



Stakeholder Group of  
**Persons with Disabilities**  
for Sustainable Development

**Presentation of the Disability Data Advocacy Working Group**

**10<sup>th</sup> Meeting of the IAEG-SDGs**

**Orsolya Bartha and Elizabeth Lockwood**

## What is the status of statistics and data collection in 2018?

- CRPD Article 31 requires States Parties (177 ratifications, countries) to collect data on persons with disabilities;
- 193 countries committed to collect data on persons with disabilities and to disaggregate data by disability by adopting the 2030 Agenda and the global indicator framework; and
- 232 global indicators, from which 11 are inclusive of disability, and there is the recommendation to disaggregate by disability.

## Overall official disability data are not reaching the global level to measure the SDGs.

- The lack of data on persons with disabilities increases marginalization and fails to address the situation and discrimination encountered by persons with disabilities.
- As a result, planning and budgeting for reasonable accommodations with effective policymaking have suffered and persons with disabilities have largely fallen off the statistical “map.” Evidence-based data on persons with disabilities at the national and global levels are instrumental in identifying the gaps and challenges of persons with disabilities that can support policymakers to address gaps and amend existing policies and regulations.

# Timeline

**2018:**  
Survey on assessment of disability data at the national level



**January 2019:**  
Launch of Disability Data Advocacy Working Group



**January 2019:**  
1. Webinar on collecting data on persons with disabilities in humanitarian settings  
2. Newsletter #1



**February 2019:**  
1. Webinar on providing practical guidance on gathering and analyzing disability data  
2. Newsletter #2



**March 2019:**  
1. Webinar on country experiences in disability data collection  
2. Newsletter #3



**April 2019:**  
1. Webinar on administrative data planned  
2. Newsletter #4

# Surveys

- IDA and CBM developed surveys for both the data webinar (April) and the data workshop (June) that were shared with a total of 550 individuals.
- These surveys had questions on the availability of disability data, knowledge on the 2030 Agenda and the CRPD.

# Survey findings

- Disability data can be insufficient, inconsistent, biased, and unreliable;
- Enumerators are not trained and thus relevant data is rarely collected;
- Available data (not disability related) are not systematically aggregated due to lack of awareness among state officials who are unaware of disability disaggregation tools;
- Data gained or produced by organizations are not recognized and are disregarded by statistical authorities.

# Survey findings

- There is a lack of cooperation between statistical offices and organizations on exchange of statistical information and other data;
- It is difficult to find reliable sources of data with disaggregated levels that can be used in proposals, projects, and programs;
- Often psychosocial disabilities and intellectual disabilities are classified as mental health conditions without any distinction, which is inaccurate.

# Solution and way forward

- We need to create understanding around data.
- We need dialogue, collaboration and partnerships to create connections and awareness.
- As a next step, the creation of an open platform for data dialogue was critical for exchange.



**Outcome:**

**Creation of the Disability Data Advocacy  
Working Group**

# Objective of the Working Group

- The Disability Data Advocacy Working Group was launched in January 2019.
- The objective of the Working Group is **to provide a global platform for information exchange, learning and dialogue, sharing of good practices, and collaboration on disability data collection, disaggregation, and analysis**

# Membership

- Membership in the Disability Data Advocacy Working Group is open to:
  - All persons with disabilities;
  - Organizations of persons with disabilities (DPOs);
  - Non-governmental and other organizations working on the rights of persons with disabilities;
  - Non-governmental donors;
  - Researchers;
  - Statisticians; and
  - Independent consultants working with persons with disabilities.

# Activities of the Working Group

- Webinars
- Newsletters
- Listserv

# Webinars

## **Webinar 1: January 31, 10-11am EST**

**Title:** Data on persons with disabilities in humanitarian settings. If you were unable to join us, [a recording of the webinar can be found here](#).

**Presented by** Humanity and Inclusion in collaboration with CBM and IDA

**Agenda:** Short introductory remarks by Jose Viera, Representative of the Stakeholder Group of Persons with Disabilities

**Accessibility:** The webinar will be accessible with International Sign interpretation and real-time captioning.

**Newsletter:** [Don't miss the newsletter that accompanies this webinar!](#)

## **Webinar 2: February 27, 10-11am EST**

**Title:** Practical guidance on gathering and analyzing data. If you were unable to join us, [a recording of the webinar can be found here](#).

**Agenda:** Presented by Washington Group in collaboration with International Centre for Evidence in Disability and ADD International

**Register:** To register for this webinar, please click [here](#).

**Newsletter:** [Don't miss the newsletter that accompanies this webinar!](#)



## **DISABILITY DATA WEBINAR SERIES**

### **Webinar #3: Country experiences on disability data collection**

**When:** Wednesday, 27 March 2019

**Time:** 10:00 AM - 11:00 AM EST (New York time)

#### **Background:**

The Stakeholder Group of Persons with Disabilities invites you to join the third webinar of our disability data webinar series on country experiences on disability data collection.

#### **Agenda for webinar:**

1. **The Disability Data Portal**, *Dr. Ola Abu Alghaib - Leonard Cheshire Disability*
2. Disability-disaggregated data collection in a hospital setting - results from a pilot at Fundacion Vision eye hospital, **Paraguay**, *Dr. Manfred Mörchen and Olmedo Zambrano - CBM International*
3. **Guatemala National Disability Study (ENDIS 2016)**, *Dr. Islay Mactaggart, International Centre for Evidence in Disability (ICED) and the International Centre for Eye Health, London School for Hygiene and Tropical Medicine*
4. Questions and Answers

# Webinars – example questions

1. When translating questions from the source to the receptor language that identify the person, do you identify and use existing terms for disabilities, coin new terms, or do something altogether different? For example, use circumlocutions like "the person who cannot walk, see, or hear".
2. Have you encountered people in your work who want to use the WG questions as a diagnostic tool (not just a tool for data disaggregation); and if so, how have you addressed this?
3. After I will get the data with local characteristics and discrepancy of social systems from the actual conditions, how can I evaluate the quality of life of persons with disabilities?
4. In countries that have used the Washington Group Short Set of Questions, did numbers of persons with disabilities always go up? Have any studies been done to show if there was any difference in how governments reacted to these large numbers? Any example for example in terms of budgeting for inclusion going up from government?

# Webinars – accessibility



- International Sign language
- Real-time captioning

# Newsletters - webinar information



## Disability Data Advocacy Working Group Newsletter #2 - February

### WELCOME!

Welcome to our February newsletter! We wish to extend a particular thanks to those who have contributed to this newsletter. We continue to welcome and encourage all of you to contribute to the future newsletters by emailing us at [HLPF2019@ida-secretariat.org](mailto:HLPF2019@ida-secretariat.org).

### I. Information on disability data webinar series

The Stakeholder Group of Persons with Disabilities held its second webinar of its series on 27 February on providing practical guidance on gathering and analyzing data. If you were unable to join us, [a recording of the webinar can be found here](#). Additionally, presentations can be found below:

- [Disability measurement and the Washington Group on Disability Statistics, presented by Jennifer Madans](#)
- [Collecting disability data - issues of translation, presented by Mitchell Loeb](#)
- [Issues in analyzing disability data, presented by Daniel Mont](#)
- [Using data to influence policymakers, presented by Mosharraf Hossain](#)

Additional resources about the Washington Group can be found below:

- [Data collection tools developed by the Washington Group](#)
- [The Washington Group Short Set on Functioning](#)
- [The Washington Group Short Set on Functioning Question Specifications](#)
- [Translation of the Washington Group Tools](#)



# Newsletters – main topic and blogs

## II. Learn more about how the disaggregation of disability data ensures no one is left behind

Do you want to learn more ahead of time about the topic of the next disability data webinar on 27 March? If yes, please read the small excerpt below taken from an article co-written by Dr Ola Abu Alghaib, *Leonard Cheshire* and Professor Nora Groce, *University College London*!

### **Empowerment, inclusivity and equity: how disaggregating data by disability ensures no-one is left behind**

Improved methodologies for collecting data on persons with disabilities, such as the [Washington Group questions](#), and increased awareness of data disaggregated by disability are pushing a change in how persons with disabilities are included in development and humanitarian processes. There is a growing body of evidence, driven by the inclusion of disability questions in many national surveys and censuses, which can be used to inform policy, plans and strategies for reaching the Sustainable Development Goals. UN agencies, NGOs and DPOs are increasingly using the Washington Group questions and donors often now require that funding applications include data disaggregated by disability using the Washington Group Short Set Questions. We are finally starting to witness a shift in political will with entities involved in data collection finally recognising and including persons with disabilities. However this does not invite complacency.

[To read the full article, follow this link.](#)

## III. Blogs

### **Blog: Self-Reporting Disabilities Among School-Aged Children in Finland**

The blog was written on Wednesday, 20th February 2019 by Kwok Ng, Postdoctoral researcher, University of Eastern Finland, Finland and co-chair of Chronic Conditions Writing Group, HBSC network; [kwok.ng@hbsc.org](mailto:kwok.ng@hbsc.org).

In Finland, researchers have been collecting health related data from young adolescents for decades. The first type of survey that covered a national representative sample was the [Adolescent Health and Lifestyle Survey \(NTTT – in Finnish\)](#) in the 1977. A few years later an international study of Finnish, Norwegian and English school-aged children was carried out in 1983. This study soon became the WHO collaborative cross-national [Health Behaviour in School-aged Children \(HBSC\) study](#) that spans over 45 countries in the WHO Europe Region and North America. In recent years, several regions around the world have been interested in linking with the HBSC study by replicating the study in their own countries. The Finnish National Institute for Health and Welfare has carried out the [School Health Promotion \(SHP\) Study](#) since 1996 and most recently the University of Jyväskylä and its partners has carried out the Finnish [School-aged Physical Activity \(FSPA\)](#):

# Newsletters – updates and resources

## IV. Updates and other news

### Update #1: UN Statistical Commission - side event

The 50th Session of the United Nations Statistical Commission will be held from 5-8 March 2019 at UN headquarters in New York. On the margins of the UN Statistical Commission, a side event will be held entitled “Making disability visible in statistics.”

[Follow this link for more information about this side event.](#)

### Update #2: IAEG-SDGs indicator framework

The ninth meeting of the Inter-agency and Expert Group on Sustainable Development Goal Indicators (IAEG-SDGs) - global SDG indicators - will be held from 25-28 March in Beirut, Lebanon. The Stakeholder Group of Persons with Disabilities has been invited to participate.

[Follow this link for more information about the IAEG-SDGs indicator framework.](#)

## V. Resources

### 1. [Communication Matters!](#)

This publication, launched in mid-January, presents the results of research on communication and information between persons with disabilities and local authorities. To learn more, the full publication can be found on [Light for the World's webpage](#).

### 2. **Washington Group Frequently Asked Questions**

The [Washington Group](#) question sets are designed to provide common definitions, concepts, standards and methodologies in the production of statistics about persons with and without disabilities. In order to produce internationally comparable data, the tools must be used consistently within every country, in line with the collection protocols defined by the Washington Group. More information can be found on [the frequently asked questions about the Washington Group webpage](#).

# Newsletters – marketplace

## VI. Marketplace

### **INPUT!** Do you have data on women and girls with disabilities in your country?

IDA has been invited to be a panelist at the sixty-third session of the Commission on the Status of Women (CSW 63) during an expert session on Monday, 18 March 2019. We are collecting inputs for the panel presentation. The title of the presentation is: “Making the SDGs count for women and girls with disabilities – the data challenge and opportunity.” Please send your inputs to [hlpf2019@ida-secretariat.org](mailto:hlpf2019@ida-secretariat.org) no later than the 7th of March.

**INPUT!** The Stakeholder Group of Persons with Disabilities has prepared the first draft submission to the High-level Political Forum 2019. The document contains five chapters in line with the Goals under review, which outline the current situation and challenges and provide relevant recommendations on how to achieve these Goals. The five chapters include: education (SDG 4), employment (SDG 8), reducing inequalities (SDG 10), climate change (SDG 13) and peaceful and inclusive societies (SDG 16) that includes access to justice, end violence and participation in decision-making processes. The submission can be viewed as a [Google document](#) or [Word document](#).

# Disability Data Listserv

- **What is it?**
  - An open and moderated forum intended to serve as a platform for exchange
- **What information is shared?**
  - Disability data webinars
  - Online learning opportunities
  - Newsletters
- **Who can join?**
  - All who are interested in engaging in the disability data dialogue

# Join the Disability Data Advocacy Working Group!

- To join:
  1. Visit the International Disability Alliance's website at [internationaldisabilityalliance.org](http://internationaldisabilityalliance.org)
  2. Click on 'SDGs'
  3. Click on 'Disability Data Advocacy Working Group'
  4. Scroll down to the link 'Join the Disability Data Advocacy Working Group listserv'

**THANK YOU**