a reporting-back session facilitated by the European Commission, agreed on the GLAD Network's approach on the issues.

Humanitarian action

DFAT facilitated the Humanitarian Action Working Group, which included presentations by the Inter-Agency Standing Committee Task Team on Inclusion of Persons with Disabilities in Humanitarian Action (IASC-TT), UNICEF and Handicap International.

GLAD calls on all relevant stakeholders who have not already done so, to endorse the [Charter on Disability Inclusion in Humanitarian Action](#) launched at the 2016 World Humanitarian Summit.

GLAD acknowledges the valuable work of the IASC-TT to develop globally endorsed guidelines to assist humanitarian actors and affected communities to coordinate, plan, implement, monitor and evaluate essential actions that foster the full and effective participation and inclusion of persons with disabilities across all phases of humanitarian action.

GLAD will promote disability-inclusive humanitarian action through:

- promoting the Charter and its universalisation and implementation; and
- raising awareness, building internal constituencies and promoting common messages across development disability and humanitarian areas

GLAD will draft and agree common messages on disability-inclusive humanitarian action, for use by Network members in influencing executive boards of UNHCR, UNICEF and the World Food Program.

The GLAD Humanitarian Action Working Group will meet in the margins of the ECOSOC Humanitarian Affairs Segment (21-23 June 2017).

Education

The Norwegian Agency for Development Cooperation (NORAD) and USAID co-facilitated the Education Working Group, supported by IDA and the Swedish International Development Cooperation Agency. The session included presentations from UNICEF, the Global Partnership on Education (GPE) and the World Bank.

The GLAD Network is concerned that equal, inclusive and equitable education does not reach persons who are most marginalized. GLAD encourages national education sector plans to include strategies that ensure marginalized children, including children with disabilities, can exercise their right to education. There is also need to address the needs of all age learners and staff with disabilities and expand the notion of education beyond preschool and primary

education. This approach would provide opportunities for all learners with disabilities to access lifelong learning and equally benefit technological and scientific progress, including application of inclusive information and communication technologies.

GLAD will seek to influence the following global and regional processes over the next 12 months:

- World Bank 2018 World Development Report, which has an education focus, including a call for good practice examples;
- UNICEF's Education Sector Analysis Methodological Guidelines, including the call to pilot, share and provide feedback on the chapter on inclusive education of children with disabilities;
- USAID's inclusive education evidence summit, scheduled for end 2017, including the call for participants/co-hosts.

There will be follow up from the GLAD co-chairs with the GPE regarding inclusive education for persons with disabilities.

USAID will work with participants of the education working group to collect specific project and program information, including resources on training tools, and mapping of programs and projects at country level. This would feed into the GLAD Network's online knowledge sharing platform system. USAID will develop a template to collect information from GLAD Network members on their inclusive-education projects and investments.

Social protection

FORMIN and GIZ facilitated the Social Protection Working Group. The GLAD Network noted that universal social protection floors are a key instrument for reducing poverty and inequality and supporting inclusive economic growth. Access to social protection programs provide the resources necessary to live a life of dignity and facilitate access to opportunities. Countries developing or reforming their social protection systems should incorporate disability inclusion in the design from the start. Both universal policies and targeted social protection services should consider the specific rights of persons with disabilities.

The GLAD Network supported in principle, and agreed to provide comments by 24 March on, a draft joint statement, *Towards inclusive social protection system supporting full and effective participation of persons with disabilities*, prepared by IDA and ILO. GLAD also committed to

drafting a joint statement on adaptive social protection in fragile and humanitarian contexts, to present in July 2017.

The working group will meet by June 2017 to define its objectives and map GLAD members' social protection work, to understand opportunities for collaboration and opportunities to influence both social protection and disability-inclusion circles. It will also circulate to the Network the outcomes of two ongoing operational processes, namely BMZ's social protection toolbox and DFID's operational guidance.

Stakeholder sessions

To support collaboration between members, GLAD is committed to facilitating opportunities for focused discussions within its constituent groups, including States, multilateral agencies, foundations and private sector. Accordingly, the GLAD Network meeting included an opportunity for stakeholder groupings separately. The World Bank facilitated a panel discussion wherein the stakeholder groups reported on the outcomes of their discussions.

State and multilateral agencies

While States and multilateral agencies are likely to meet separately at future GLAD meetings, on this occasion they met together, facilitated by GIZ, to discuss issues of common interest. The combined group discussed FORMIN's experience in introducing a policy marker to track funding and welcomed DFID's proposal to jointly work towards a new OECD DAC policy marker on disability inclusion. Group members expressed the timely need for a systematic and international approach for monitoring both the implementation of the CRPD and for tracking the achievement of the Sustainable Development Goals (SDGs) for people with disabilities. The group discussed and agreed the importance of the Washington Group on Disability Statistics short set of questions and the UNICEF/Washington Group module on Child Functioning for SDG data disaggregation for children as a cost-effective tool for the collection of disability-disaggregated data in census and population surveys.

Private sector engagement

Business Disability International facilitated a discussion on the relationship between members of the GLAD Network and the private sector. The launch of the Business & Sustainable Development Commission by the World Economic Forum in 2016 highlights the emerging

corporate interest in the SDG agenda. There is great potential to leverage the collective influence of GLAD Network members to shape how the private sector engages on disability-inclusive development and humanitarian action. Likewise, there is great potential for GLAD Network members to enhance inclusive practices through learning from the expertise of the private sector.

In order for GLAD to maximise its impact, it will invite mainstream business networks at the global level to become members of GLAD, rather than their individual corporate members. Examples include the Business & Sustainable Development Commission and Business for Social Responsibility (BSR). GLAD will also approach the UN Global Compact to consider GLAD Network membership.

Additionally, each of GLAD's thematic working groups will consider how private sector entities can contribute to their forward work plans. In the longer term, there is potential to develop agreed disability-inclusive messaging that GLAD members can use when engaging private sector entities and when building the capacity of developing country governments to call for inclusive services through engagements the Private Sector.

Engagement with Foundation members

The Disability Rights Fund/Disability Rights Advocacy Fund facilitated a discussion on GLAD's engagement with foundations and philanthropies. The group discussed the importance of maintaining realistic targets for the group as well as feasibility of a high-level event during the 10th Session of the Conference of States Parties in June 2017, including participation from Directors of New-York based Foundations, and Ministers of Member States. GLAD members were encouraged to introduce additional foundations to the GLAD Network.

Measuring equality through disability data

The GLAD Network recognised the urgent need for better data on the situation of people with disabilities globally. The 2030 Agenda for Sustainable Development clearly commits to disaggregating data wherever possible to monitor progress in implementing the SDGs so that no one is left behind.

The GLAD Network acknowledges that the Washington Group has developed and tested internationally comparable, cost-effective tools for use in all national data collection efforts to monitor equality of outcomes for people with disabilities.

The GLAD Network endorses the use of the short set of questions developed by the Washington Group for the SDG disaggregation of data for adults, and the UNICEF/Washington Group module on Child Functioning for the SDG disaggregation of data for children. The GLAD Network recognises the importance of supporting national statistics offices to implement these tools and analyse the resulting data to inform better policy and programs.

Furthermore, the GLAD Network will work towards including the short set of questions developed by the Washington Group tools within their own organisations in program-level monitoring and evaluation systems to assess our own progress in supporting the inclusion of people with disabilities.

Towards a new OECD DAC Disability Marker

The GLAD Network endorsed DFID's proposal to work towards a new policy marker on disability-inclusive development under the auspices of the OECD Development Assistance Committee (DAC). The GLAD Network sees value in being able to monitor and analyse trends in funding to support disability-inclusive development over time. This information will be valuable in supporting the case for greater investment in disability-inclusive development, and improve our understanding of where more effort is needed. This work is particularly timely, given the imperative mandate of the 2030 Agenda to track the achievement of the SDGs for people with disabilities.

Next steps

In closing, co-chairs re-iterated a number of themes that had emerged during the meeting, including:

- the need, given the initial phase of the GLAD Network, to control the growth of GLAD membership and focus efforts on the selected themes, such that GLAD can make progress towards its agreed goals;
- the importance of working with people with disabilities and their representative organizations in all of the GLAD Network's activities;
- the opportunity that GLAD provides for members to motivate their organizations to mainstream disability inclusion internally;

- the value of members' individual and collective contributions to advancing GLAD goals.

Upcoming meetings

GLAD Steering Committee will meet in New York on Friday 16 June 2017, following the Conference of States Parties to the UN Convention on the Rights of Persons with Disabilities.

It is anticipated that the next GLAD Network meeting will be held at least four months after the Conference of States Parties, and probably in early 2018. The GLAD Secretariat is seeking volunteers to host the 2018 GLAD Network meeting. The 16 June 2017 Steering Committee meeting will consider possible dates and locations. This timely announcement will facilitate early arrangements for Ministerial representation.

The GLAD Secretariat will seek volunteers to lead each of the working groups, and to progress work plans out of session, in consultation with the working group members and the GLAD Secretariat. The GLAD Secretariat will also seek volunteers to support the development of the stakeholder mapping exercise and the knowledge-sharing platform.

Governance and new members

The permanent co-chair of the GLAD Network is IDA. The second rotating co-chair, currently DFAT until the end of 2017, is a GLAD member agreed by a simple majority of GLAD members. The GLAD Secretariat will prepare and circulate for consideration by Network members an options paper on possible amendments to the GLAD governance arrangements and seek out of session nominations for the next rotating co-chair.

Admission of new GLAD members, which requires agreement by a majority of existing members, will continue to be considered out of session.



Global Action on Disability (GLAD) Network Meeting

2 to 3 March 2017, Berlin

Participant list

**Denotes GLAD Network Member*

***Denotes GLAD Steering Committee Member*

African Disability Forum

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Consultant / CRPD Committee Member

Anjeline Okola – Charles
Programme Coordinator

Abilis**

Kalle Konkola
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Big Lottery Fund

Christopher Manion
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Business Disability International**

Susan Scott-Parker
CEO & Founder

Disabled People's International

Dinah Radtke
Vice-Chair

Disability Rights Fund and Disability Rights Advocacy Fund**

Diana Samarasan
Founding Executive Director

Yumi Sera
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Alicia Martin Diaz
Programme Manager, DG International
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Global Partnership for Education

Ruchi Singh
Education Specialist- Inclusive Education

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Senator the Hon Concetta Fierravanti-
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Appendix 5

**Excerpt
Conference of State Parties
(COSP)
June 15, 2017**

Excerpt from: ROUGH EDITED COPY

United Nations Headquarters
Conference of the State Parties – CR4
June 15, 2017

This is being provided in a rough-draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings

* * * *

I would like to give the floor to New Zealand.

>> Thank you very much and thank you to all of the panelists for their presentations. They were very informative. I have delivered a statement on behalf of the group of countries, Argentina, Australia, Austria, Brazil, Bulgaria, Canada, Costa Rica, Dominican Republic, Finland, Iceland, Jamaica, Jordan, Norway, Panama, Poland, Spain, Tunisia, Turkey, the United Kingdom, United States, and New Zealand. We strongly recommend the Washington Group questions to be used as a tool to segregate data by disability, particularly in household surveys and national agendas. It requires member states to desegregate data by disability. The Washington Group short list of questions is an appropriate and broadly tested methodology already in place to desegregate data by disability. We urge the United Nations Statistical Division to utilize the Washington Group's short set of questions and recommend this tool to national statistical officers and the interagency and expert group on the Sustainable Development Goals indicators. Delays in doing so could have detrimental consequences to the implementation processes of the SDGs which will leave persons with disabilities uncounted and behind.

We call for the continued establishment of focal points on persons with disabilities and U.N. agencies as well as the inclusion of persons with disabilities and strategic plans and reporting an indicator framework for U.N. agencies in line with the CRPD and 2030 Agenda. The rights of persons with disabilities by states, parties and the U.N. cannot be achieved in the rights of persons with disabilities are not mainstreamed across the U.N. system. Despite commitments contained in the CRPD and agenda 2030, we understand that some U.N. agencies may be preparing to scale down or have not established focal points on persons with disabilities. These roles are crucial to mainstream of disability issues across the agenda and leaving no one behind.

We wish to commend the COSP bureau, the full and meaningful participation and inclusion of persons with disabilities and their representative organizations and the preparation and official program of conference. We urge member states to maintain this practice in the future. Thank you.



Appendix 6

Towards Further Improvements in Disability Statistics

Joint Statement by UNSD and the Washington Group

Towards Further Improvements in Disability Statistics

-Joint Statement by UNSD and the Washington Group-

We recognize that fundamental improvements in statistics on disability require a holistic approach including improvement in the collection, analysis, dissemination and utilization of statistics on disability. At the same time, we also recognize the urgent need for high-quality and relevant statistics on disability for monitoring the full inclusion of persons with disabilities as required by the UN Convention on the Rights of Persons with Disabilities (CRPD) as well as the 2030 Agenda for Sustainable Development.

The United Nations Statistics Division (UNSD) is a substantive Division of the Department of Economic and Social Affairs (DESA) and the secretariat to the United Nations Statistical Commission. UNSD's disability statistics programme that started in the early 1980s covers a range of areas including the development of international guidelines on measurement of disability, technical assistance for strengthening national statistical capacity, and compilation and dissemination of statistics on disability. Hence, as a goal, UNSD, strives towards an overall development of national statistical systems in advancing statistics on disability in the long-run.

The Washington Group on Disability Statistics (WG), a city group under the aegis of the United Nations Statistical Commission, was established in 2001 to address the need for cross-nationally comparable population-based measures of disability. The WG has developed a Short Set (WG-SS) of six questions on disability for use in censuses and surveys, an extended set (WG-ES) for use in surveys, and, jointly with UNICEF, a Child Functioning Module (CFM) and is conducting regional implementation workshops to facilitate their adoption. The WG-SS and the WG-UNICEFCFM have been tested extensively and when added to ongoing data collections provide an efficient approach to monitor implementation of the UN CRPD and the SDGs by disaggregating data by disability status. The data collection tools are in use by a significant number of National Statistical Offices and have been endorsed by a number of UN agencies, development ministries and civil society organisations.

We recognize that, in addition to addressing the current, urgent needs for data, there must be a long-term and coordinated strategy across all international partners for strengthening national capacity to generate robust statistics on disability for national planning and monitoring. Together, and building on our complementary roles, these approaches will ensure that persons with disabilities are included in national development.

We hereby reaffirm our commitments to collaborate closely and effectively under the guidance of the UN Statistical Commission to achieve further improvements in statistics on disability.

New York, Washington, Sydney, 31 October 2017,

**2rSchw
f,or**
Statistics Division/DESA

Jennifer Madans



Chair

Washington Group on Disability Statistics