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The Washington Group on Disability Statistics

Prepared by The Washington Group on Disability Statistics



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The Washington Group on Disability Statistics

Background Document

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Washington Group on Disability Statistics: History

In 2001, the International Seminar on the Measurement of Disability organized by the UN 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. Additionally recognized was the need for a clearer understanding of disability, including the numbers of individuals living with a disability, their characteristics and their access to all mainstream policies, systems and services (e.g. education, health, social inclusion, and transportation).

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 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 15 years, over 135 (developed and developing) 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. Collection of data on disability under the UN CRPD (Convention of the Rights of Persons with Disabilities) is now the responsibility of every government that has ratified the Convention.

The WG has received funding from the World Bank and collaborated with the Statistics Division in The Economic and Social Commission for Asia and the Pacific. The US National Center for Health Statistics (NCHS) staffs the Secretariat. 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

Washington Group Tools

The WG questions are designed to provide comparable data cross-nationally 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, in 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 go to <u>http://www.washingtongroup-disability.com/</u>

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 allow 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. include the WG-SS within a larger survey or registration form to enable disaggregation of other measures (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)

Because the WG Short Set 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 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 devises and their impact of functioning.

WG/UNICEF Child Functioning Module (CFM)

While the WG-SS can identify many children with functional difficulties, the WG determined 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) 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) will include both the WG-SS for adults and the CFM for children. 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 extensively both cognitively and in the field to achieve this goal.

The CFM was designed to do the following:

- Expand the functional domains relative to children and child development: The distribution of types of disability are different for children compared with adults. In adults, the major problems are mobility, sensory, and personal care especially with advancing years. In children, the main disabilities are related to intellectual functioning, affect and behavior.
- Incorporate a fuller age range: The reference age is 2-17 years. The workgroup decided it was not feasible to capture disabilities among children under 2 years of age through population surveys. There are different question sets for children age 2-4 and those age 5-17.

Annual Meetings

The WG meets annually. Since its inception, the group has met 17 times in different regions of the world making access to WG meetings more accessible to 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). The 2018 meeting is being planned for 6-9 November, just outside of Rome, Italy.

1.	Washington DC, USA	2/2002	10. Luxembourg	11/2010
2.	Canada	1/2003	11. Bermuda	11/2011
3.	Belgium	2/3004	12. Thailand	10/2012
4.	Thailand	9/2004	13. Jordan	10/2013
5.	Brazil	9/2005	14. Argentina	10/2014
6.	Uganda	10/2006	15. Denmark	10/2015
7.	Ireland	9/2007	16. South Africa	12/2016
8.	Philippines	10/2008	17. Australia	10/2017
0	Tonzonio	10/2000		

9. Tanzania 10/2009

Workgroups

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

- Analysis 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. The current work plan is being developed and may address the determination of mutually exclusive categories such as mild, moderate, and severe disability; and burden measures such as the number of domains involved at different cut-offs.
- Child Functioning chaired by NCHS; this workgroup is focusing on the cognitive and field testing of a module on Inclusive Education to be used in conjunction with the child functioning module that would address barriers and facilitators to education among all children.
- Psychosocial Functioning Co-chaired by South Africa and Italy; this workgroup has examined the performance of the WG questions on depression and anxiety. To date, the group has examined cross-cultural performance using data collected in Cameroon, Canada, India and the US, and assessed approaches to creating a summary WG-Mental Health indicator. Future plans include conducting further analyses of the current WG affect measures using data collected in other countries, identifying additional universally-applicable psychosocial functioning measures, and examining additional domains of psychosocial functioning not currently captured by the existing WG affect measures.
- Disability Module for Labor Force Surveys Co-chaired by ILO and the Secretariat, this workgroup is developing a module for use in labor force surveys that will include the WG-SS plus some elements from the WG-ES; namely, upper body functioning and affect (anxiety and depression). The disability module for Labor Force Surveys was cognitively tested in the United States, and after minor revisions was tested in India. Plans are for the next round of cognitive testing to be carried out in Mongolia. A full report of the results of cognitive testing will be available upon completion.

 Administrative data – Co-chaired by South Africa and the Secretariat, this workgroup focuses on the use of administrative systems for the collection of disability information. The workgroup was constituted at the 17th meeting of the WG and is developing a work plan to assess the feasibility of collecting disability data through administrative sources.

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/

- 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 syntax
- Regional guide to improve disability data collection and analysis in Arab speaking countries (with ESCWA: Economic and Social Commission for Western Asia)

WG Website

The WG has recently revised its website (<u>http://www.washingtongroup-disability.com/</u>), 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 (<u>http://www.washingtongroup-disability.com/washington-group-blog/</u>), and Frequently Asked Questions (FAQs) (<u>http://www.washingtongroup-disability.com/frequently-asked-questions/</u>).



Regional Implementation Workshops

Over the past two years, (and with the support from the Australian Department of Foreign Affairs and Trade (DFAT)), UNSD, UNICEF and the WG have carried out regional workshops to meet the varied needs of data producers and users. With the exception of the regional UNSD workshop in Bangkok, the WG has been represented at all UNSD workshops, and has co-sponsored all regional UNICEF workshops.

UNSD Workshops on Disability Measurement and Statistics focusing on the 2030 Agenda for Sustainable Development and the 2020 Round of Population and Housing Censuses

- Bangkok, Thailand (SE Asia)*
- Bridgetown, Barbados (Caribbean)
- Kampala, Uganda (Africa)
- Muscat, Oman (Western Asia)
- Santiago, Chile (Latin America)
- Almaty, Kazakhstan (Central Asia)
 * No WG representation

UNICEF Workshops on Disability Measurement with a focus on Child Functioning and Disability

- Tunis, Tunisia (National)
- Geneva, Switzerland (Central Asia)
- Westchester, NY (Latin America)
- Westchester, NY (SE Asia+)
- Dakar, Senegal (Africa)

WG Workshops on Disability Measurement with a focus on the Implementation of WG tools in National Statistical Systems

- Nadi, Fiji (South Pacific)
- Casablanca, Morocco (Western Asia)
- Rome, Italy (non-regional)
- Port of Spain, Trinidad & Tobago (Caribbean)
- Mexico City, Mexico (Latin America)
- SE Asia (planned April 2018)
- Africa (planned May 2018)
- Central Asia (planned 2018)

Recent Adoption and Endorsements of the WG-SS

Over 75 NSOs have reported implementing the WG-SS in a national census or survey. In addition to NSOs, WG and WG/UNICEF tools are being adopted and incorporated into data collection systems by a growing number and variety of actors globally, including international organizations, NGOs, DPOs and academia. A few examples:

- UNICEF: deployment of the Child Functioning Module (CFM) in the Multiple Indicator Cluster Surveys (MICS)
- USAID: development of a disability module to include the WG-SS in the Demographic and Health Surveys (DHS)
- World Bank: inclusion of the WG-SS into the Living Standards Measurement Study (LSMS)

- Handicap International: implementation of WG-SS in HI-sponsored projects, and development of e-learning tools: <u>https://hilearngo.handicap-</u>international.org/workspaces/176/open/tool/home#/tab/-1
- Sightsavers: use of the WG-SS in a programmatic setting in several developing countries: http://www.washingtongroup-disability.com/washington-group-blog/everybody-counts-puttingwashington-group-questions-action/
- Syria Relief UK: implementation of the CFM in data collections on Children with reduced functionality in Syria
- United Nations High Commissioner for Refugees: webinars focusing on the use of the WG-SS for the identification of persons with disability in refugee settings
- CBM International: promotion of data disaggregation by disability status using the WG-SS: http://www.cbm.org/Disaggregation-by-Disability-A-way-forward--498229.php

Several International aid agencies have adopted the WG-SS in their programs and supported projects:

- UK Department for International Development (DFID)
- Australian Department of Foreign Affairs and Trade (DFAT)
- US Agency for International Development (USAID)

The WG-SS has been recommended as the means to collect disability data for the 2020 round of censuses:

- UN Department of Economic and Social Affairs (DESA) Statistics Division (UNSD) (core topic) <u>https://unstats.un.org/unsd/demographic-social/Standards-and-</u> <u>Methods/files/Principles_and_Recommendations/Population-and-Housing-</u> Censuses/Series_M67rev3-E.pdf
- UN Economic Commission for Europe (ECE) (non-core topic)
 https://www.unece.org/fileadmin/DAM/stats/publications/2015/ECECES41_EN.pdf

The WG-SS has been recommended as the disability tool of choice for the purposes of monitoring the UN Convention on the Rights of Persons with Disability (CRPD) and the 2030 Sustainable Development Goals (SDGs):

- UN DESA/UNESCO Expert Group Meeting, Paris, July '14
- Follow-up conference on disability data, London, Oct '14

Endorsement of WG-SS: Recommendations for Disaggregation

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

For more information on the WG, contact the WG Secretariat at WG_Secretariat@cdc.gov

Washington Group on Disability Statistics

9 February 2018

Appendix 1

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



Washington Group on Disability Statistics

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.

This first in a series of <u>Washington Group</u> 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.washingtongroupdisability.com/.

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

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

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, communication, cognition (learning), accepting change, controlling behavior, relationships and

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.

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.

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 predetermined 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

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%) then 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.

		% working	
Person with disability has at least:	Overall prevalence	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

Employment¹ disaggregated by disability status²: adults 18-64 years

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/

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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 Washington Group on Disability Statistics

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Appendix 3

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



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).

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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, <u>Senator the Hon Concetta Fierravanti-Wells</u>, 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 programing, 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 disabilityinclusive 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 <u>Charter</u> <u>on Disability Inclusion in Humanitarian Action</u> 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 expend 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 or 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 Samuel Njuguna Kabue Consultant / CRPD Committee Member

Anjeline Okola – Charles Programme Coordinator

Abilis** Kalle Konkkola Chair

Bezev Gabriele Weigt Executive Board

Big Lottery Fund Christopher Manion Portfolio Manager

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 Director of Partnerships & Communications **European Commission** Alicia Martin Diaz Programme Manager, DG International Cooperation and Development

Global Partnership for Education Ruchi Singh Education Specialist- Inclusive Education

Sabine Terlecki European Advocacy Coordinator

Government of Australia

Senator the Hon Concetta Fierravanti-Wells Minister for International Development and the Pacific

Karen McNamara Adviser

Carolyn Jack Media Adviser

Department of Foreign Affairs and Trade, Australia**

Alison Chartres Assistant Secretary, Development Policy & Education Branch

Mika Kontiainen Director, Disability Jade Cooper Policy and Program Officer, Disability

Australian Permanent Mission to the

United Nations Geneva Tristen Slade Counsellor (Humanitarian)

Australian Embassy in Berlin Lauren Bain Deputy Head of Mission

Amanda Annamalay Second Secretary

Margalit Levin Second Secretary

Julia Kaute Cultural Relations Officer

Government of Canada *Global Affairs Canada* Sarah D'Aoust Governance Specialist

Government of Finland

Ministry for Foreign Affairs of Finland** Eppu Mikkonen-Jeanneret Senior Social Policy Adviser

Katariina Sario Senior Adviser, Non-discrimination & Rights of Persons with Disabilities

Government of Germany Bundesministerium für wirtschaftliche Zusammenarbeit und Entwicklung (BMZ)

Michael Krake, Head of Political Analysis and Strategic Planning Department

Annette Seidel Head of Division 302: Human Rights, Gender Equality, Inclusion of Persons with Disabilities

Lukas Groß

Division 302: Human Rights, Gender Equality, Inclusion of Persons with Disabilities

Jobelle-Diana Manalac-Knighton Division 302: Human Rights, Gender Equality, Inclusion of Persons with Disabilities

Bundesministerium für Arbeit und Soziales (BMAS) Friederike Kilian

Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ)** Carsten Schmitz-Hoffmann Head of the Economic and Social Development Division

Esther Sommer Advisor, Sector Initiative Inclusion of Persons with Disabilities

Simon Neuland Advisor, Sector Initiative Social Protection

Helle Deertz Junior Advisor, Sector Initiative Inclusion of Persons with Disabilities

Magnus Schmid Head of the implementation Unit -Secretariat Partnership for Sustainable Textiles

Bernd Schramm Project Manager, Sector Initiative Inclusion of Persons with Disabilities

Teresa Braun Sector Initiative Inclusion of Persons with Disabilities

Government of Ireland

Department of Foreign Affairs and Trade, Ireland** Patrick McLoughlin Executive Officer

Government of Japan

Japan International Cooperation Agency** Kenji Kuno Senior Advisor

Government of Norway Norwegian Agency for Development Cooperation** Ivar Evensmo Senior Advisor

Government of the United Kingdom *UK Department for International*

*Development*** Carrie Sunderland Head of Disability Policy

Joanna McGilvray Disability Policy Officer

Government of the United States of America USAID**

Robert Horvath Chief, Empowerment and Inclusion Division

Leah Maxson Disability Technical Advisor

Handicap International

Camille Gosselin Humanitarian Advocacy Manager

Inter-Agency Support Group on the Rights of Persons with Disabilities

Alarcos Cieza Co-chair of IASG, World Health Organisation

International Disability Alliance** Colin Allen Chair

Vladimir Cuk Executive Director

Alexandre Cote Capacity Building Program Manager Talin Avades Executive Assistant

International Disability and Development Consortium** Priscille Geiser Chair

International Labour Organization* Esteban Tromel Senior Disability Specialist

ONCE Lourdes Marquez Head of Strategic Planning

Javier Guemes Technical Director of International Relations

Open Society Foundations** Kimberly O'Haver Program Officer

UNESCO Irmgarda Kasinskaite-Buddeberg Programme Specialist

UNICEF

Gopal Mitra Program Specialist - Children with Disabilities

Natasha Graham Inclusive Education Consultant

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9 February 2018

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 on 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.

Washington Group on Disability Statistics

9 February 2018

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-UNICEF CFM 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 longterm 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,

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