30. JAHRGANG / AUSGABE 2/2019 / 30nd YEAR / ISSUE 2/2019

Behinderung und internationale Entwicklung
Disability and International Development

Themen: Daten und Behinderung
Themes: Data and Disability

Inhalt

Disability Data Collection: Emerging Opportunities from Recent Global Initiatives
Ola Abu Alghaib/Pauline Thivillier/Gemma Cook 4

Disaggregating the Sustainable Development Goals by Disability: To Leave No One Behind
Daniel Mont 11

Comparing the Washington Group Questions and the Model Disability Survey: A Review of Methodological Approaches to Disability Data Collection
Nora Ellen Groce 16

Including the Furthest Left Behind: Disability Data and the 2030 Agenda for Sustainable Development
Elizabeth Lockwood/Orsolya Bartha 23

Disability Disaggregated Data to Support Inclusive Education: Findings from the Disability Data Portal
Ola Abu Alghaib/Elaine Green 28

Bericht/Report
Die Titchfield-City-Gruppe 32

Kurzmeldungen/Announcements 36

Literatur 44

Impressum

Impressum | Masthead
Behinderung und internationale Entwicklung
Disability and International Development

Herausgeber | Editor
Behinderung und Entwicklungszusammenarbeit e.V.
Disability and Development Cooperation

Anschrift | Address
Altenessener Straße 394-398
45329 Essen
Tel.: +49 (0)201/17 89 123
Fax: +49 (0)201/17 89 026
E-Mail: info@inie-inid.org
Internet: www.zeitschrift.bezev.de

Für blinde und sehbehinderte Menschen ist die Zeitschrift im Internet erhältlich:
www.zeitschrift.bezev.de
For persons with visual impairment, an electronic version of the journal is available at
www.zeitschrift.bezev.de

Schriftleitung | Editorship
Gabriele Weigt
Redaktionsassistenz | Editorial Assistance
Katharina Silter
Gestaltung | Layout
Amund Schmidt
Druck | Print
Druckerei Nolte, Iserlohn
Bankverbindung | Bank Details
Bank für Sozialwirtschaft
BIC: BFSWDE33XXX
IBAN: DE08 370 205 000 008 040 706

Die Zeitschrift Behinderung und internationale Entwicklung ist eine Pubilikation des Instituts für inklusive Entwicklung. Das Institut wird getragen von Behinderung und Entwicklungszusammenarbeit e.V.
The journal Disability and International Development is a publication of the Institute for Inclusive Development. The Institute is part of Disability and Development Cooperation.

ISSN 2191-6888 (Print)
ISSN 2199-7306 (Internet)

Editorial

Liebe Leserinnen und Leser,

vom 24.-25. September wird zum ersten Mal seit Verabschiedung der Agenda 2030 ein Gipfel der Staats- und Regierungschefs stattfinden. Dabei wird Bilanz gezogen, aber voraussichtlich auch ein Aufruf zur verstärkten Umsetzung der Nachhaltigkeitsziele verabschiedet werden, weil bereits erkennbar ist, dass die bisherigen Anstrengungen nicht ausreichen werden, um die gesteckten Ziele zu erreichen.

Mit der Agenda 2030 und dem Anspruch, niemanden zurückzulassen, verbindet sich auch die Forderung nach einer Datenrevolution, um die Fortschritte messbar und sichtbar zu machen. In der Vergangenheit blieben Menschen mit Behinderung oft unsichtbar, da sie in internationalen Vereinbarungen, wie z.B. den Millenniumsentwicklungszielen nicht explizit erwähnt worden waren. Dies hat sich mit der Agenda 2030 verändert, da Menschen mit Behinderung darin nicht nur explizit erwähnt werden, sondern auch ein Paragraph zur Disaggregierung der Daten nach Behinderung mit aufgenommen worden ist. Eine Expertengruppe der Vereinten Nationen arbeitet daran, die Disaggregierung zu ermöglichen. So sind einige (aber wenige) Indikatoren der Nachhaltigkeitsziele bereits mit Bezug auf Menschen mit Behinderung aufgeschlüsselt vorhanden.

Mit der Agenda 2030 existiert nun neben der UN-Konvention über die Rechte von Menschen mit Behinderung ein weiteres internationales Abkommen, das zur Datenerhebung über die Lage von Menschen mit Behinderung weltweit beiträgt. Sie stärkt die Bemühungen, die großen Wissenslücken zur Lebenssituation von Menschen mit Behinderung weltweit zu schließen.

In dieser Ausgabe geben wir einen Einblick in die Initiativen und Entwicklungen, die es in diesem Bereich gibt und stellen beispielhaft Ansätze vor, die bereits zur differenzierten Datenerhebung genutzt werden können.

Wir wünschen Ihnen eine interessante und anregende Lektüre.

Ihre Redaktionsgruppe

Dear readers,

since the approval of the Agenda 2030 there has not been a meeting of Heads of Government and Heads of States. The first such meeting takes place on the 24th and 25th of September. At this meeting progress will be reviewed, and in all probability, an appeal for stronger implementation towards the targets for sustainability will be agreed. Already it is recognised that the efforts made to date are not adequate to reach the agreed goals.

The Agenda 2030 aims to ensure that nobody will be left behind and demands a data revolution in order to be better able to measure progress. In the past persons with disabilities were invisible, as they are not explicitly referred to in international protocols, such as the Millennium Development Goals (MDGs). In the MDGs there is no reference to goals in relation to persons with disabilities. This has changed with the Agenda 2030, now people with disabilities are specifically referenced and a paragraph is included for the disaggregation of data by disability. An expert group at the United Nations is actively working on achieving this disaggregation. Already some of the necessary indicators have been developed in relation to sustainability, more is still to be done.

The Agenda 2030 and the United Nations Convention on the Rights of Persons with Disabilities together advance the collection of relevant data on the situation of persons with disabilities world-wide. This data will reinforce the efforts to alleviate the dearth and lack of knowledge about the realities of life for persons with disabilities.

In this edition we wish to provide insight into the initiatives and developments that are being undertaken in relation to disaggregation. We also show some exemplary approaches that already make it possible for more specific data collection.

We wish you an interesting and stimulating read.

The Editorial Group

Disability Data Collection: Emerging Opportunities from Recent Global Initiatives

Ola Abu Alghaib/Pauline Thivillier/Gemma Cook

Global disability data collection has progressed in recent years, catalysed by the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD)[1] in 2006, and the 2030 Agenda for Sustainable Development in 2015, which set forth explicit requirements to disaggregate data by disability. Disability data collection is a complex and dynamic process, with multifarious challenges to its quality and coherence. There are several measurement tools available for measuring disability, which continue to develop in response to these challenges. Subsequent to the CRPD and the 2030 Agenda, a number of additional global initiatives have emerged to build capacity in disability data collection, the focus of this paper. These include: the Inclusive Data Charter; commitments made at the 2018 Global Disability Summit; capacity-building initiatives; disability mainstreaming; data sharing initiatives; and inter-agency collaboration. These new developments are unparalleled and resoundingly positive; however the global community must continue to recognise the complexity and importance of collecting disability data, keeping it at the forefront of the development agenda, ensuring the allocation of adequate resources to capitalise on this opportunity and to sustain improvement.

Introduction

Global disability data collection has progressed considerably in recent years. This has been catalysed by the adoption of the widely ratified UN Convention on the Rights of Persons with Disabilities (CRPD)[1] in 2006, with Article 31 of the Convention explicitly outlining requirements for data collection. As a result, subsequent global frameworks such as the Sustainable Development Goals (SDGs) and the Sendai Framework for Disaster Risk Reduction have included explicit requirements within their indicator frameworks to disaggregate data by disability. Additionally, the development of the UN Disability Inclusion Strategy (UNDIS) will also play a crucial role in supporting the UN system to mainstream disability inclusion as well provide support to Member States in implementation of the CRPD, the SDGs and other global commitments. These efforts are especially important in identifying those left furthest behind, as data is increasingly disaggregated by sex, age, disability, and geographic location as well as other characteristics[2].

The complexity of disability data collection is widely acknowledged. The most common challenge is a lack of consistency across disability data collection efforts. Inconsistency exists for a number of reasons, not least because disability itself is a complex phenomenon, with constant evolution of its definition and understanding. Other factors include the diverse contexts in which data is collected, the different ways in which tools are administered, and the variation in time available to administer questions. Further complications include poor quality data collection and a lack of outcome measurement in disability targeted programming. Compounding all of this, data that is collected is not always made available, often for political reasons[3], limiting the comprehensive central storage and international comparison of data.

There are several tools available for measuring disability, with ongoing debate over which are best suited to which context. The two main global disability measurement methodologies are the Washington Group Questions and the Model Disability Survey, most frequently endorsed and recommended in international guidelines, and the most commonly applied in the international context. They are underpinned by the World Health Organisation's theory of disability and the International Classification of Functioning, Disability and Health (ICF) framework. This is recognised as an ongoing area for investigation and improvement, with further research required. This paper will not assess the strengths of these particular methodologies, but instead will focus on some of the new, complementary resources and recent commitments to disability data collection at the global level which provide significant emerging opportunities to enhance global data collection efforts.

Disability Measurement and the SDGs

The 2030 Agenda for Sustainable Development, adopted by all UN Member States in 2015, brings unprecedented opportunity for people with disabilities. The international disability community successfully advocated for the inclusion of disability within the Agenda, and as a result the term disability appears eleven times across six of the SDGs[4]. In addition to the explicit references to disability, persons with disabilities have been included in the definition of *vulnerable persons*, which in turn has been mentioned six times. Of most significance in terms of global disability data collection, is SDG indicator 17.18 which specifically asserts the requirement for data disaggregation by "income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national context"[5]. All countries are expected to report on their national-level progress towards the SDG targets at least once by 2030, through a multi-stakeholder Voluntary National Review process presented at the UN High-level Political Forum, the official global-level follow-up and review mechanism for the SDGs.

Emerging Opportunities for Global Disability Data Collection

The current momentum around disability data collection, catalysed by the CRPD, and further influenced by Agenda 2030, has encouraged a cascade of multiple new global-level initiatives and commitments around disability data. Although many of these remain in the early stages of implementation, they provide significant and unprecedented opportunity.

Recent Commitments to Disability Data Collection

In addition to the general requirement to collect disability stipulated by the SDGs and the CRPD, some organisations have made explicit commitments to collect and monitor against disability disaggregated data. The Charter on Inclusion of Persons with Disabilities in Humanitarian Action which states the obligation for humanitarian actor to "ensure that data collected on persons with disabilities is disaggregated by age and sex, and analysed and used on an ongoing basis to assess and advance accessibility of humanitarian services and assistance, as well as participation in policy and program design, implementation and evaluation"[6]. This Charter is open for endorsement by States and governments, UN agencies, organisations involved in humanitarian contexts and organisations of persons with disabilities. It has currently been endorsed by more than 100 stakeholders. The online Platform for Action, Commitments and Transformations[7] was created to house the commitments and provide a hub for transparency, mutual accountability and voluntary progress reporting.

The Inclusive Data Charter (IDC),[8] an initiative of the Global Partnership for Sustainable Development Data (GPSSD), was launched at the High Level Political Forum in 2018 with the aim "to improve the quality, quantity, financing, and availability of inclusive and disaggregated data as well as the capacity and capability to produce and use it, in accordance with internationally accepted standards and ongoing processes under the auspices of the United Nations."[9] Signatories to the Charter include governments, UN agencies, National Statistical Offices, the World Bank, INGOs, and private sector organisations with each developing its own action plan, according to its own capacity. It is expected that each actor will produce an annual monitoring report on the implementation of their action plans on voluntary basis. In its *One Year On: 2019 Monitoring Report*[10], the GPSSD reports significant progress made by many of its signatory organisations in the first year of the Charter.

Further commitments to disability data collection were made at the Global Disability Summit (GDS) which took place in July 2018 in London, co-hosted by the governments of the United Kingdom and Kenya, and the International Disability Alliance. The GDS Charter for Change[11] was signed by 350 governments

Multiple new global-level initiatives and commitments around disability data provide significant and unprecedented opportunity.

and organisations with over 170 sets of commitments to action collected from governments, development agencies, civil society, and the private sector. All commitments have been recorded on a searchable portal developed by the GDS co-chairs[12]. Initial findings from DFID's post-GDS report found that progress has been recorded against 75% of these commitments so far[13] with full report due to be published in September 2019. DFID, in collaboration with members of the Key Stakeholder Group on Accountability for GDS commitments, is currently developing the proposed long term accountability process for the GDS18 commitments[14]. As the GDS18 commitments align closely with the CRPD, it is proposed that the Committee on the CRPD can function as a link between States Parties and the GDS18 Secretariat in providing information on how State Parties are implementing their GDS commitments, as well as continuing to remind State Parties of their obligations. In turn, it is proposed that the GDS Secretariat will support by sharing with the Committee relevant information relating to the GDS commitments of specific State Parties coming up for national review under CRPD. In addition, DFID is reviewing how best to support Disabled People's Organisations (DPOs) to hold governments and institutions to account.

Capacity Building Opportunities

Capacity building of organisations that collect and analyse disability data is essential to ensure the generation of good quality data. The Washington Group has organised regional implementation workshops to support National Statistical Offices in their use of the Washington Group Questions, essential to the accurate collection of high quality data. In addition, Humanity & Inclusion developed a Learning Toolkit[15] on the use of the Washington Group Questions in humanitarian action. This is aimed to support organisations collecting data on persons with disabilities using the Washington Group Questions. At the coordination level, as part of DFID Humanitarian Investment Programme, a guidance paper[16] was recently launched to provide support to seven UN entities on how to strengthen inclusion of disability in Humanitarian Response Plans through data collection. They refer to the Washington Group and the Model Disability Survey as data collection tools. These two initiatives complement each other and have been drafted in a participatory manner with the same stakeholders involved to ensure coherence and consistency. Additionally, the upcoming Inter Agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action which will be published later this year will include a chapter on disability data and will be the overall framework – in humanitarian action – under which these initiatives will fall.

Disability Data Collection and Mainstreaming

Disability data collection is now more commonly being built into mainstream initiatives. The UN in particular is building disability inclusion into its frameworks. One such initiative includes the aforementioned UNDIS, launched at the Conference of State Parties in June 2019 which provides a foundation for sustainable and transformative progress on disability inclusion through all pillars of the United Nations' work[17]. This clarifies the UN's responsibilities to mainstreaming disability inclusion and includes an accountability framework with performance indicators that measure the UN system's institutional mainstreaming and achievement of results.

There is also an emphasis on disability data in mainstreaming initiatives such as the Humanitarian Inclusion Standard for Older People and People with Disabilities[18]. The recently launched Protection mainstreaming toolkit[19] also contains reference to disability data and the Washington Group Questions. Additionally, UNHCR published its *Working with Persons with Disabilities in Forced Displacement* guidance paper with a section on improving identification and disability data collection[20]. Similarly, the World Bank launched its Disability Inclusion and Accountability Framework[21] in June 2018 to offer a roadmap for including disability in its policies, operations, and analytical work, including promoting the collection of disability disaggregated data in accordance with the requirements set by the SDGs. These initiatives are

essential to support the idea that disability is not an *add on* to existing programming but should be mainstreamed in the day to day work of every organisation.

Data Sharing Initiatives

Contrary to the common misconception, a large body of data which can be disaggregated by disability does exist. Unfortunately, as this data is collected through a range of national censuses, surveys, studies and reviews and is not consistently analysed and published, much of it remains difficult to find, use and compare[22]. To address this issue, the Disability Data Portal – a data sharing platform – was launched by Leonard Cheshire with support from UK Aid, at the GDS in 2018[23]. This portal provides a central place to store and compare disability data from different sources across the world, with some quality control, by collecting pre-existing sources of population level data that has been disaggregated by disability, with data primarily gathered from censuses and Demographic and Health Surveys (DHS), as well as some other national household surveys. It currently captures data on 40 countries, providing a snapshot of the situation of people with disabilities in relation to education (SDG 4), economic empowerment (SDG 8), innovation (SDG 9), and stigma and discrimination (SDG 10). As the portal develops to collect more data on more SDGs, and from more countries, it has the potential to be a critical tool for monitoring and assessing global disability data and progress towards the SDGs.

The UN Statistics Division also have an international repository known as the United Nations Disability Statistics Database. It contains data and metadata on disability from official statistics, showing basic prevalence in countries, with some attempt to illustrate socio-economic characteristics with a view to measure equalisation of opportunity[24]. The Centre for Humanitarian Data is making disability more widely available by encouraging organisations to share disability data on the inter-agency (non-disability specific) Humanitarian Data Exchange platform[25].

Inter-Agency Collaboration

In a time where numerous tools and guidelines are being produced, there needs to be a coherent approach to disability data collection across the spectrum and a need for these initiatives to be articulated better together. There have been several moves to collaborate with UNICEF and Humanity & Inclusion organising two global multi-stakeholder workshops[26,27], the International Disability Alliance launching a Disability Data Advocacy Working Group[28] to promote inter-agency collaboration, and with Leonard Cheshire hosting a Washington Group Working Group to promote collaboration amongst development and humanitarian actors.

Conclusion

There is an unprecedented drive to improve global disability data collection, with many of the resulting initiatives still in their early stages. The SDGs bring unparalleled opportunity for disability data collection, mandating disability data disaggregation across all 17 SDGs and calling on the international community to *leave no one behind*. As the momentum for data collection grows, data collection methods become more sophisticated. Measurement tools are constantly evolving to meet ever-arising new challenges, but concurrently are evermore scrutinised, with consensus still forming around the best approaches to use.

Widespread commitments to disability data collection, underpinned by the frameworks of the CRPD and the SDGs, have been undertaken across the international community, including national governments, UN agencies, INGOs, and the private sector. Some of these new initiatives include; capacity building initiatives to improve quality and consistency of data collection efforts; disability mainstreaming across major organisations such as the UN and the World Bank; the launch of the global Disability Data Portal by Leonard Cheshire; and increased collaboration across inter-agency actors through global workshops and working groups.

It is imperative that the global community continue to recognise the importance of collecting quality, comprehensive and comparable global data, as well as rising to the challenge of the complexities of this undertaking. This will require investing adequate resources across all areas of programming including research, programme and policy design, budgeting and delivering training. Disability data collection is a complex but essential process and adequate investment will ensure that the incredible opportunity brought about by the CRPD and the SDGs will not be missed.

NOTES

1 UNDESA (2016) Convention on the Rights of Person's with Disabilities (CRPD). Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. Visited on 22 July 2019.

2 UN (2018) The Sustainable Development Goals Report 2018. Available at: https://unstats.un.org/sdgs/files/report/2018/TheSustainableDevelopmentGoalsReport2018-EN.pdf. Visited on 22 July 2019.

3 Leonard Cheshire (2018) Disability Data Review: A collation and analysis of disability data from 40 countries. Available at: https://

www.disabilitydataportal.com/fileadmin/uploads/lcdp/Documents/report-web_version.pdf. Visited on 22 July 2019.

4 International Disability Alliance, Sustainable Development Advocacy [Online]. Available at: http://www.internationaldisabilityalliance.org/Sustainable-Development-Advocacy. Visited on 22 July 2019.

5 UN, Sustainable Development Agenda [Online]. Available at: http://www.un.org/sustainabledevelopment/development-agenda/. Visited on 22 July 2019.

6 Charter on inclusion of Persons with Disabilities in Humanitarian Action (2016). Available at: http://humanitariandisabilitycharter.org/ Visited on 22 July 2019.

7 Agenda for Humanity Platform for Action, Commitments and Transformations. Available at: https://www.agendaforhumanity.org/about-us. Visited on 21 August 2019.

8 Global Partnership for Sustainable Development Data (2018) The Inclusive Data Charter. Available at: http://www.data4sdgs.org/initiatives/inclusive-data-charter. Visited on 22 July 2019.

9 Global Partnership for Sustainable Development Data (2018) Everybody Counts: A commitment to ensure that no one is left behind in the pursuit and measurement of social and economic progress. Available at: http://www.data4sdgs.org/sites/default/files/2018-08/IDC_onepager_Final.pdf. Visited on 22 July 2019.

10 Global Partnership for Sustainable Development Data (2019) One Year of the Inclusive Data Charter: What have we achieved, changed and learned? Available at: http://www.data4sdgs.org/sites/default/files/2019-07/IDC%20One%20Year%20On.pdf. Visited on 22 July 2019.

11 Global Disability Summit (2018) 'Charter for Change'. Available at: http://www.internationaldisabilityalliance.org/gds-charter. Visited on 12 July 2019.

12 International Disability Alliance (2018), Global Disability Summit Commitments Portal. Available at: http://www.internationaldisabilityalliance.org/commitments. Visited on 12 July 2019.

13 This finding was announced by Baroness Buscombe during the 'Global Disability Summit: One Year On' event hosted by the Permanent Mission of the United Kingdom to the UN which took place during the twelfth Conference of State Parties, Conference Room C, UN HQ, New York, June 12th 2019.

14 DFID (2019) 'Meeting minutes', Key Stakeholder Group on Accountability for GDS commitments, 16th May 2019, London, UK.

15 Humanity and Inclusion, Disability Data in Humanitarian Action. Available at: https://humanity-inclusion.org.uk/en/disability-data-in-humanitarian-action#8. Visited on 22 July 2019.

16 DFID (2017) Guidance on strengthening disability inclusion in Humanitarian Response Plans. Available at: https://reliefweb.int/sites/reliefweb.int/files/resources/Guidance_on_strengthening_disability_inclusion_in_Humanitarian_Response_Plans.pdf. Visited on 22 July 2019.

17 UN (2019) United Nations Disability Inclusion Strategy. Available at: https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/03/UNDIS_20-March-2019_for-HLCM.P.pdf. Visited on 22 July 2019.

18 Humanity and Inclusion, CBM, HelpAge International (2018) Humanitarian Inclusion Standards for Older People and People with Disabilities. Available at: https://reliefweb.int/report/world/humanitarian-inclusion-standards-older-people-and-people-disabilities. Visited on 22 July 2019.

19 Global Protection Cluster (2017) Protection Mainstreaming Toolkit: Field Testing Version. Available at: http://www.globalprotectioncluster.org/_assets/files/aors/protection_mainstreaming/gpc-pm_toolkit-2017.en.pdf. Visited on 22 July 2019.

20 UNHCR (2019) Working with Person's with Disabilities in Forced Displacement. Available at: https://www.unhcr.org/4ec3c81c9.pdf. Visited on 22 July 2019.

21 World Bank (2018) Disability Inclusion and Accountability Framework. Available at: http://documents.worldbank.org/curated/en/437451528442789278/Disability-inclusion-and-accountability-framework. Visited on 22 July 2019.

22 Leonard Cheshire (2018) Disability Data Review: A collation and analysis of disability data from 40 countries. Available at: https://www.disabilitydataportal.com/fileadmin/uploads/lcdp/Documents/report-web_version.pdf. Visited on 22 July 2019.

23 Leonard Cheshire (2018) Disability Data Portal. Available at: https://www.disabilitydataportal.com/. Visited on 22 July 2019.

24 UNSD, Disability Statistics [Online]. Available at: https://unstats.un.org/unsd/demographic-social/sconcerns/disability/statistics/#/home. Visited on 23 July 2019.

25 OCHA, Humanitarian Data Exchange. Available at: https://data.humdata.org/. Visited on 23 July 2019.

26 Humanity and Inclusion et. al. (2017) Collecting Data on Persons with Disabilities in Humanitarian Contexts. Available at: https://humanity-inclusion.org.uk/sn_uploads/document/2018-03-27-workshop-report-new-york-collecting-data-pwd-in-humanitarian-contexts.pdf. Visited on 22 July 2019.

27 UNICEF, et al. (2019) Strengthening Collection and Use of Data on Persons with Disabilities for Inclusive Humanitarian Action. May 9-10th 2019, The Hague, Netherlands. Available at: https://drive.google.com/file/d/1GCwPoRf-RyniEPHvyvhgYhwgJP9lBI_I/view. And here https://centre.humdata.org/improving-data-on-persons-with-disabilities/. Visited on 23 July 2019.

28 International Disability Alliance (2019) Disability Data Advocacy Working Group: Activities for 2019. Available at: http://www.internationaldisabilityalliance.org/data-advocacy-activities. Visited on 22 July 2019.

REFERENCES

DFID (2017) Guidance on strengthening disability inclusion in Humanitarian Response Plans. Available at: https://reliefweb.int/sites/reliefweb.int/files/resources/Guidance_on_strengthening_disability_inclusion_in_Humanitarian_Response_Plans.pdf. Visited on 22 July 2019.

GLOBAL DISABILITY SUMMIT (2018): Charter for Change. Available at: http://www.internationaldisabilityalliance.org/gds-charter.

Visited on 12 July 2019.

GLOBAL PARTNERSHIP FOR SUSTAINABLE DEVELOPMENT DATA (2018): Everybody Counts: A commitment to ensure that no one is left behind in the pursuit and measurement of social and economic progress. Available at: http://www.data4sdgs.org/sites/default/files/2018-08/IDC_onepager_Final.pdf. Visited on 22 July 2019.

GLOBAL PARTNERSHIP FOR SUSTAINABLE DEVELOPMENT DATA (2018): The Inclusive Data Charter. Available at: http://www.data4sdgs.org/initiatives/inclusive-data-charter. Visited on 22 July 2019.

GLOBAL PARTNERSHIP FOR SUSTAINABLE DEVELOPMENT DATA (2019): One Year of the Inclusive Data Charter: What have we achieved, changed and learned? Available at: http://www.data-4sdgs.org/sites/default/files/2019-07/IDC%20One%20Year%20On.pdf. Visited on 22 July 2019.

GLOBAL PROTECTION CLUSTER (2017): Protection Mainstreaming Toolkit: Field Testing Version. Available at: http://www.globalprotectioncluster.org/_assets/files/aors/protection_mainstreaming/gpc-pm_toolkit-2017.en.pdf. Visited on 22 July 2019.

HUMANITY AND INCLUSION ET AL. (2017): Collecting Data on Persons with Disabilities in Humanitarian Contexts. Available at: https://humanity-inclusion.org.uk/sn_uploads/document/2018-03-27-workshop-report-new-york-collecting-data-pwd-in-humanitarian-contexts.pdf. Visited on 22 July 2019.

HUMANITY AND INCLUSION/CBM/HELPAGE INTERNATIONAL (2018): Humanitarian Inclusion Standards for Older People and People with Disabilities. Available at: https://reliefweb.int/report/world/humanitarian-inclusion-standards-older-people-and-people-disabilities. Visited on 22 July 2019.

INTERNATIONAL DISABILITY ALLIANCE (2019): Disability Data Advocacy Working Group: Activities for 2019. Available at: http://www.internationaldisabilityalliance.org/data-advocacy-activities. Visited on 22 July 2019.

INTERNATIONAL DISABILITY ALLIANCE (n.d.): Sustainable Development Advocacy. Available at: http://www.internationaldisabilityalliance.org/Sustainable-Development-Advocacy. Visited on 22 July 2019.

LEONARD CHESHIRE (2018): Disability Data Review: A collation and analysis of disability data from 40 countries. Available at: https://www.disabilitydataportal.com/fileadmin/uploads/lcdp/Documents/report-web_version.pdf. Visited on 22 July 2019.

OCHA (n.d.): Humanitarian Data Exchange. Available at: https://data.humdata.org/. Visited on 22 July 2019.

UN (2018): The Sustainable Development Goals Report 2018. Available at: https://unstats.un.org/sdgs/files/report/2018/thesustainabledevelopmentgoalsreport2018-EN.pdf. Visited on 22 July 2019.

UN (2019): United Nations Disability Inclusion Strategy. Available at: https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/03/UNDIS_20-March-2019_for-HLCM.P.pdf. Visited on 22 July 2019.

UNDESA (2016): Convention on the Rights of Person's with Disabilities (CRPD). Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. Visited on 22 July 2019.

UNHCR (2019): Working with Person's with Disabilities in Forced Displacement. Available at: https://www.unhcr.org/4ec3c81c9.pdf. Visited on 22 July 2019.

UNICEF ET AL. (2019): Strengthening Collection and Use of Data on Persons with Disabilities for Inclusive Humanitarian Action. May 9-10th 2019, The Hague, Netherlands. Available at: https://drive.google.com/file/d/1gcwporf-ryniephvyvhgyhwgjp9lbi_I/view. Visited on 23 July 2019.

UNSD (n.d.): Disability Statistics. Available at: https://unstats.un.org/unsd/demographic-social/sconcerns/disability/statistics/#/home. Visited on 23 July 2019.

WORLD BANK (2018): Disability Inclusion and Accountability Framework. Available at: http://documents.worldbank.org/curated/en/437451528442789278/Disability-inclusion-and-accountability-framework. Visited on 22 July 2019.

ZUSAMMENFASSUNG

Die globale Erhebung von Daten zu Behinderung ist in den letzten Jahren vorangeschritten, angetrieben durch die Verabschiedung der UN Konvention über die Rechte von Menschen mit Behinderungen (UN-BRK) 2006 und die 2030 Agenda für nachhaltige Entwicklung, die explizite Anforderungen an die Aufschlüsselung von Daten nach Behinderung festlegt. Die Erhebung von Daten zu Behinderung ist ein komplexer und dynamischer Prozess, der vielfältige Herausforderungen an Qualität und Kohärenz stellt. Es gibt einige Messinstrumente zur Erhebung von Behinderung, die sich als Antwort auf diese Herausforderungen entwickelt haben. Im Anschluss an die Verabschiedung der UN-BRK und die 2030 Agenda hat sich eine Anzahl an zusätzlichen globalen Initiativen entwickelt, um Kapazitäten zur Erhebung behinderungsspezifischer Daten aufzubauen. Diese beinhalten: Das Inclusive Data Charter Projekt; Zusagen aus dem 2018 Global Disability Summit; Initiativen zum Aufbau von Handlungskompetenz; Disability Mainstreaming; Initiativen zur gemeinsamen Nutzung von Daten; und sektorübergreifende Zusammenarbeit. Diese neuen Entwicklungen sind beispiellos und außerordentlich positiv; dennoch muss die globale Gemeinschaft weiterhin die Komplexität und Relevanz der behindertenspezifischen Datensammlung anerkennen, um sie im Mittelpunkt der Entwicklungsagenda zu halten, die Bereitstellung adäquater Ressourcen sicherzustellen, um die Möglichkeiten auszuschöpfen und nachhaltig zu verbessern.

RÉSUMÉE

La collection des dates globales sur les handicaps a progressée dans les dernières années, catalysées par la Convention des Nations Unis pour les droits des personnes ayant des handicaps (CRPD) en 2006, et l'agenda pour l'année 2030 de 2015, qui a pour but le développement soutenable et qui a fortement demandé de collectionner des dates concernant les handicaps. La collection des dates globales sur les handicaps est un procès complexe et dynamique avec des

multiples défis concernant sa qualité et sa cohérence. Il y a certains outils disponibles pour mesurer les handicaps, qui continuent à se développer à regard de ses défis. Suite au CRPD et l'agenda 2030, un nombre des initiatives globales supplémentaires se sont crées pour construire une capacité concernant la collection des dates sur le handicaps. Ceci sont dans le centre d'attention de ce document. Cela inclue: la Charte des dates inclusives, l'engagement qui a été fait en 2018 au sommet des handicaps globale, le mainstream des handicaps, les initiatives des partages des dates, et la collaboration entre les agences. Ces développements nouveaux sont étourdissement positifs, même si la communauté globale doit continuer a percevoir la complexité et l'importance de collectionner les dates sur les handicaps et de mettre en première place de l'agenda du développement, assurant l'attribution des resources adéquats pour se concentrer sur cette possibilité et de maintenir l'amélioration.

RESUMEN

La recopilación mundial de datos sobre discapacidad ha progresado en los últimos años, reforzada por la adopción de la Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad (CDPD) en 2006, y la Agenda 2030 para el Desarrollo Sostenible en 2015, que establece requisitos explícitos para desglosar los datos por discapacidad. La recopilación de estos datos es un proceso complejo y dinámico, con múltiples desafíos para su calidad y coherencia. Existen varias herramientas de medición disponibles para medir la discapacidad, que siguen desarrollándose en respuesta a estos desafíos. Después de la CDPD y la Agenda 2030, han surgido varias iniciativas globales adicionales para crear capacidad en la recopilación de datos sobre la discapacidad, que es el tema central de este documento. Entre ellas figuran: la Carta sobre datos inclusivos; los compromisos contraidos en la Cumbre Mundial sobre la Discapacidad de 2018; las iniciativas de fomento de la capacidad; la incorporación de la perspectiva de la discapacidad; las iniciativas de intercambio de datos; y la colaboración interinstitucional. Estos nuevos avances no tienen comparación y son rotundamente positivos; sin embargo, la comunidad mundial debe seguir reconociendo la complejidad y la importancia de recopilarlos, manteniéndolos al frente de la agenda de desarrollo, asegurando la asignación de los recursos adecuados para aprovechar esta oportunidad y mantener la mejora.

Authors: Dr. Ola Abu Alghaib, Director Global Influencing and Research, Leonard Cheshire; Pauline Thivillier, Technical Advisor, Humanity & Inclusion; Gemma Cook, Policy Manager International, Leonard Cheshire.

Contact: Ola.AbuAlghaib@leonardcheshire.org; thivillierp@gmail.com; gemma.cook@leonardcheshire.org.

Disaggregating the Sustainable Development Goals by Disability: To Leave No One Behind

Daniel Mont

Ensuring that the SDG's fulfill their promise of *Leave No One Behind*, it is important that the SDG indicators can be disaggregated to monitor the well-being of people with disabilities. Doing this requires the availability of an internationally comparable, efficient way of identifying people with disabilities in surveys, and then their inclusion into the current statistical infrastructure. Fortunately, such questions exist, and their inclusion is straightforward and already starting to get underway in some countries.

The overarching goal of the 2030 Agenda for the Sustainable Development Goals (SDGs) is the elimination of all types of disadvantage faced by people throughout the world. Thus, the associated indicators established by the UN are designed to monitor outcomes across a wide range of sectors, encompassing every aspect of life. The SDGs recognise that central to the idea of eradicating disadvantage is the concept of *leave no one behind*. Too often development efforts have excluded the consideration of barriers faced by certain sub-populations, for example, women, ethnic minorities, and people with disabilities.

Generally speaking, it has not often been possible to know the extent to which people with disabilities are being left behind, because high quality, timely data has not been collected, or when collected, analysed. Even when extensive data on people with disabilities has been collected, it at times is segregated into special disability studies that do not adequately serve the purpose of regularly monitoring the gaps in outcomes between people with and without disabilities.

To address this problem, the SDGs call for the disaggregation of outcome indicators by disability status. Disaggregation is simply comparing the value of indicators between different populations. For example, instead of only reporting the employment rate of the entire working-age population, the employment rate is reported separately for people with and without disabilities. If the rates are the same, that is evidence that there are no significant disability-specific barriers to employment. The larger the gap, the more significant are the barriers to employment faced by people with disabilities.

A country as a whole can be making progress on an indicator – for example, universal education – but that does not necessarily mean that all groups in that country are progressing. As a matter of fact, because people with disabilities are a relatively small minority, any movement in an indicator for the entire population will be dominated by the experience of people without disabilities. Consider for example that in a year before a policy is implemented 50% of children without disabilities are in school but only 25% of children with disabilities. For sake of argument, say that 10% of children have a disability. The overall enrolment rate would be 47.5%. If after the policy is enacted the enrolment of children with a disability is unchanged but the enrolment of children without a disability increases to 90% the overall indicator will show an enrollment rate of 83.5%. The policy

Box 1 – Washington Group Short Set of Questions

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Response categories: No – no difficulty, Yes – some difficulty, Yes – a lot of difficulty, Cannot do at all

A person is identified as having a disability if he or she answers Yes- a lot of difficulty or Cannot do at all to at least one question. For more information see: washingtongroup-disability.com

would appear to be huge success. Overall enrolment has nearly doubled, but the indicator totally hides the fact that it was completely exclusive.

There are only two main requirements to be able to disaggregate SDG indicators by disability status:

1. The availability of an internationally comparable, effective, and efficient question set for identifying people with disabilities in quantitative data instruments
2. The inclusion of this question set into the statistical infrastructure currently in place to generate the SDG indicators.

Fortunately, recent international efforts have resulted in fulfillment of the first requirement. Recognising the need for internationally comparable data on disability, the UN Statistical Commission established a city group to develop an improved, internationally comparable methodology. The UN Statistical Commission sets up many of these groups to deal with various statistical challenges, and are composed of representatives from the national statistical offices (NSOs) of UN member states, named after the first city in which they meet. The Washington Group on Disability Statistics (WG) was launched in 2001 in Washington, DC. Since then, the WG has developed and tested several tools for internationally comparable disability statistics. It meets annually with representatives from a range of National Statistics Offices (NSOs). In the past 17 years, over 135 countries have had representation within the WG[1]. Various international agencies, DPOs, and NGOs have also attended the annual meetings and participated in various working groups.

The first tool developed by the WG, Washington Group Short Set (WG-SS), is a high quality, low cost, quickly implementable, internationally comparable tool for identifying most people with disabilities tested in many low and high income countries throughout the world (Altman 2016).

Prior to the WG-SS, there were two main ways data on disability were collected. Either respondents were asked if they had a *disability* or they were asked if they had one of a list of medical conditions, for example epilepsy, paralysis, or autism. These methods have been shown to greatly undercount the number of people with disabilities (Mont 2007). Asking a person if they have a disability does not work well for a few reasons:

- Stigma often prevents people from wanting to say they have a disability
- The word *disability* is often associated only with people with severe impairments, so can miss people with more mild or moderate impairments that still put them at risk of non-participation
- Elderly people often do not see themselves as having a *disability* even if they have serious functional limitations. Age is often not seen as a cause of disability, but as something different.

Asking about a list of medical conditions also under-identifies people with disabilities:

- No list of medical conditions is complete
- Many people, especially if they do not have access to health care, may not know what their condition is

Functional limitations associated with aging, malnutrition, or other factors that are not connected to a specific medical condition can be missed

But even more fundamentally, a medical diagnosis does not provide much information on a person's functioning and the barriers they may face. Two people with the same medical diagnosis – for example, cerebral palsy – might have very different limitations and face very different barriers.

The approach of the WG-SS is based on the bio-psychosocial model of disability embodied in the International Classification of Functioning, Disability, and Health[2]. People are identified as having a disability if they have a lot of difficulty or cannot do one of six basic activities (see Box 1). This puts them at risk of not being able to participate if they face barriers in the environment. This is the exact population by which we want to disaggregate the SDGs. We want to determine

Disaggregating SDG indicators by disability status is essential to ensure no one is left behind, and the methodology for doing so is straightforward and doable.

if the people at risk of exclusion because of functional impairments are actually being excluded.

Some disability advocates have expressed concern that the WG-SS is not consistent with the social model of disability because it does not specifically ask about participation or environmental barriers. As they rightfully argue, according to the social model, disability arises from the interaction of a person's functional limitations with barriers in the environment. Disability is not embodied in a person but created by an unaccommodating environment. However, we cannot use a participation measure for disaggregating outcome indicators because that undermines the purpose of disaggregation.

Consider if we identified people as having a disability with a question like "are you unable to work because of a health problem (or impairment)?" Maybe the question could add a clause referring to barriers people face that prevent work. Such a question would not classify someone as having a disability if they were working to the extent they desired, even if they had severe functional limitations. Therefore, an indicator disaggregated by this question would not be able to identify who is and is not affected by employment barriers. Nor will it be able to track improvements in outcomes. *Everyone* identified by this question will not be working, so it makes no sense to compare their employment rate with the general population. We want an indicator that will be able to capture the fact that someone with a disability was not working, but now is working.

A general consensus has emerged that the WG-SS approach is the proper one for disaggregation. It has been recommended by the United Nations Statistical Commission and the UN Economic Commission for Europe's Council of European Statisticians as the method for collecting information on disability in the upcoming 2020 round of censuses, and endorsed by a Disability Data Expert Group under the auspices of the UN Department of Economic and Social Affairs as the means to disaggregate the SDG's by disability status. The WG-SS has also been adopted by the UN Economic and Social Commission of Asia and the Pacific as a way of identifying people with disabilities for constructing their Incheon *Making the Right Real* Strategy indicators, by Development Initiative's P20 effort on monitoring outcomes for the world's poorest twenty percent, and by the United Kingdom's Department for International Development (DFID) and Australia's Department of Foreign Affairs and Trade (DFAT) for monitoring the impact of their programs.

The next question is, how should the WG-SS be implemented? For the purposes of disaggregation, a special disability survey is not needed. In fact it would be inappropriate for this purpose. A better approach is to include the WG-SS in the data instruments already being used for monitoring the SDGs. This not only reduces costs by utilising the existing statistical infrastructure, but ensures that indicators are constructed in the same way for people with and without disabilities. For an indicator to be comparable across two populations it must be collected with the same instrument and sampling design, and at the same time. Simply adding the WG-SS to an existing survey – which adds between one and two minutes per respondent to the length of the survey – allows for the disaggregation of *all* indicators generated by that survey. Besides, the creation of a parallel data system for collecting data on disability for SDG disaggregation would be costly and unsustainable. That is not to say that national disability surveys are not useful and important, but they are not appropriate for SDG disaggregation. National disability surveys (or special survey modules on existing household surveys) can provide more detailed information, and are especially vital when it comes to identifying the barriers and facilitators for inclusion. After all, SDG disaggregation only reveals gaps in outcome indicators, it does not provide information important for designing policies to address those gaps.

Disaggregating SDG indicators that are already being produced is very doable. Countries of different income levels are already including the WG-SS in their data collection instruments. For example, they have been used in the United States, Thailand, Uganda, Mexico, Bangladesh, Jordan and dozens of other

countries. Even more are including disability questions in some capacity, so replacing them with the WG-SS questions would add no time to some existing surveys. Expanded use of the WG-SS, and using them in place of these other questions, will improve the quality of that disaggregation and provide consistency, without imposing a noticeable burden on current data collection programs.

However, we should note some limitations of the WG-SS.

Children. The WG questions do not work for children under the age of 5, and have been shown to miss many children with developmental disabilities between the age of 5 and 17. For this reason, UNICEF and the WG created the Child Functioning Module (CFM) (Loeb/Mont/Cappa/De Palma/Madans et al. 2018). For population wide indicators – such as poverty in the entire population – under-identifying children with disabilities will not affect the comparison between people with and without disabilities much, since disability is strongly associated with age. The percentage of people with disabilities who are children is small. Also, for indicators like employment that don't apply to children it is not relevant. For some indicators, though, as such as school enrolment, it can be very important. Use of the CFM on household surveys can address this. In fact, the CFM has been included in UNICEF's Multiple Indicator Cluster Survey which is currently being implemented (or slated to be implemented) in dozens of low and middle income countries.

Psycho-social functioning. The WG-SS does not directly ask about psychological issues, therefore some people with difficulties in those areas will not be identified. It turns out, that many of those people are still identified as having a disability through the cognition, self-care, and communication questions, but they are not identified specifically as having a psychosocial difficulty. Data from the United States shows that about half of those with difficulties related to depression and anxiety are identified by the WG-SS (Loeb 2019). Still, if countries are concerned about this – especially if they are in conflict areas are experiencing other humanitarian crises – it is possible to add four questions from the WG Extended Set of questions. These four questions are shown in Box 2. However, for comparability's sake those questions should be used for internal purposes, not for international comparisons.

Special conditions. In some countries, particular conditions are very stigmatising even if they are not associated with functional limitations. A prime example is albinism. While many people with albinism have difficulties seeing, some will not and thus will not be identified as having a disability by the WG-SS. Another condition that is associated with discrimination but not the functional issues addressed by the WG-SS are people with severe facial burns. Again, for population-based comparisons of SDG indicators, missing these people in surveys will not significantly affect measured gaps – and even less so trends in those gaps. However, if they are important in a country context, such questions can be added to surveys, but should not be used for international comparisons of SDG indicators but for country specific purposes.

For both psychosocial and other special conditions, though, it is important that any added questions come after the WG-SS and not before it, as they will influence how the WG-SS are interpreted and answered by respondents.

Box 2 WG Extended Set questions on anxiety and depression

How often [do/does] [you/he/she] feel worried, nervous or anxious? Would you say…

- Every day
- A few times a week
- A few times a month
- A few times a year
- Never

Thinking about the last time [you/he/she] felt worried, nervous or anxious, how would [you/he/she] describe the level of these feelings? Would [you/he/she] say…

- A little
- Somewhere in between a little and a lot
- A lot

How often [do/does] [you/he/she] feel depressed? Would [you/he/she] say…

- Every day
- A few times a week
- A few times a month
- A few times a year
- Never

Thinking about the last time [you/he/she] felt depressed, how depressed did [you/he/she] feel? Would you say…

- A little
- Somewhere in between a little and a lot
- A lot

A person is considered to have a disability if they feel a lot of anxiety or depression on a daily basis.

For more information see washingtongroup-disability.com

Space is limited on surveys. To disaggregate the SDGs, it would be great if the WG Extended Set and CFM were asked on every survey, and even more questions to identify people with conditions like albinism. However, realistically this is not feasible. The more questions we ask to be put on a survey, the less chance that they will be included because of cost and time constraints. We must consider diminishing returns. How much extra value will be added for the purpose of disaggregating the SDGs?

A national disability survey can be useful for obtaining a broader and deeper knowledge of people with disabilities, but for disaggregation of SDGs, the WG-SS is the most appropriate. The main purpose of the WG-SS is to be able to disaggregate indicators by disability status to see if outcomes for people with disabilities are different from those without disabilities – in other words, the disability gap. Statistically speaking, it is not necessary to identify one hundred percent of people who have a disability – only the large majority, in order to pick up associations between disability and various outcomes in the data. Leaving out the small percentage of people not identified by the WG-SS will have a small impact on measuring the disability gap. And importantly, leaving out that small percentage will not have a significant impact on measuring trends in the disability gap. Because whatever that initial underestimation would be, it is most likely going to be constant across time so that the changes in the measured disability gap will not be affected.

The bottom line is that through a broad international effort, reliable, internationally comparable questions on disability have been developed, tested, and are beginning to be widely implemented. These questions are well-suited for disability disaggregation as they are short and easy to administer and identify the large majority of people with disabilities. By adding them to the existing statistical infrastructure, all SDG indicators that are already set to be generated can be disaggregated by disability status in an efficient, sustainable manner.

NOTES

1 www.washingtongroup-disability.com.

2 https://www.who.int/classifications/icf/en/.

REFERENCES

ALTMAN, B. M. (Ed.). (2016): International measurement of disability: Purpose, method and application, (Vol. 61). Springer.

MONT, D. (2007): Measuring Disability Prevalence, Social Protection Discussion Paper No. 0706, The World Bank.

LOEB, M./MONT, D./CAPPA, C./DE PALMA, E./MADANS, J./CRIALESI, R. (2018): The development and testing of a module on child functioning for identifying children with disabilities on surveys. I: Background. Disability and health journal, 11(4), 495-501.

LOEB, M. (2019): Data Production and Analysis Using the WG Tools, Presentation at Washington Group training session in London, UK: 9 May 2019.

ZUSAMMENFASSUNG

Um sicherzustellen, dass die SDGs ihr Versprechen *Leave No One Behind* erfüllen, ist es wichtig, dass die SDG Indikatoren aufgeschlüsselt werden können, um das Wohlbefinden von Menschen mit Behinderungen zu überprüfen. Dies zu tun, erfordert die Verfügbarkeit eines international vergleichbaren, effizienten Verfahrens, um Menschen mit Behinderungen in Erhebungen zu identifizieren und darüber hinaus ihren Einbezug in die gegenwärtige statistische Infrastruktur. Glücklicherweise existieren solche Fragen und ihr Einbezug ist nicht kompliziert und wurde in einigen Ländern bereits begonnen.

RÉSUMÉ

Pour assurer que les buts du développement global accomplissent leur promet *de ne pas laisser personne en arrière*, il est important que les indicateurs de ces buts ne peuvent pas être détachés du surveillance du bien-être des personnes ayant des handicaps. Pour faire cela, on a besoin de l'existence d'une stratégie efficace pour identifier des personnes ayant un handicap qui peut être comparée internationalement et par conséquent être inclue dans l'infrastructure statistique. Heureusement ces stratégies existent déjà et leur inclusion est en train d'être démarrée dans certains pays.

RESUMEN

Asegurarse de que los Objetivos de Desarrollo Sostenible (ODS) cumplan su promesa de *No dejar a nadie atrás*, es importante que los indicadores de los ODS puedan ser desagregados para monitorear el bienestar de las personas con discapacidades. Para ello es necesario disponer de una forma eficaz e internacionalmente comparable de identificar a las personas con discapacidad en las encuestas y, a continuación, incluirlas en la infraestructura estadística actual. Afortunadamente, tales preguntas existen, y su inclusión es directa y ya está empezando a ponerse en marcha en algunos países.

Author: Daniel Mont is the co-president of the Center for Inclusive Policy. He was previously a Senior Economist at the World Bank, and has worked on many aspects of inclusive policy for many UN and other developmental agencies, and has published widely on issues of disability and poverty, education, employment and social protection.

Contact: daniel.mont@inclusive-policy.org

Comparing the Washington Group Questions and the Model Disability Survey: A Review of Methodological Approaches to Disability Data Collection

Nora Ellen Groce

Growing awareness that accurate data is needed to understand and address the rights and needs of the world's one billion people with disabilities has led to a rapid evolution in methodologies intended to provide better data for governments, practitioners, researchers and advocates. Two key methodologies are now widely used for disability data, the Washington Group Questions and the Model Disability Survey. These are often discussed and described as competing methodologies, leading to confusion in many quarters. In this paper, I compare the two methodologies in terms of intended use and potential benefits, and I argue that in fact, the confusion is unnecessary as the methodologies are for the most part, designed to serve different purposes.

Introduction & Overview

The realisation that people with disabilities make up 15% of the world's population and are disproportionately poorer and more marginalised than all other groups (WHO/ World Bank 2011) has prompted urgent calls for more accurate data to better understand the needs of this population (Leonard Cheshire/DFID 2019). Monitoring the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006) and the Sustainable Development Goals (United Nations 2015) – with their call to *leave no one behind* – has generated further interest in accurate disability statistics.

To improve global disability data, two methodologies have received considerable attention:

1 The Washington Group Questions
2 The Model Disability Survey

However, government officials, practitioners, civil society groups, advocates and researchers are often unsure about which methodology to use.

I argue here that the confusion is unnecessary. The methodologies are for the most part designed to serve different purposes. This paper presents a quick introduction:

- The Washington Group (WG) Questions are targeted questions on individual functioning intended to provide a *quick way to collect data with minimal additional costs, which allows disaggregation by disability status*. Designed initially for National Statistical Offices to be incorporated into population-based censuses and surveys, the WG Questions are also widely used by non-governmental organisations, researchers and advocates in a range of data collection tools. The Short Set of WG Questions (WG SS) has only 6 questions and can be answered in about 1.5 minutes; the Enhanced Short Set contains 6 additional questions; the Extended Set (WG ES) has 35 questions and can be answered in 10-12 minutes.
- The Model Disability Survey (MDS) has been developed *as a stand-alone data*

collection instrument to provide in-depth information about persons with disabilities at regional or national levels. Designed to be implemented every 5-10 years, the full MDS has 294 questions and takes 120-150 minutes (2 hours to 2.5 hours) to administer. A *Brief Version* of the MDS has 38 questions and is intended to be integrated into existing data collection tools, taking about 12 minutes to administer. Functioning questions in the Brief Version do not overlap entirely with the Washington Group Questions; the Brief Version also includes questions about assistive devices and personal support. The Brief MDS is new and has yet to be widely implemented.

Note that neither methodology is intended for clinical diagnosis or determination of disability status at the individual level.

The Washington Group Questions

The Washington Group on Disability Statistics[1] is a UN City Group established under the United Nations Statistical Commission. Guided by a Secretariat that represents 135 National Statistical Offices, the work of the WG addresses the urgent need for cross-nationally comparable population-based measures of disability.

There are a range of WG tools, but best known is the *Washington Group Short Set (WG-SS)*. These 6 questions, which focus on difficulties in seeing, hearing, mobility, communication, cognition and self-care, allow self-reporting of functioning at the household head or individual level[2]. Each question has one of four response categories: *No, no difficulty; Yes, some difficulty, Yes, a lot of difficulty, Cannot do at all*. For the purposes of data disaggregation, people are usually identified as *disabled* if they respond '*a lot of difficulty*' or '*unable to do*' to at least 1 of the 6 questions, although depending on the purpose of the study, the category '*some difficulty*' is sometimes also included to identify persons with disabilities that would limit functioning.

The 6 questions are intended to be inserted, without modification, into any number of censuses and surveys routinely used to collect demographic and outcome data – (i.e. income, education, rural vs urban status)[3].

These questions enable the rapid collection and disaggregation of population data by level of functional difficulty, on a graded scale of the population in these 6 domains and across combinations of domains which are used as a proxy indicator for risk of disability. This enables policy makers, practitioners and advocates to see how individuals identified as disabled are doing compared to their non-disabled peers in key domains; for example, rates of education, income, access to health care and so forth.

A longer version of the methodology is found in the Extended Set (WG-ES) with 38 questions – the 6 WG SS questions plus additional questions on affect, pain, fatigue, communications and upper body functioning as well as use of assistive devices/aids and environmental factors.

An additional version has been developed: the Enhanced Short Set. The WG SS does not include questions that address cognitive functioning, but these can be found in the Washington Group Extended Set. However, because space is often limited in data collection instruments, the WG has identified 6 additional questions from the WG-ES, including 2 on anxiety and 2 on depression, thus providing additional information on mental health concerns in a concise way.

The questions offer a quick picture and simple way of comparing how people with disabilities fare in comparison with their non-disabled peers whose demographic information is being collected in the same censuses or surveys[4].

The methodology has been internationally validated and cognitively tested in a number of low, middle and high-income countries.

Washington Group Questions

Short Set (WG-SS)

- 6 qestions - takes about 1.5 minutes to administer.
- Easy to include in range of censuses, surveys and other data collection instruments.
- Widely used by national governments as well as non-governmental organisations (NGOs) and civil society organisations, including Disabled Peoples Organisations (DPOs).
- Analysis is straightforward. Disaggregation can be done by anyone with a basic knowledge of statistics using SPSS and SAS syntax available on the WG website[5]. When backup is needed, assistance is available from the WG Secretariat.

Enhanced Short Set

- 12 questions – the 6 WG SS and 6 additional questions specifically on cognitive functioning form the WG –ES.
- Easy to include in a range of censuses, surveys and other data collection instruments
- Quick to administer – takes 4-6 minutes.
- Analysis is straightforward – (see WG-SS above).

Extended Set (WG-ES)

- 35 questions – takes about 10-12 minutes to administer.
- The WG-ES can be used in their entirety – however, options allow inclusion of some but not all questions, depending on need. This is true not only of the

Enhanced Short Set's cognitive questions. A combination other WG-ES questions are also an option as an addition to the core Short Set of questions.
- Increasingly used in surveys that have a major focus on disability.
- Analysis is straightforward. Disaggregation can be done by anyone with a basic knowledge of statistics using SPSS or syntax available on the WG website[6]. (See WG-SS above)

UNICEF/WG Child Functioning Module (CMF).
- UNICEF has collaborated with the WG to develop the CMF, building on the WG methodology with additional questions, including more related to cognitive functioning. It is now included in UNICEF's Multiple Indicator Cluster Surveys (MICs) (UNICEF 2017) to better identify children with disabilities.

Question Sets under development
- Further WG linked questions sets are being developed to be used in conjunction with the WG-SS, WG-ES and CMF. This includes new questions focusing on barriers and facilitators to participation in a question set for labor force surveys in collaboration with the International Labor Organisation (ILO) and a question set on inclusive education in collaboration with UNICEF[7].

Washington Group - Summary

In summary, the Washing Group questions are low cost, quick and easy to administer. They describe functional status. They are easy to analyse and through disaggregation, this tool may provide prevalence information which is useful for planning for government and civil society, although more detailed data will be needed for specific planning and implementation of projects or programs. It is useable for monitoring and evaluation related to the UN Convention on the Rights of Persons with Disabilities (Madans/Loeb/Altman 2011) and the Sustainable Development Goals. Where needed, backup advice and support can be obtained directly from the Washington Group Secretariat at http://www.washingtongroup-disability.com/contact/.

There are some drawbacks as well. The WG SS provides disaggregated data in 6 domains for analysis but misses more detailed information on which to develop in-depth services to enhance social participation and inclusion. The WG-SS does not have a question concerning cognitive functioning. However, the Enhanced WG-SS adds 6 questions from the WG-ES, including 2 on anxiety and 2 on depression, significantly improving the quality of data on psychosocial functioning.

This paper provides an introduction to and comparison of the Washington Group Questions and the Model Disability Survey.

Both the WG-SS and WG-ES identify individuals with more severe disabilities but may miss some individuals with less severe disabilities. The WG-SS and WG-ES Questions are not considered accurate for individuals below the age of 5 years. Also, they miss many children with developmental disabilities. However, the CFM (now included in the MICS) specifically provides proxy indicators for younger children (2 to 4 years) as well as those 5 to 17 years.

The Model Disability Survey (MDS)

The MDS has been developed by the Disability Unit of the World Health Organisation in collaboration with the World Bank. It is designed as a *stand-alone* data collection instrument '*providing comprehensive and systematic documentation on all aspects of functioning within a population*' (WHO, n.d.).

The MDS (and the Brief MDS) are general population household surveys, so questions are intended for a representative sample of the whole population, allowing comparison between persons with disability and persons without disability in the community.

The full MDS has been internationally validated and cognitively tested in 6 countries (including low, middle and high-income countries); and piloted in 3 more. The Brief MDS is new and has not yet been independently validated nor cognitively tested, but questions selected are based on analytical results from the full MDS.

Model Disability Survey (MDS)

- A comprehensive, in-depth survey providing detailed data about persons with disabilities at regional or national levels for in-depth analysis, discussion and planning.
- The individual questionnaire (answered by a randomly selected person in the household) has 294 questions[8]. The accompanying household survey has an additional 21 questions.

- The full survey takes 120-150 minutes (2 hours to 2.5 hours). Analysis focuses on building a *disability scale* ranging from 0-100 that can then be partitioned into different levels of disability, using *fit-for-purpose* cut offs, based on scores of people with medical conditions that are highly associated with disability. This allows comparisons between both disabled and non-disabled members of the community as well as nuanced differences between people with different types of disability and levels of severity. Such analysis relies on rigorous calculations to create a detailed continuum of functioning.
- Data collection and analysis are specific to this survey – the survey questions are stand-alone and are not intended to be added to other data collection efforts.
- Analysis is intended to be undertaken by people with some technical expertise in statistics, but is assumed to be within the technical capacity of National Statistics Offices. Where needed backup assistance is available via the WHO MDS team[9].
- Intended to be administered once every 5-10 years.

Brief Model Disability Survey (Brief MDS)

- A new Brief version of the MDS is being implemented in 2018 (WHO, n.d.).
- It has 38 questions, and is intended to be added to other surveys and censuses.
- A range of questions related to functioning, which are similar but not identical to the Washington Group questions. In addition, there are a series of questions on environmental factors, assistive devises and personal assistance.
- Analysis uses the same methodology as the full MDS. It creates a disability scale from 0-100, allowing identification of local and national barriers faced by people with disabilities.
- Analysis is intended to be undertaken by people with some technical expertise in statistics, but is assumed to be within the technical capacity of National Statistics Offices. When needed, backup assistance is available from the WHO MDS team.

Model Disability Survey – (Full and Brief) Summary

The Full MDS provides in-depth understanding of how people with disabilities fare at community and country level. It provides solid longitudinal data. The Full MDS is an in-depth tool for short and long-term planning. It is recommended for use every 5-10 years. Thus, the in-depth information it offers is most valuable if the survey is repeated over time to allow comparison.

The Full MDS is useable for monitoring and evaluation related to the UN Convention on the Rights of Persons with Disabilities, although not intended to be implemented annually or to provide annual data. Analysis for both the full and the Brief MDS is based on building a *disability scale* from 0-100 and then establishing cut-off points and identifying different levels of severity, with interpretation benefiting from understanding of local/national laws.

The Full MDS is comprehensive, but long and expensive to administer. As it is not intended to be an annual data collection tool, the expense may be balanced by the in-depth information it offers. Analysis is complex, although assumed to be within the technical capacity of National Statistics Offices (Sabariego/Oberhauser/Posarac et al. 2016). Backup assistance is available via the WHO. It requires a commitment to competent levels of analysis and interpretation.

The level of detail about persons with disabilities generated by the MDS is not needed in all development programs, government outreach efforts or civil society initiatives. UN CRPD and SDG relevant data is collected but it is not recommended for use for SDG monitoring because data not collected annually, (designed to be administered every 5-10 years); and SDG indicators must be collected the same way for people with and without disabilities. So, for example, if a country is using its annual Labor Force Survey for the employment SDG, users cannot compare an employment indicator from the Labor Force Survey with one from the MDS because the instruments will have different samples and different employment questions.

The Brief Model Disability Survey is still relatively new. Designed to be added to other data collection instruments. Surveys and censuses that are concerned with length may find 38 additional questions problematic. The survey itself is not yet independently validated nor cognitively tested, however the selection of the questions are based on analytical results from data from full MDS implementations.

As with full MDS, analysis is complex, being based on a disability *score* from 0-100. Backup assistance is available via the WHO MDS team in Geneva. It is intended to be usable with SDGs, but extensive data collection and analysis has yet to be implemented in field. Proper validation is needed before this can be fully evaluated (Sabariego 2017).

Table 1: Washington Group & Model Disability Survey: Key Points for Users

	Number of Questions	Time to Administer	Questions can be disaggregated	Analysis	CRPD	SDGs
WG-Short Set	6	1.5 minutes	Yes	Basic Statistical Knowledge/ SPSS syntax on WG website.	Yes	Yes
WG-Extended	35	10-12 minutes	Yes	Basic Statistical Knowledge/ SPSS syntax on WG website.	Yes	Yes
MDS (Full)	294	120-150 minutes	Yes	More advanced knowledge/ WHO Assistance available	Yes – but not annually	No
MDS (Brief)	38	12 minutes	Yes	More advanced knowledge/ WHO Assistance available	Yes	Unclear – new methodology

Who is Using Which Methodologies?

Washington Group: The WG, particularly the WG-SS are widely used (Groce/Mont 2017): 60 countries have used WG-SS or WG-ES in national censuses with this number to increase significantly in the 2020 round of censuses. Most UN agencies now collect disability data using either the WG-SS or WG-ES or MICs. Many bilateral organisations – including UK's DFID and Australia's DFAT strongly support the inclusion of WG questions in many/most funded development efforts. The UNICEF/WG Child Functioning Module is now included in UNICEF's Multiple Indicator Cluster Survey (MICS) and is expected to rollout in 70 countries by 2020. The World Bank Living Standards Measurement Studies (LSMS) which covers 70 countries has officially endorsed the WG-SS for use. A growing number of NGOs and DPOs (Groce/Mont 2017) as well as advocates and researchers now use the WG-SS, Enhanced and Extended Sets. It is also widely used by UN agencies, national governments and civil society organisations in a range of monitoring and evaluation efforts.

Model Disability Survey: Current use of the MDS and Brief MDS is more limited than for the WG instruments; however, the MDS has been used in 7 countries: Chile; Sri Lanka; Philippines; Qatar; Dubai, UAE; Pakistan and Cameroon – with survey sizes ranging from 500-11,000. Another 7 countries are scheduled to use it in the near future. The Brief Survey is new. Recently tested, future use will provide more insights into which groups are using this methodology and how useful they are finding it. The full MDS is not implemented regularly enough for use with SDGs, though the use of the new Brief MDS for annual or regular data collection may make it more applicable for the CRPD and SDGs although cross-national comparability with data gathered through the more widely used WG questions will be an issue.

Common Ground

- Both methodologies are based on the WHO International Classification of Functioning, Disability and Health (WHO, n.d.).
- Neither methodology is intended for clinical diagnosis or determination of disability status at the individual level.

Can you use both methodologies?

- WG-SS, Enhanced WG-SS, or WG-ES; or the CFM (in the MICS or in other surveys), could be included on a national census, an education, labor force or a household expenditure survey. If there is time and funding, an MDS could also be undertaken to provide complementary in-depth information every 5 to 10 years, as recommended by the WHO.
- Governments and others who chose to use both methodologies are encouraged to consider how both sets of information can be combined to ensure that optimum benefit is derived from such an undertaking.
- Use of both methodologies might generate more data than is needed to explore many demographic and international development concerns, such as health, education, employment and social protection[10, 11].

For more Information

Washington Group on Disability Statistics Website:
www.washingtongroup-disability.com | Model Disability Survey
http://www.who.int/disabilities/data/mds/en/

Notes

1 UN Groups are named after the first city in which a meeting of the group is held. In this case, the first meeting was in Washington, DC in 2002. The Washington Group has no affiliation with the US Government.

2 The 6 questions are: 1) Do you have difficulty seeing even if wearing glasses?; 2) Do you have difficulty hearing even if wearing a hearing aid?; 3) Do you have difficulty walking or climbing the stairs?; 4) Do you have difficulty remembering or concentrating?; 5) Do you have difficulty with self-care such as washing all over or dressing?; 6) Using your local language, do you have difficulty communicating (for example, understanding or being understood by others)? The response categories are: 1. No – No difficulty; 2. Yes – some difficulty; 3. Yes – a lot of difficulty; 4. Cannot do at all.

3 The questions are designed to be used as part of larger data collection instruments. Therefore, if the survey or census is interviewing household heads, the WG questions are answered by the household head. If data is being collected at the individual level, then the questions are asked of the individual, or the person (i.e.parent; caregiver) who is providing information on behalf of the individual.

4 FOR EXAMPLE: if you want to find out about education using a census or a survey, your question might be 'in region X what is the average level of education for adults.' Added into a general census or survey, the WG-SS allows quick identification of individuals with disabilities. In the analysis, you can then ask, 'in region X what is the average level of education for individuals with disabilities?' But you can *also* find out about educational status and disability in greater detail. You can ask 'in region X, what is the average level of education for adults with disability over 18?' Or 'in region X what is the average level of education for disabled adults over 18 compared to their non-disabled peers?' The WG-SS also allows you to analyse by type of disability, gender etc. For example: 'in region X, what is the average level of education for blind women above the age of 18 compared to blind men above 18; *and* compared to women with other disabilities; *and* compared to non-disabled women in the same community?' Thus, a very limited number of questions can generate a range of findings that allow governments, NGOs or DPOs (Disabled People's Organisations) to more effectively target interventions and monitor progress over time.

5 http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-5-Analytic-Guidelines-for-the-Washington-Group-Short-Set.pdf . Accessed July 1, 2019.

6 http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-6-Analytic-Guidelines-for-the-Washington-Group-Extended-Set.pdf. Users need access to SPSS, which can be expensive without institutional support.

7 For more in-depth discussion, see Washington Group Website: www.washingtongroup-disabilty.com Accessed July 1, 2019.

8 Although there are 294 questions, respondents do not answer quite this number because of skip patterns for some questions.

9 https://www.who.int/disabilities/data/mds/en/.

10 For more information: Washington Group on Disability Statistics Website: www.washingtongroup-disability.com; Model Disability Survey http://www.who.int/disabilities/data/mds/en/.

11 An earlier version of this paper was published as: Groce N. 2018. Which One to Choose: The Washington Group Questions or The Model Disability Survey. UCL International Disability Research Centre. Working Paper No 31.https://www.ucl.ac.uk/epidemiology-health-care/which-one-use-washington-group-questions-or-model-disability-survey-0.

REFERENCES

WHO/WORLD BANK (2011): World Report on Disability.

LEONARD CHESHIRE/DFID (n.d.): The Disability Data Portal. Available at: https://www.disabilitydataportal.com/. Visited on 1st January 2019.

UNITED NATIONS (2006): Convention on the Rights of Persons with Disabilities. Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. Visited on 1st January 2019.

UNITED NATIONS (2015): Sustainable Development Goals. Available at: www.un.org/sustainable.development/sustainable-development-goals/ Visited on 1st January 2019. UNICEF (2017): Multi Indicator Cluster Surveys. Available at: http://mics.unicef.org/. Visited on 1st January 2019.

MADANS, J./LOEB, M./ALTMAN, B. (2011): Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. BMC Public Health. 11(Suppl 4): S4. May 31.

WORLD HEALTH ORGANISATION (n.d.): The Model Disability Survey. Disability and Rehabilitation section: World Health Organisation. Available at: http://www.who.int/disabilities/data/mds/en/. Visited on 1st January 2019.

WORLD HEALTH ORGANISATION (n.d.): Model Disability Survey. Available at: http://www.who.int/disabilities/data/brief-model-disability-survey5.pdf?ua=1. Visited on 1st January 2019.

SABARIEGO, C./OBERHAUSER, C./POSARAC, A./BICKENBACH, J./KOSTANJSEK, N./CHATTERJI, S./OFFICER, A./COENEN, M./CHAN, L./CIEZA, A. (2016): Response to Madans et al. Comments on Sabariego et al, Measuring Disability: Comparing the Impact of Two Data Collection Approaches. International Journal of Environmental Research and Public Health. 13:666.

SABARIEGO, C. (2017): The role of the World Bank and WHO Model Disability Survey in public health. Public Health Forum. Available at: https://www.degruyter.com/view/j/pubhef.2017.25.issue-4/pubhef-2017-0039/pubhef-2017-0039.xml. Visited on 1st January 2019.

GROCE, N. E./MONT, D. (2017): Counting disability: emerging consensus on the Washington Group questionnaire. The Lancet Global Health, 5 (7), 649-650.

WORLD HEALTH ORGANISATION (n.d.): UN International Classifica-

tion of Functioning, Disability and Health. Available at: http://www.who.int/classifications/icf/en/. Visited on 1st January 2019.

ZUSAMMENFASSUNG

Ein zunehmendes Bewusstsein, dass genaue Daten erforderlich sind, um die Rechte und Bedürfnisse der weltweit eine Milliarde Menschen mit Behinderungen zu verstehen und zu berücksichtigen, hat zu einer raschen Entwicklung von Methoden mit dem Ziel einer besseren Datenlage für Regierungen, die Praxis, Forschende und Verbände geführt. Zwei Hauptmethoden sind momentan zur Erhebung behinderungsbezogener Daten verbreitet, die Wahington Group Questions und das Model Disability Survey. Diese werden häufig als konkurrierende Methoden diskutiert und beschrieben, was auf vielen Seiten zu Verunsicherungen führt. In diesem Artikel werden die beiden Methoden hinsichtlich ihres Verwendungszwecks und ihrer möglichen Vorzüge verglichen und argumentiert, dass die bestehende Verunsicherung unnötig ist, da die Methoden größtenteils unterschiedlichen Zwecken dienen.

RÉSUMÉ:

Suite à la découverte du besoin des dates exactes pour comprendre et adresser les droits et besoins des 1 billions de personnes avec handicap dans ce monde, on a développé rapidement des méthodologies avec le but de mettre à la disposition des dates meilleures pour les gouvernements, pratiquants, chercheurs et avocats. Il y a deux méthodologies clés qui sont utilisées maintenant progressivement pour les dates sur les handicaps: Les questions du groupe du Washington et la recherche du modèle du handicap. Les deux sont souvent discuté et décrits comme méthodologies concurrentes ce qui mène à la confusion dans beaucoup de quartiers. Dans ce document je compare ces deux méthodologies sous l'aspect du besoin entendu et des bénéfices probables et j'argumente que la confusion n'est pas nécessaire comme chaque de ces deux méthodologies sert -pour la plus grande partie- aux buts différents.

RESUMEN

La creciente conciencia de que se necesitan datos precisos para comprender y abordar los derechos y necesidades de los mil millones de personas con discapacidad en el mundo, ha conducido a una rápida evolución de las metodologías destinadas a proporcionar mejores datos para los gobiernos, los profesionales, los investigadores y los defensores. En la actualidad se utilizan ampliamente dos metodologías claves para los datos sobre discapacidad, las preguntas del Grupo de Washington y la Encuesta Modelo sobre Discapacidad. A menudo se discuten y describen como metodologías que compiten entre sí, lo que provoca confusión en muchos sectores. En este documento, comparo las dos metodologías en términos de uso previsto y beneficios potenciales, y sostengo que, de hecho, la confusión es innecesaria, ya que las metodologías son en su mayor parte, diseñadas para servir a diferentes propósitos.

Author: Professor Nora Groce is Chair and Director of the University College London's International Disability Research Centre. An anthropologist by training, Professor Groce has worked widely in international health and development and served on the faculties of Harvard University and Yale University before coming to UCL in 2008. She is author or co-author of over 350 articles and reports, and regularly serves as an advisor to UN agencies, national governments, NGOs and DPOs.

Contact: nora.groce@ucl.ac.uk; UCL International Disability Research Centre, Department of Epidemiology and Health Care, University College London.

Including the Furthest Left Behind: Disability Data and the 2030 Agenda for Sustainable Development

Elizabeth Lockwood/Orsolya Bartha

The UN Convention on the Rights of Persons with Disabilities (CRPD) and the 2030 Agenda for Sustainable Development require that statistics and data be disaggregated by disability whenever applicable, yet persons with disabilities remain left behind after four years into the implementation of the Sustainable Development Goals (SDGs). Despite having indicators that can be disaggregated by disability in the global indicator framework and the availability of disability data, disability data overall is not being collected by National Statistical Offices for SDG monitoring. Consequently, there is lack of information on persons with disabilities, which is a major barrier for inclusion. To address this, we recommend that data disaggregated by disability be collected using the short set of questions developed by the Washington Group on Disability Statistics while also consulting persons with disabilities and their representative organisations on the design, implementation, and monitoring of SDG plans in line with CRPD Article 33.

Background

Persons with disabilities comprise an estimated 15 percent of the world's population or one billion people and are overrepresented among the most impoverished in the world. In fact, the 2030 Agenda for Sustainable Development (2030 Agenda) states that more than 80 percent of persons with disabilities lives in poverty. Persons with disabilities encounter widespread exclusion from all areas of economic, political, social, civil, and cultural life, including employment, education, and health care. Persons with disabilities experience higher rates of poverty and deprivation and lower levels of income than the general population and, there is a strong link between having a disability and being in poverty (Banks and Polack 2015). This all stems from pervasive discrimination and stigma, unequal opportunities, and institutional, physical, communication, legal, and attitudinal barriers that persons with disabilities encounter worldwide and are among those most left behind.

Marginalisation is exacerbated by a lack of measurable disaggregated data on persons with disabilities, particularly at the global level, which in turn does not provide an accurate picture of what persons with disabilities encounter. Consequently these gaps cannot be adequately addressed or addressed at all. It is with the implementation of the 2030 Agenda for Sustainable Development that the situation of the most left behind can be addressed, including persons with disabilities, with a focus on social inclusion and recognising the rights of those who are often the least able to access or benefit from development programs. In order to achieve a world in which no one is left behind, the 2030 Agenda and its interlinked Sustainable Development Goals (SDGs), should be carried out in line with the UN Convention on the Rights of Persons with Disabilities (CRPD) that promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.

Specifically, CRPD Article 31 Statistics and data collection calls for States Parties to collect appropriate information, including statistical and research data,

to enable them to formulate and implement the Convention. The 2030 Agenda calls for significant increase of "the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts" (Target 17.18). In addition, that follow-up and review processes at all levels "will be rigorous and based on evidence, informed by country-led evaluations and data which is high-quality, accessible, timely, reliable and disaggregated by income, sex, age, race, ethnicity, migration status, disability and geographic location and other characteristics relevant in national contexts" (para 74, g).

In 2017 Member States called for global SDG indicators to be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, disability and geographic location, or other characteristics. Moreover, the Addis Ababa Action Agenda calls for disaggregation of data by sex, age, geography, income, race, ethnicity, migratory status, disability and other characteristics relevant in national circumstances. However, there remains a significant lack of financial resource allocation for conducting household-level surveys with adequate levels of disaggregation. While there is much work going on to improve the disaggregation of data, challenges remain such as a notable lack of disaggregated statistics on persons with disabilities. For example, the Report of the Inter-agency Task Force on Financing for Development included that "there is much work going on to improve the disaggregation of data, but challenges remain…there is a notable lack of disaggregated statistics on persons with disabilities (IATF 2017: 118).

While there is an overall increased representation of persons with disabilities within global human rights and development arenas, lack of disability data collection persists globally. Moreover, the SDGs are putting high demands on national statistical systems everywhere. Most countries have not yet started collecting data for many indicators in global SDG indicator framework. The risk is that without basic data about people and the planet, incentives will be weak and there will be lack of capacity to fill these gaps. The lack of data on persons with disabilities, both at the national level and in international development, is a major barrier to achieving inclusion. To realise the inclusion of persons with disabilities, we recommend that policymakers be informed by collecting evidence-based data disaggregated by disability using the short set of questions developed by the Washington Group on Disability Statistics and by properly consulting persons with disabilities and their representative organisations on the design, implementation and monitoring of SDG plans.

The Inter-Agency Expert Group on SDG Indicators

The Inter-agency Expert Group on SDG-Indicators (IAEG-SDGs) was established by the UN Statistical Commission at its 46th session in March 2015 to develop an indicator framework for the monitoring of the Goals and targets of the 2030 Agenda at the global level and to support its implementation. The global indicator framework was agreed upon, including refinements of several indicators, at the 48th session of the UN Statistical Commission in March 2017, and was subsequently adopted by the General Assembly on July 6, 2017. The global indicator framework contains 11 indicators explicitly referencing persons with disabilities in the areas of poverty eradication, education (2 references), employment (2 references), reducing inequalities, sustainable and inclusive cities (3 references), and peaceful and inclusive societies (2 references). In addition, the chapeau on disaggregation states that "Sustainable Development Goal indicators should be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, disability and geographic location, or other characteristics, in accordance with the Fundamental Principles of Official Statistics."

Data Disaggregation

For the review of the 2030 Agenda, the IAEG has compiled metadata from UN agencies, offices, and entities as well as other international and regional organisations. The IAEG also formed a work stream on data disaggregation to respond to the central theme of the 2030 Agenda to ensure that no one is left behind. As an outcome, the IAEG developed a minimum disaggregation set that included all disaggregation dimensions specifically mentioned in the target or indicator name and continued to work on compiling a more comprehensive summary of disaggregation standards that currently exist for all SDG indicators. Furthermore, in 2018 the disaggregation work stream developed a stocktaking document titled *Overview of Standards for Data Disaggregation* that highlights disability and proposes the Washington Group Short Set of Questions as standard for monitoring the SDGs.

Subsequently, the UN Statistical Commission requested the IAEG-SDGs to clearly determine the dimensions and categories of data disaggregation required for the indicators in the framework. A series of

expert group meetings and other events were organised that contributed to the work on disaggregation of the SDGs. One of these meetings took place following the eighth IAEG-SDGs meeting in Sweden in 2018, and for the first time invited the Stakeholder Group of Persons with Disabilities and other stakeholders to participate. Data disaggregation by disability was discussed throughout the meeting, including challenges on the lack of available disability data, yet also, a clear willingness to disaggregate data by disability. As a result, constituencies were tasked to work with UN (custodian) agencies to identify key policy areas. In addition, IAEG members, in light of the meeting recommendations, produced a report to strengthen the availability of comparable data at the global-level to be used for evidence-based policymaking and to push Member States to undertake Voluntary National Reviews supported by data.

This report called *Data Disaggregation and SDG Indicators: Policy Priorities and Current and Future Disaggregation Plans* was used as an official background document at the UN Statistical Commission in March 2019. The document contains a compilation of all categories and dimensions of data disaggregation currently in place as well as those planned by custodian agencies. Also included are the policy priorities concerning the most marginalised population groups including, among others, persons with disabilities, migrants, refugees and older persons. Disability data are strongly included in the document, such as the availability of current and future indicators that disaggregate data by disability (15 additional indicators). Current indicators collected are on social protection and unemployment rate (1.3.1 and 8.5.2). Moreover, the Stakeholder Group of Persons with Disabilities directly contributed to policy priority areas for different population groups. In a consultative manner and obtained from a larger priority list of indicators, the Stakeholder Group of Persons with Disabilities identified five key policy areas to be disaggregated by disability to support policy makers to address gaps and amend existing policies and regulations. The five key policy areas included poverty eradication, education, employment, health, and accessibility.

This positive outcome indicates a positive step to include the most left behind by gathering data where data are most needed to create real change in the global development agenda. The following section illustrates two good practices in terms of measuring progress of the SDGs for persons with disabilities.

Gathering data on those most left behind can create positive change in the global development agenda.

Good Practices: Washington Group on Disability Statistics

The Washington Group on Disability Statistics has made considerable progress in improving disability measurement and statistics. Important methodological work has been conducted over the last decade to develop standardised data collection tools that are in line with the CRPD and produce comparable estimates. More importantly, the Washington Group Short Set has been proven and widely tested as sustainable and suitable for SDG data disaggregation by disability. Below is an example of a best practice conducted by the Washington Group.

Due to the importance of data collection and disaggregation of SDG indicators by disability, the Washington Group reviewed, among its member countries, the extent that currently available data on SDG indicators can be disaggregated by disability status. Requests for disaggregated data for 13 selected SDG indicators were sent to 146 member countries with 48 responses and 39 providing data. Nineteen of the 39 countries that provided data used the Washington Group Short Set[1]. The SDG-indicators were selected and defined for the most part according to the global indicator framework. As a result, the findings illustrate that countries can, with available data, disaggregate a number of SDG indicators by disability status[2]. Comparability among countries reporting ultimately is dependent on cross-country consistency in both the means of disability determination for disaggregation and the operationalisation of the SDG indicator in question.

Good Practices: ESCWA

In the Arab region, it was shown that disability statistics existed in most Arab countries, but disseminated data were not harmonised or comparable. As a result, in 2016 the Social Development and the Statistics Divisions of the UN-Economic and Social Commission

for Western Asia (ESCWA) embarked on a project with Arab countries to compile, verify, and harmonise national data to the extent possible to allow for better comparability and improve national reporting. The outcome of this work was presented at the first joint meeting between statisticians, policy makers, and organisations of persons with disabilities (DPOs) from Arab countries to discuss refining the collection of data on persons with disabilities in Cairo in 2018. It was the very first time a meeting such as this has ever been convened globally.

Participants reviewed best practices for collecting data in accordance with standardised UN methodologies and tools developed by the Washington Group, to identify official sources of each indicator (survey and census data or administrative records). It was a positive step to bring statisticians and policy makers together to discuss ways to collaborate and to identify accurate data and relevant sources about persons with disabilities. Overall, Arab national statistical offices have taken big strides and are among the first countries in the world to produce disaggregated standardised data on persons with disabilities in the areas of demography, education and work and this can be used as a model and be replicated in other regions and countries. Yet to do this, it is important that the users and producers of disability data talk more about use of these data in relation to the advantages and limitations of different data sources and see how to use them in complementarity for monitoring the SDGs, the CRPD and the progress countries are making to improve the inclusion of persons with disabilities in society.

Conclusion

Ensuring that the rights of persons with disabilities are included in all development efforts requires the routine collection of evidence-based data across all sectors as a means to monitor and ensure that persons with disabilities are fully participating in society. The short set of questions developed by the Washington Group is well tested and suitable for this purpose, along with the UNICEF/Washington Group Child Functioning Module that supports identification of children with disabilities. These modules are internationally comparable, efficient, low cost, and easy to incorporate into ongoing data collection of national statistical systems, making them sustainable and suitable for disaggregating by disability status and monitoring progress in attaining the SDGs on an ongoing basis.

In addition to using these modules, we strong recommend that persons with disabilities and their representative organisations be consulted on the design, implementation, and monitoring of SDG plans in line with CRPD Article 33. Also, it is imperative for governments to allocate budget for the inclusion of persons with disabilities and to measure inclusion to leave no one behind, and statisticians, policy makers, DPOs, and allies need to learn from each other and use available data to address challenges and gaps in policies. Governments, also, should ensure that those who are most marginalised and at risk of being left behind are included in decision-making, planning and implementation, with adequate financial support and delivery of systems and services central to support their wellbeing in the face of environmental shocks and stresses.

While there have been significant strides in the collection, disaggregation, research and analysis of evidence-based disability data, gaps remain, particularly in identifying persons with psychosocial disabilities and children with disabilities ages 0-23 months. As such, we recommend that concerted efforts are carried out to include those most left behind by gathering data where data are most needed to create positive change in the global development agenda.

Notes

1 Countries using the Washington Group Short Set include: Afghanistan, Bosnia & Herzegovina, Egypt, Israel, Jamaica, Myanmar, New Zealand, Palestine, Peru, South Africa, Trinidad and Tobago, Turkey, and Zimbabwe. Countries using the Washington Group Short Set and other tools include: Australia, Canada, Italy, Mexico, United States, and Yemen.

2 The most common SDG disability data provided include the following:

- disability prevalence, specifically Disability status by domain of difficulty, age and sex for population 5 years and over (31 countries)
- SDG 8.5.2* Employment status disaggregated by disability status and sex for population 15-64 years (23 countries)
- SDG 4.1x* School completion rates disaggregated by disability status and sex for relevantly aged population (20 countries)
- SDG 4.5x* University completion rates disaggregated by disability status and sex for relevantly aged population (12 countries)
- SDG 1.2.1 Poverty status disaggregated by disability status and sex for population 15 years and older (11 countries)
- SDG 3.8.1 Health insurance coverage disaggregated by disability status and sex for population years and older (10 countries)
- SDG 7.1.1 Access to electricity disaggregated by disability status and sex for population 15 years and older (10 countries)

*Indicators that were *derived* include 4.1.x Primary, Lower secondary, and Upper secondary school completion rates, 4.5.x University completion rates, and 8.5.2 Employment status.

REFERENCES

BANKS, L. /POLACK, S. (2015): The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities: Evidence from

Low and Middle Income Countries. CBM, International Centre for Evidence in Disability, & London School of Hygiene & Tropical Medicine.

IAEG-SDGS (2017): Report of the Inter-agency Task Force on Financing for Development 2017.

IAEG-SDGS (2018): Overview of standards for data disaggregation.

IAEG-SDGS (2019): Data Disaggregation and SDG Indicators: Policy Priorities and Current and Future Disaggregation Plans, Statistical Commission Background document Fiftieth session.

INTER-AGENCY TASK FORCE ON FINANCING FOR DEVELOPMENT (2017): Financing for Development: Progress and Prospects, Report of the Inter-agency Task Force on Financing for Development 2017, (p. 118).

OECD DEVELOPMENT CO-OPERATION (2017): *Development Co-operation Report* focuses on Data for Development.

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2006): Article 33 (3).

UN GENERAL ASSEMBLY (July 2015): Addis Ababa Action Agenda of the Third International Conference on Financing for Development (Addis Ababa Action Agenda) (A/RES/69/313).

UN GENERAL ASSEMBLY (September 2015): Transforming our world: the 2030 Agenda for Sustainable Development (A/RES/70/1).

UN GENERAL ASSEMBLY (2017): Work of the Statistical Commission pertaining to the 2030 Agenda for Sustainable Development (A/RES71/313).

WASHINGTON GROUP ON DISABILITY STATISTICS (2018): 2030 Agenda for Sustainable Development: Selected SDG Indicators Disaggregated by Disability Status.

ZUSAMMENFASSUNG

Die UN-Konvention über die Rechte von Menschen mit Behinderungen (UN-BRK) und die 2030 Agenda für nachhaltige Entwicklung fordern die Aufschlüsselung von Daten in Bezug auf Behinderung, soweit anwendbar, dennoch bleiben Menschen mit Behinderungen nach vier Jahren in der Umsetzung der Ziele der nachhaltigen Entwicklung (SDGs) zu wenig berücksichtigt. Trotz vorhandener Indikatoren im globalen Indikatorensystem, die nach Behinderung aufgeschlüsselt werden können und der Verfügbarkeit behinderungsbezogener Daten, werden behinderungsbezogene Daten für die Überprüfung der SDG durch nationale statistische Ämter nicht umfassend erhoben. Somit gibt es einen Mangel an Informationen über Menschen mit Behinderungen, was ein großes Hindernis für Inklusion darstellt. Um dem zu begegnen empfehlen wir, dass Daten aufgeschlüsselt nach Behinderung mithilfe der Kurzversion der Fragen, die durch die Washington Group on Disability Statistics entwickelt wurden, erhoben werden und zudem Menschen mit Behinderungen und ihre Vertretungsorganisationen zur Gestaltung, Implementation und Überwachung der SDG Pläne in Übereinstimmung mit Artikel 33 der UN-BRK zu befragen.

RÉSUMÉ

La Convention des Nations Unis sur les droits des personnes avec un handicap (UN-Convention on the Rights of Persons with Disabilities (CRPD)) et l'agenda de 2030 pour un développement soutenable, demande que les statistiques et dates sont au mieux dégagés par handicap, mais en ce moment les personnes ayant un handicap sont laissées derrière, quatres ans après avoir mis en place les buts d'un développement soutenable (Installable Devolopment Goals (SDGs). Quoiqu'il éxistent des indications dans la structure des indicateurs globales et l'existence des dates sur les handicaps qui permettent de diviser les différents handicaps, ces dates ne sont pas collectionnées par les offices nationaux statistiques qui sont responsable pour la surveillance des SDGs. Par conséquent, il y a une lacune sur les personnes ayant un handicap, ce qui est une des plus grandes barrières de l'inclusion. Pour répondre à cela, les dates qui divisent les handicaps doivent être collectionnées en utilisant le bref kit des questions développé par le groupe de Washington sur les statistiques des handicaps, et en même temps par consulter des personnes ayant un handicap et leurs organisations représentatives sur le dessin, l'implémentation et la surveillance des plans SDG en cohérence avec l'article 33 du CRPD.

RESUMEN

La Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad (CDPD) y la Agenda para el Desarrollo Sostenible de 2030 requieren que las estadísticas y los datos sean desagregados por discapacidad cuando sea aplicable, sin embargo, las personas con discapacidad permanecen rezagadas después de cuatro años en la implementación de los Objetivos de Desarrollo Sostenible (SDG). A pesar de tener indicadores que pueden ser desagregados por discapacidad en el marco de los indicadores globales y la disponibilidad de datos sobre discapacidad, los datos sobre discapacidad en general no están siendo recopilados por las Oficinas Nacionales de Estadística para el seguimiento del SDG. En consecuencia, hay una falta de información sobre las personas con discapacidad, lo que constituye un obstáculo importante para la inclusión. Para abordar este problema, los datos desagregados por discapacidad deben recopilarse utilizando el breve conjunto de preguntas desarrolladas por el Grupo de Washington sobre Estadísticas de Discapacidad, a la vez que se consulta a las personas con discapacidad y a las organizaciones que las representan sobre el diseño, la implementación y el seguimiento de los planes de los SDG, de conformidad con el Artículo 33 de la CDPD.

Authors: Elizabeth Lockwood, Ph.D. is the CBM Representative at the United Nations. Orsolya Bartha is the Senior Advisor at the International Disability Alliance.

Contact: elizabeth.lockwood@cbm.org; obartha@ida-secretariat.org

Disability Disaggregated Data to Support Inclusive Education: Findings from the Disability Data Portal

Ola Abu Alghaib/Elaine Green

Despite a growing effort at the international, national and provincial levels to collect data on people with disabilities, challenges in gathering, analysing and accessing comparable, quality data means that people with disabilities are being left behind in key development indicators, including on education. This article summarises the key findings on inclusive education gathered through Leonard Cheshire's Disability Data Portal project. We highlight the opportunity afforded by centralised data repositories, allowing organisations and advocates to more easily access available data as a crucial first step towards disability inclusion and achieving the global commitment to *leave no one behind*.

Introduction

Over the past 15 years there has been a growing effort at the international, national and provincial levels to collect data on people with disabilities, spurred on by the inclusion of data collection provisions in the UN Convention on the Rights of Persons with Disabilities (UNCRP) – now ratified by over 170 countries – and the inclusion of disability within the Sustainable Development Goals (SDGs) with their call to *leave no one behind*. This momentum has been facilitated by the development of various validated tools for measuring disability status including the Washington Group questions, USAID's Demographic and Health Survey (DHS), UNICEF's Multiple Indicator Cluster Surveys (MICS), the Child Functioning Modules (CFM) developed by the Washington Group and UNICEF, and the World Health Organisation's (WHO) Model Disability Survey (WHO, n.d) (MDS). This growth in information is promising. However, a lack of consistency, variations in methodologies used, and limited analysis and dissemination of data often make it difficult to fully use the data to improve inclusive national policies or to provide global overviews of progress and gaps for people with disabilities.

Leonard Cheshire's Disability Data Portal project is an attempt to address this issue. The Portal provides a snapshot of the data that is globally available on people with disabilities, identifying sources of available data and existing data gaps across 40 countries[1] – mostly concentrated on the Global South – on four key themes, including inclusive education. This article presents the key findings from the project in relation to inclusive education, highlighting the opportunity provided by centralised repositories such as the Disability Data Portal to enable organisations and advocates to more easily access the available data as a crucial first step towards disability inclusion. The project findings are outlined in full in the Disability Data Portal report (Leonard Cheshire 2018).

Disability Data Portal

The Disability Data Portal project mainly gathered data from censuses and Demographic and Health Surveys (DHS) (USAID, n.d.), as well as some other reports and national household surveys (ibid.). The choice of indicators was made through a collaborative process, with most being drawn from the SDGs indicator framework. Further information outlining the indicator selection process, the availability of datasets and methods of calculation used are outlined in full in the Disability Data Portal report (ibid.).

The project team selected five indicators related to inclusion in education:

1. School completion rates (primary and secondary).
2. Participation rate in organised learning (one year before the official primary entry age), by sex.
3. Participation rate of youth and adults in formal and non-formal education and training in the previous 12 months, by sex.
4. University completion rates (or university access rates as proxy).
5. Proportion of population in a given age group achieving at least a functional level of proficiency in basic literacy skills, by sex.

Key Findings on Inclusive Education from the Disability Data Portal

This section presents a snapshot of the key findings on inclusive education from the analysis of the data provided through the Disability Data Portal. A more comprehensive analysis, including further disaggregation by gender, is outlined in Leonard Cheshire's Disability Data Portal report (ibid.).

School Completion Rates (Primary and Secondary)

It was possible to disaggregate this indicator for 35 of the 40 countries sampled. Analysis of the data reveals that children with disabilities are less likely than children without disabilities to complete primary education. The average completion rates for primary school are 48% for children with disabilities and 70% for those without disabilities. Statistics on the completion rate for secondary education shows that on average 32% of people without disabilities and 21% of people with disabilities have graduated from secondary school, revealing an 11% gap between people with and people without disabilities. For the remaining 36 countries, the gap between those with and those without disabilities ranges from 0 percentage points (Burkina Faso, Liberia and Mali) to 43 percentage points (Egypt). The highest completion rates for secondary education are observed in Trinidad and Tobago: 85% for people without disabilities and 62% for people with disabilities. However, the gap between these two groups (23 percentage points) is higher than the average gap calculated for the 35 countries, (11 percentage points).

However, there are also outliers. In Gambia and Nigeria the completion rate for primary education observed among children with disabilities exceeds that of children without a disability (59% versus 55% in Gambia; 100% versus 78% in Nigeria). Results calculated for these two countries should be interpreted cautiously, however, as the sample used for this indicator in each of these two countries is composed of fewer than 50 unweighted observations.

Participation Rate in Organised Learning (One Year Before the Official Primary Entry Age), by Sex

Out of the indicators, the indicator for participation in organised learning pre-primary age was the most limited. This indicator could be calculated for 31 countries, with Rwanda standing out as the only one where all children (100%) aged one year before the official primary entry age participate in organised learning. Ranking second is Uruguay (97% and 98% respectively for those without a disability and people with disabilities) in terms of participation rate in organised learning.

Participation Rate of Youth and Adults in Formal and Non-Formal Education and Training in the Previous 12 months, by Sex

This indicator could be produced for 35 countries. The participation rate in formal and non-formal education is separated into two groups. Firstly, youth aged 15-24 years old and then adults aged 25-64 years old.

In the sample of people aged from 15 to 24 years old, there are only three out of 35 countries where the participation rate of people with disabilities exceeds 50% (Colombia: 55%; Costa Rica: 53%; Botswana: 52%). In contrast, the participation rate of people with disabilities is lower than 10% in Burkina Faso (9%). Egypt presents the highest gap observed between the groups with and without disabilities (47 percentage points) while Botswana (47% for people without disabilities and 52% for people with disabilities) and Colombia (46% for people without disabilities and 55% for people with disabilities) are the only countries where a gap in favour of people with disabilities was observed.

We were able to estimate the indicator for the age group 25-64 in a total of 23 countries. We observed

the highest participation rates for people with disabilities in the Dominican Republic and Ecuador (6.5%). The largest gaps between the groups with and without disabilities are observed in Liberia (5.5% and 11% respectively, leading to a 5.5 percentage point gap) and Nigeria (0.5% and 4.5% respectively, leading to a four percentage point gap).

University Completion Rates (or University Access Rates as Proxy)

Calculations for this indicator considered two age groups for university completion rates. The first group is composed of those who are 25 to 54 years old (35 countries) while the second group is composed of people who are at least 55 years old (34 countries).

For the 25-54 years age group, the average university completion rates for people with disabilities and those without a disability are 4.5% and 7.9% respectively. The university completion rate among people with disabilities varies from 0% in Senegal to 25% in Colombia. Panama presents the widest gap between the two groups (19% and 7% for people without and people with disabilities respectively). Out of 35 countries, Gambia (8.2% and 6.1% for people with and without disabilities respectively) and Colombia (25% for people with disabilities and 21% for those without disabilities) are the only ones with gaps in favour of people with disabilities.

In relation to the age group 55 and above, university completion rates of people with disabilities (1.8%) with that of people without disabilities (3.7%) revealed a 1.9% gap. Costa Rica is observed to be the country with the widest gap between people with and without disabilities (5.8% and 13% respectively - a gap of 7.2 percentage points). Once again, we observe a gap in favour of people with disabilities in Colombia (6.7% and 5.6% respectively for people with and without disabilities-a gap of 1.1 percentage point) and Gambia (5.7% and 3.4% respectively for people with and without disabilities-a gap of 2.3 percentage points).

Proportion of Population in a Given Age Group Achieving at Least a Fixed Level of Proficiency in Functional Literacy Skills, by Sex

For the 32 countries for which this calculation is possible the population was divided into three groups. The first group is composed of individuals who are under 25 years of age[2], the second group is composed of those who are at least 25 years old and the third group is composed of people who are at least 15 years old.

For those under 25, we observe that in five countries (Uruguay: 100%; Panama: 98%; Rwanda: 97%; Ecuador: 93%; Vietnam: 93%) more than 90% of the population of people without disabilities have functional literacy skills. However, when the population with a disability is considered, the proportion of individuals with literacy skills is always lower than 90% except in Rwanda (96%). Regarding the sample of people who are at least 25 years old, we notice that the proportion of people with disabilities with functional literacy skills varies from 10% in Burkina Faso to 100% in Rwanda.

DHS datasets only ask information about literacy skills to individuals aged at least 15 years old. From this group, we notice that the lowest literacy rates of the countries analysed are observed in South Sudan (22% and 27% for people with and without disabilities respectively) and Burkina Faso (12% and 25% for people with and without disabilities respectively); however in Vietnam (59% and 94% for people with and without disabilities respectively – a gap of 35 percentage points) and Tanzania (45% and 77% for people with and without disabilities respectively – a gap of 32 percentage points) the widest gap is presented.

Conclusions and Recommendations

Leonard Cheshire's experience of gathering data through the Disability Data Portal reveals that data on disability is available and disaggregation is possible, with data on indicators relating to education being the most widely available across the countries and datasets considered. Disability disaggregated data on all five education indicators was available for the majority of countries sampled.

Analysis of data clearly shows that, for the majority of countries, people with disabilities are being left behind in key indicators related to education, with a 22 percentage point difference in school completion rates for children with disabilities and children without disabilities. Samples of people in formal and non-formal education also revealed significant gaps. In just three out of 35 countries did the participation rate of young disabled people, aged 15-24, in formal and non-formal education or training exceed 50%. This pattern is mirrored in university completion rates whereby the data gathered through the disability data portal revealed that, for the 25-54 years age group, average university completion rates for people with disabilities was 4.5% compared to 7.9% for those without a disability. A gender-based analysis of educational achievements reveals additional nuances in the data. Further disaggregation and analysis by gender is

outlined in Leonard Cheshire's Disability Data Portal report (Leonard Cheshire 2018).

Overall, this paper demonstrates that a substantial amount of data on disability exists and it is improving in quality. A consensus is emerging on the use of the Washington Group questions to identify people with disabilities, making it easier for countries to meet standards of international comparability. Existing data, however, is widely scattered and collected from a range of different sources such as national censuses, surveys, studies and reviews, meaning that current data is difficult to analyse, use and compare across countries[3]. To enable better use, analysis and comparison of existing data there is a need to invest in strengthening centralised repositories, such as the Disability Data Portal, to make this data more easily accessible and available to organisations and advocates as a crucial first step towards disability inclusion.

The data gathered on education reveals that despite significant investments in improving access to inclusive education, children with disabilities are still finding it more difficult to access education than their non-disabled peers in accessing education. Learners with disabilities, at all ages, continue to be falling behind those without disabilities and are significantly less likely to complete primary, secondary or tertiary education than learners without disabilities.

To improve the collection of disability-disaggregated data, States must generate appropriate indicators, including disability-specific indicators outlined in the SDGs, and disaggregate all national indicators by disability in line with Article 31 of the UNCRPD. It is recommended that the UN system and National Statistics Offices take a leading role in coordinating efforts to ensure disability data disaggregation is undertaken in all national data collection exercises. Donors can also play a role in targeting their support to strengthen national data collection systems, with an enhanced focus on disability in national surveys and censuses.

Improved disaggregation of data will make it easier for national governments and donors to identify where those with disabilities are being left behind, thereby enabling them to identify and prioritise the key barriers to inclusion. For education, as indicated by the data captured in the disability data portal, this means governments and donors need to increase their efforts to ensure all children with disabilities are able to access primary school; need to provide more individualised support to learners with disabilities to enable them to improve their learning outcomes and remain in education for longer; and need to work with formal and non-formal education and training institutions, as well as universities, to provide people with disabilities with the same opportunities for learning as those without disability.

Notes

1 Albania, Bangladesh, Botswana, Burkina Faso, Cambodia, Cameroon, Chad, Colombia, Costa Rica, Dominican Republic, Egypt, El Salvador, Ecuador, Gambia, Ghana, India, Kenya, Liberia, Malawi, Maldives, Mali, Mexico, Myanmar, Nigeria, Pakistan, Panama, Rwanda, Senegal, South Africa, South Sudan, St. Lucia, Tanzania, Timor-Leste, Trinidad and Tobago, Uganda, Uruguay, Vietnam, Yemen, Zambia, Zimbabwe.

2 The lower age limit varied by country. In Burkina Faso, for example, the question is asked to people who are at least 3 years of age.

3 To ensure quality of data, the information included in the disability data portal was primarily drawn from validated data sources such as Integrated Public Use Microdata Series (IPUMS) and Demographic and Health Surveys.

References

LEONARD CHESHIRE (2018): Disability Data Report. Available at: https://www.disabilitydataportal.com/fileadmin/uploads/lcdp/Documents/report-web_version.pdf. Visited on 10 July 2019.

USAID DEMOGRAPHIC AND HEALTH SURVEYS (n.d.): Available at: https://dhsprogram.com/. Visited on 10 July 2019.

WORLD HEALTH ORGANISATION (n.d.): Model Disability Survey. Available at: https://www.who.int/disabilities/data/mds/en/. Visited on 10 July 2019.

ZUSAMMENFASSUNG

Trotz steigender Bemühungen Daten über Menschen mit Behinderungen auf internationalem, nationalem und regionalem Level zu erheben, bleiben Schwierigkeiten bei der Erfassung, Analyse und dem Zugang zu vergleichbaren, zuverlässigen Daten, was bedeutet, dass Menschen mit Behinderungen bei zentralen Entwicklungsindikatoren, einschließlich Bildung, unberücksichtigt bleiben. Dieser Artikel fasst zentrale Ergebnisse über inklusive Bildung aus Leonard Cheshires Projekt eines Datenportals über Behinderung zusammen. Die Möglichkeiten zentralisierter Datenbestände, die Organisationen und Verbänden einen einfachen Zugang zu Daten als einen ersten entscheidenden Schritt in Richtung disability inclusion und zur Erreichung der globalen Verpflichtung *leave no one behind*, wird hervorgehoben

RÉSUME

Quoiqu'il existe des efforts croissants sur le niveau international, national et régional de collectionner des dates sur les personnes ayant un handicap, il y a des défis pour collectionner, analyser et d'avoir l'accès aux dates de qualité comparables ce qui veut dire que les personnes ayant des handicaps sont laissées derrière dans les questions clés du développement, l'éducation inclue. Cet article

résume les découvertes clés sur l'éducation inclusive collectionnées par le projet du Leoard Cheshire sur le portail des dates sur le handicap. On souligne que l'autorisation d'avoir l'accès aux dates par des dépôts centralisés, permet aux organisations et avocats plus facilement l'accès au dates existants ce qui est un première pas crucial vers l'inclusion des handicaps et d'obtenir l'obligation globale de *ne pas laisser aucune*.

RESUMEN

A pesar de los crecientes esfuerzos a nivel internacional, nacional y provincial para recopilar datos sobre las personas con discapacidad, la dificultad de recopilar, analizar y acceder a datos comparables y de calidad significa que las personas con discapacidad se están quedando rezagadas en los principales indicadores de desarrollo, incluida la educación. Este artículo resume las principales conclusiones sobre educación inclusiva recogidas a través del proyecto del Portal de Datos sobre Discapacidad de Leonard Cheshire. Destacamos la oportunidad que ofrecen los repositorios de datos centralizados, que permiten a las organizaciones y defensores acceder más fácilmente a los datos disponibles como un primer paso crucial hacia la inclusión de las personas con discapacidad y el logro del compromiso global de *no dejar a nadie atrás*.

Authors: Dr Ola Abu Alghaib is Director of Global Influencing and Research Leonard Cheshire, and Elaine Green is Policy Manager Leonard Cheshire.

Contact: Ola.AbuAlghaib@leonardcheshire.org; Elaine.Green@leonardcheshire.org.

Bericht/Report

Die Titchfield-City-Gruppe

Datenrevolution: UN-Gruppe für Verbesserung der Datengewinnung über ältere Menschen gegründet

Leave No One Behind, also das völkerrechtlich verbindliche Versprechen der *Agenda 2030*, eröffnet die einmalige Chance, nationale und internationale Entwicklungspolitik inklusiver zu gestalten, Ungleichheiten, die u.a. mit Alter und Beeinträchtigung verbunden sind, sowie die weltweite Armut zu reduzieren. Dennoch bleiben ältere Menschen und Menschen mit Beeinträchtigung oft unsichtbar für politische Entscheidungsträger genauso wie für Hilfsorganisationen. Ein fehlendes Bewusstsein für die Situation vulnerabler Menschen erschwert bislang Fortschritte in der Formulierung und Implementierung inklusiver Maßnahmen. Ein Grund dafür liegt in der schlechten Datenlage. Diese offensichtlichen Lücken sollen durch die sog. *Titchfield-City-Group* geschlossen werden.

Gründung der Titchfield-City-Group

Es gibt eine Vielzahl von Herausforderungen in der Sammlung, Analyse und Nutzung von Daten zum Altern und zu älteren Menschen. Datenerhebungen sind nicht miteinander koordiniert, auf vergleichbare Weise aufgeschlüsselt und gehen von unterschiedlichen Basiswerten aus. Im März 2018 kam es daher zu einer Einigung in der UN-Statistikkommission,

die *Titchfield-City-Group on Ageing and Age-disaggregated Data*, oder kurz *Titchfield-City-Group* (TCGA), einzusetzen, um diese Lücken zu schließen. City Groups sind informelle Beratergruppen, die in der Regel nach dem Ort benannt sind, an dem sie ihr erstes Treffen abhalten. Dazu gehören VertreterInnen der nationalen statistischen Ämter, die freiwillig teilnehmen, um spezifische thematische Herausforderungen bei der Entwicklung und Umsetzung statistischer Methoden zu diskutieren und anzugehen. Die *Titchfield-City-Group* wurde vom Vereinigten Königreich nach Diskussionen auf dem *World Data Forum* auf der Sitzung der Statistikkommission der Vereinten Nationen in ihrer 48. Sitzung im Jahr 2017 vorgeschlagen. Es folgte ein technisches Seminar über die vorgeschlagene City Group, das im August 2017 im Vereinigten Königreich stattfand, um Wissen und Erfahrungen im Zusammenhang mit den Kernfragen der altersdisaggregierten Daten und alterskorrelierten Statistiken auszutauschen. An diesem Seminar nahmen der UN-Focal Point on Ageing, UNDP, WHO, UNWOMEN, UNFPA, HelpAge International und andere teil. Die Diversität der beteiligten Akteure zeigt, wie groß der Bedarf an besser aufbereiteten Daten generell war und ist, sowohl von Supraorganisationen bis hin zu nationalen und internationalen Organisationen. So rief im Sommer dieses Jahres die UN-Sonderberichterstatterin zur UN-Konvention über die Rechte von Menschen mit Behinderungen (UNCRPD) zur offenen Berichterstattung über die Situation von älteren Menschen mit Behinderung auf (OHCHR: Juli 2019). Der Vorsitzende der UN-OEWG-A (UN-Open Ended Working Group on Ageing), forderte in seinem Schlussbericht zur 10 Sitzung der OEWG-A im April 2019 die Staaten dazu auf, die bereits in 2018 von der Arbeitsgruppe ausgegebenen Fragebögen zu beantworten, um eine bessere Datenlage zu erzielen und somit geeignete Maßnahmen zur Verbesserung der Situation älterer Menschen zu erreichen (OEWG-A: Schlussreport April 2019).

Verankert ist die *Titchfield-City-Group* innerhalb des UN-Systems bei der UN-DESA, (United Nations Department of Economic and Social Affairs) https://www.un.org/development/desa/en/, das gleichzeitig Focal Point für alle Fragen von *Senior Citizens Affairs* innerhalb der UN ist und die Ergebnisse der *Titchfield-City-Group* veröffentlicht.

Die Leitung der Gruppe hat das UK Office for National Statistics übernommen, das Statistische Bundesamt ist seit Juni 2018, dem ersten Treffen der *Titchfield-City-Group*, an dem Prozess beteiligt. In ihren fünf Jahren Laufzeit will die TCGA folgende Bereiche bearbeiten:

- Arbeitsbereich 1: Bewertung der Verfügbarkeit von altersdisaggregierten Daten in bestehenden Datenquellen unter Verwendung einer ausgewählten Gruppe von Ländern.
- Arbeitsbereich 2: Antizipation des zukünftigen Datenbedarfs und Auseinandersetzung mit der Frage, wie gut die Länder aufgestellt sind, um diesen Bedarf zu decken.
- Arbeitsbereich 3: Konzeption zur Schaffung einheitlicher Schemata der Datenerhebung sowie Analyserahmen, wobei unterschiedliche Definitionen von Alter zwischen den Ländern anerkannt wird.
- Arbeitsbereich 4: Förderung der Zusammenarbeit und des Austausches über bewährte Praktiken und Berücksichtigung des Alterns im Rahmen der Ziele für nachhaltige Entwicklung (SDGs).
- Arbeitsbereich 5: Empfehlungen zur Altersnormung, die eine vergleichende Analyse ermöglicht und aussagekräftige Fortschrittsmessungen liefert. Außerdem wird eine Harmonisierung der Daten und Konzepte angestrebt, damit die Länder über eine einheitliche Datenlage verfügen und geeignete Vergleiche ziehen können.
- Arbeitsbereich 6: Entwicklung einer Plattform für den Informationsaustausch.

Ziel und Aufgaben der Titchfield-City-Group

Hauptziel der *Titchfield-City-Group* ist es, standardisierte und harmonisierte Instrumente und Methoden zur Erhebung von Daten über die Situation vulnerabler Menschen sowie die Aufschlüsselung nach Alter zu entwickeln. Darüber hinaus soll sie das laufende Monitoring der Agenda 2030 (Sustainable Development Goals 2030) der Vereinten Nationen durch die Entwicklung global nutzbarer Indikatoren unterstützen.

Der Schlüssel zum Verstehen der Intersektionalität von Vulnerabilitätskriterien wie z.B. Geschlecht, Alter und Beeinträchtigung liegt in der Sammlung der richtigen Daten – disaggregiert nach Geschlecht, Alter und Beeinträchtigung (SADD: sex, age, disability disaggregated data). Die in den SADDD gesammelten Daten gelten dabei als Mindestmenge an Datenfluss, um ein Gerüst vergleichbarer Daten zu kreieren. Je nach Gegenstand der weiteren Untersuchung werden diese noch mit Zahlen zu Querschnittsthemen wie unterschiedliche wirtschaftliche und soziale Entwicklungen der Länder, Migration oder Fluchtbewegungen ergänzt. Ohne die Erhebung und Analyse von SADDD kann die Situation von Zielgruppen und ihren Lebensumfeldern also nicht angemessen verstanden werden. Fehlendes Bewusstsein dafür erschwert bislang Fortschritte in der Formulierung und Implementierung

inklusiver Maßnahmen. (HelpAge, 2018, S. 35) Denn wenn die Bedarfe und Kapazitäten bestimmter Gruppen unsichtbar bleiben, werden sie auch in Programmen nicht adressiert (HelpAge und International Displacement Monitoring Center, 2012, S. 5).

Nicht nur werden besonders vulnerable Menschen im Rahmen von Datenerhebungen oft nicht erreicht, sondern Daten werden nicht ausreichend aufgeschlüsselt. Sie umfassen zu große Kohorten (z.B. Zusammenfassung der Gruppe *60+*) oder enthalten keine Informationen zu Geschlecht und Beeinträchtigung. Diese Ungenauigkeit in den Daten führt zu Fehlinterpretationen und Trugschlüssen – wie zum Beispiel der stereotypen Annahme, dass geschlechtsbasierte Gewalt typischerweise jüngere Frauen betrifft (HelpAge, 2017, S.2). Daten über physische und sexuelle Gewalt gegen Frauen über 49 Jahren belegen jedoch, dass sie gleichermaßen von Gewalt betroffen sind (Fundamental Rights Agency, 2014, Main Results). Eine Mehrheit der von HelpAge in den vergangenen Jahren untersuchten Studien basiert aber auf Datensätzen, die nur bis zum Alter von 49 Jahren reichen. So basiert der *Global and Regional Estimates of Fiolence Against Older Women*-Bericht der Weltgesundheitsorganisation (WHO, 2013) weitgehend auf Datenerhebungen, die die Altersgruppe 15-49 abdecken.

Auch die Daten, die von der UN zur Messung der Indikatoren für SDG-Unterziel 5.2 („Alle Formen von Gewalt gegen alle Frauen und Mädchen im öffentlichen und im privaten Bereich einschließlich des Menschenhandels und sexueller und anderer Formen der Ausbeutung beseitigen") herangezogen werden, haben eine Altersgrenze von 49 Jahren (SDG-Indicators, 2019, Target 5.2, Indikator 5.2.1, S. 4).

Ebenso ist die Diskrepanz zwischen der Prävalenz von nicht-übertragbaren Krankheiten (non-communicable diseases, NCDs) und der Fokussierung auf andere Themenbereiche wie Mutter-Kind-Gesundheit oder Infektionskrankheiten, sowohl durch staatliche Gesundheitsakteure als auch durch medizinische Sektororganisationen, ist auf eine mangelnde Datenverfügbarkeit und -analyse zurückzuführen. So wurden bei der im Juni 2019 veröffentlichten Fortschrittsstudie WHO STEPS der Weltgesundheitsorganisation (WHO) in 34 der 40 untersuchten Staaten keine Daten von Personen über 64 Jahren erhoben (WHO: STEPwise June 2019). Das Auftreten von NCDs ist eng mit einem höheren Alter verbunden, ein Trend, der sich aufgrund des demografischen Wandels weiter verstärken wird. Die Sterblichkeitsrate an NCDs liegt in Ländern des sog. *Globalen Südens* bei 85% und belastet im Schnitt bereits heute mit ca. 90% die nationalen Gesundheitsbudgets die Länder des *Globalen Südens* (WHO, Key Facts August 2018).

In der Studie *Missing Millions* wird festgestellt, dass die Nutzung von SADDD zu besseren Programmen geführt hat: „Global and local key informants noted that collecting age and disability data led to better programmes" (HelpAge 2018, S. 39). Die Studie hebt jedoch auch die Herausforderungen bei der Erhebung von Daten nicht nur älterer Menschen, sondern auch über Menschen mit Beeinträchtigung hervor, einschließlich des Fehlens eines Konsenses über die Messbarkeit von Beeinträchtigung, sowie der Besorgnis, dass die Erhebung von Daten zu viel Zeit benötige. „However, population-based surveys containing data on people with disabilities in humanitarian settings are sorely lacking. There is an urgent need for disability surveys to be carried out in different crises-affected populations to inform policies, programmes and advocacy for inclusive humanitarian action" (HelpAge 2018, S. 40).

Die erwähnten Schwierigkeiten in der Sammlung von Daten über Beeinträchtigungen spiegeln sich auch in der Sammlung über Altersdaten wider: Es gibt keine Standardisierung von Alter als objektivem Wert. Während zum Beispiel in den USA Menschen ab dem 50. Lebensjahr zur Gruppe der *Senior Citizens* gerechnet werden, definiert die UN Menschen ab dem 60. Lebensjahr zur Gruppe der älteren Menschen. Ebenso ist die Disaggregierung nach Alter nicht harmonisiert, so dass Daten über *ältere Menschen* nicht vergleichbar und repräsentativ sind. Zudem werden Daten über Ältere, die außerhalb traditioneller Haushalte leben (z.B. im Seniorenheim) selten erhoben, und die Beziehungen zwischen Alter, Geschlecht, Beeinträchtigung, Lebensort und weiteren Faktoren werden nicht berücksichtigt. Ältere Menschen werden nur in 22 der 169 Ziele und Unterziele der SDGs einbezogen, und nur acht der SDG-Indikatoren sind nach Alter aufgeschlüsselt. Um zu messen, ob tatsächlich *niemand zurückgelassen* wird, muss auch die im Rahmen der SDG-Entwicklung geforderte *Datenrevolution* umgesetzt werden und die Qualität und der Umfang von Daten müssen verbessert werden.

Was bedeutet das in der Praxis?

Die oben beschriebenen Beispiele zeigen: Werden Daten nicht differenziert erhoben, werden auch Bedarfe der jeweiligen Personengruppen nicht erkannt. In der Folge bleiben auch Forschungsaktivitäten entweder begrenzt oder undifferenziert, noch werden Maßnahmen entwickelt, um die Lebenssituation oder einzelne Lebensbereiche, wie den

Gesundheitszustand Älterer zu verbessern. Auch die nachhaltigen Entwicklungsziele (SDGs) der Agenda2030 messen ihren Erfolg darin *niemanden zurückzulassen* anhand von Datensätzen, die teilweise nur bis zum Alter von 49 Jahren reichen – ältere Menschen bleiben weiterhin ausgeschlossen.

HelpAge und alle beteiligten Akteure haben mit der *Titchfield-City-Group* einen wichtigen Schritt zur zeitnahen Verbesserung der Datenlage geleistet, in dem künftig alle Altersgruppen erfasst sowie die Koordination der Daten und Zusammenarbeit der nationalen Statistikämter der Mitgliedstaaten vorangebracht werden.

NOTES

1 OHCHR: Questionnaire on The Rights of Older People with Disabilities, Juli 2019, https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/SupportingTheAutonomyOlderPersons.aspx; abgerufen am 21. August 2019

2 OEWG-A, Report of the Open-ended Working Groupon Ageing on its tenth working session, April 2019; https://undocs.org/en/A/AC.278/2019/2; abgerufen am 21. August 2019

3 HelpAge, 2018, Missing millions: How older people with disabilities are excluded from humanitarian response; https://www.helpage.org/newsroom/latest-news/millions-of-older-people-with-disabilities-risk-being-excluded-from-humanitarian-assistance-new-helpage-report-reveals/; abgerufen am 21. August 2019

4 HelpAge und International Displacement Monitoring Center, 2012, The neglected generation – the impact of displacement on older people; https://fiapam.org/wp-content/uploads/2013/11/helpage-theneglected-01.pdf; abgerufen am 21. August 2019.

5 HelpAge, 2017, Violence against older women; www.helpage.org/download/5a1848be4c5ee; abgerufen am 21. August 2019.

6 Fundamental Rights Agency, 2014, Violence Against women: an EU-wide survey; https://fra.europa.eu/en/publication/2014/violence-against-women-eu-wide-survey-main-results-report; abgerufen am 21. August 2019

7 WHO, 2013, Global and Regional estimates of violence against women; http://apps.who.int/iris/bitstream/10665/85239/1/9789241564625_eng.pdf; abgerufen am 21. August 2019.

8 SDG Indicators metdata repository, 2019, https://unstats.un.org/sdgs/metadata/; abgerufen am 20.August 2019.

9 WHO, STEPwise approach to surveillance, June 2019; abgerufen am 21. August 2019 https://www.who.int/ncds/surveillance/steps/reports/en/; abgerufen am 21. August 2019.

10 WHO, Key Facts, August 2018 https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases; abgerufen am 21. August 2019.

11 HelpAge, 2018, Missing millions: How older people with disabilities are excluded from humanitarian response; https://www.helpage.org/newsroom/latest-news/millions-of-older-people-with-disabilities-risk-being-excluded-from-humanitarian-assistance-new-helpage-report-reveals/; abgerufen am 21. August 2019

12 HelpAge, 2018, Missing millions: How older people with disabilities are excluded from humanitarian response; https://www.helpage.org/newsroom/latest-news/millions-of-older-people-with-disabilities-risk-being-excluded-from-humanitarian-assistance-new-helpage-report-reveals/; abgerufen am 21. August 2019.

Carolin Reintjes, Referentin Humanitäre Hilfe und Entwicklungszusammenarbeit
Jürgen Focke, Referent Policy & Advocacy

Resolution des UN-Sicherheitsrats zu Menschen mit Behinderungen im bewaffneten Konflikt

Am 20. Juni verabschiedete der UN-Sicherheitsrat als erste ihrer Art einstimmig eine Resolution zu den Rechten von Menschen mit Behinderungen im bewaffneten Konflikt – ein großer Erfolg auch von zivilgesellschaftlichen Akteuren, denn diese Thematik lag bisher trotz der besonderen Schutzbedürftigkeit in Krisensituationen nicht im Fokus des Rats. Laut der Resolution sollen künftig bei Reaktionen auf die Auswirkungen bewaffneter Konflikte und der damit verbundenen humanitären Krisen Menschen mit Behinderungen bewusst berücksichtigt werden. Humanitäre Operationen sollen betroffenen Zivilist/-innen mit Behinderungen, insbesondere Frauen und Kinder, durch Rehabilitation und psychologische Unterstützung eine bedarfsgerechte Versorgung bieten, damit sie sich in Folge der durchgeführten Maßnahmen wieder in die Gesellschaft eingliedern können. Jeder UN-Mitgliedstaat wird dazu ermutigt, geeignete Lösungen zu finden, um sicherzustellen, dass Menschen mit Behinderungen gleichberechtigt Zugang zu grundlegenden Dienstleistungen haben, die im Kontext von bewaffneten Konflikten erbracht werden, einschließlich dem Bildungswesen, Gesundheitsdiensten, dem Verkehrswesen sowie Informations- und Kommunikationstechnologien.

Der UN-Generalsekretär wird durch die Resolution ersucht, Informationen über Menschen mit Behinderungen in bewaffneten Konflikten in thematische und geografische Berichte und regelmäßige Unterweisungen an den Rat aufzunehmen, um das Bewusstsein aller Beteiligten nachhaltig zu fördern. Die Mitgliedstaaten sollen außerdem in Aktivitäten der humanitären Hilfe, Konfliktprävention und -bearbeitung Menschen mit Behinderungen und ihre Vertretungsorganisationen einbeziehen. Dabei wird auch die Notwendigkeit der Bewusstseinsbildung und den Aufbau von Kapazitäten innerhalb der UN-Behörden betont. Schließlich werden in der Resolution noch die an bewaffneten Konflikten beteiligten Parteien dazu aufgerufen, gewalttätige Handlungen gegen alle Menschen und insbesondere Menschen mit Behinderung einzustellen.

Insgesamt nimmt die Resolution Bezug auf die Verpflichtungen der Behindertenrechtskonvention (CRPD), die Strategie der Vereinten Nationen zur Einbeziehung von Menschen mit Behinderungen (UNDIS), die Charta zur Einbeziehung von Menschen mit Behinderungen in humanitäre Maßnahmen und die IASC-Leitlinien.

Information: https://undocs.org/s/res/2475(2019) .

New UN Disability Inclusion Strategy

The UN chief launched a new UN Disability Inclusion Strategy in June 2019, to raise the standards of the UN's performance on disability inclusion across the board and to bring about a unified and transformative change. With an accountability framework to monitor progress and address challenges, the new strategy has clear benchmarks and will encourage more persons with disabilities to work in, and be better supported by the UN. The UN wants to become accessible for everyone, especially as an employer of persons with disabilities.

Secretary-General Guterres cited last year's first-ever UN Flagship Report on Disability and Development, which highlights core challenges, including disproportionate levels of poverty, lack of access to education, health services, employment and the under-representation of persons with disabilities in decision-making and political participation. There is also a focus on discrimination and exclusion of girls and women with disabilities and on building inclusive societies. Transportation, infrastructure and information and communication technologies should be used to reach that goal. Addressing delegates in the General Assembly Hall, Catalina Devandas, Special Rapporteur on the Rights of Persons with Disabilities, stressed that despite multiple agendas and competing priorities, the rights of people with disabilities cannot be marginalised. She lauded the new UN Disability Inclusion Strategy to ensure that people with disabilities are included in all development, human rights and humanitarian aid efforts. While calling it an ambitious and far-reaching proposal that can mean a turning point for the inclusion of people with disabilities in all pillars of the UN's work, she warned that the strategy is just the starting point of a long process. The UN expert called for the Member

States to politically and financially support the strategy, flagging it as a good investment in strengthening the UN's capacity to provide better and greater support to national efforts to realise the rights of people with disabilities.

Information: https://news.un.org/en/story/2019/06/1040231.

93 Million Children with Disabilities Among the Most Likely to be Left Behind

UN High Commissioner on Human Rights Bachelet highlighted at the Human Rights Council event how disabled youngsters are more exposed to violence, abuse and neglect. Their empowerment depends particularly on the equal right to education. Both environmental factors and attitudes must change to empower children and youth with disabilities to reach their full potential and they must have a say in all matters that affect the course of their lives, Bachelet demanded. Discrimination against children with disabilities can begin as soon as they are born, the High Commissioner noted, from authorities choosing not to register births, to separating them from families and placing them in care institutions. Another key factor preventing the inclusion of disabled youngsters in their communities, and their ability to exercise their rights, is the ongoing segregation into special schools, institutions and sheltered homes. Catalina Devandas Aguilar, Special Rapporteur on the rights of persons with disabilities said that this is a legacy of a model which has caused exclusion and marginalisation. Addressing the Council, Ms. Aguilar insisted that children with disabilities face stigma, discrimination, prejudice and barriers. They are abandoned, neglected, socially excluded, segregated, overprotected, not given accessibility and the services and support they need. In addition to these challenges, one in three school-age children with disabilities do not have a primary education, while a child with learning difficulties is almost five times more likely to suffer sexual violence than their peers.

Information: https://news.un.org/en/story/2019/03/1034011

2019 GLAD Network Annual Meeting

The Global Action on Disability (GLAD) Network held its third meeting in Ottawa, Canada, with a focus on enhancing the inclusion of persons with disabilities in international development and humanitarian action. The meeting further developed a shared commitment to disability inclusive development and humanitarian action in line with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The importance of including a gender focus when talking about the inclusion of persons with disabilities in international development and humanitarian action was underlined. The network discussed how to implement disability inclusive commitments, in particular through meaningful engagement with Organisations of Persons with Disabilities (DPOs), and how DPOs can be held to account. It also tracked progress of the GLAD Strategic Plan 2018-2020 and discussed ways of increasing GLAD Network's collective influencing power to enhance the inclusion of persons with disabilities globally. During the event, participants also reviewed areas for improvement and reflection on the implications of disability inclusion with regard to gender, intersectionality, and inclusion. Since its inception, the GLAD Network has steadily grown, attracting the largest donors and agencies in the field of disability rights internationally, including many of the agencies of the United Nations.

Information: https://inclusion-international.org/2019-glad-network-annual-meeting/; https://gladnetwork.net/.

Third Meeting of the Forum of the Countries of Latin America and the Caribbean on Sustainable Development

The Forum of the Countries of Latin America and the Caribbean on Sustainable Development is a regional mechanism to follow up and review the implementation of the 2030 Agenda for Sustainable Development, including the Sustainable Development Goals and targets established at the 36th session of the Economic Commission for Latin America and the Caribbean (ECLAC), held in Mexico City in May 2016. The goals of equality, ending poverty, education and creating a healthy environment are particularly relevant for persons with intellectual disabilities and their families because they are usually among the poorest and most invisible members of society. On April 23rd the Latin America and the Caribbean civil society consultation was held, prior to the 3rd meeting of the Forum. There, mechanisms of participation which have been under a temporary working gourp since 2016 were replaced by permanent groups of stakeholders, and permanent coordinators of each group were elected. The Quadrennial report on regional progress and challenges in relation to the 2030 Agenda for Sustainable Development in Latin America and the Caribbean was presented. Particular challenges in the region, including corruption, poverty, and weakness of democracies, were highlighted. It also shows the

problems of measuring progress on the basis of GDP, which conceals the real situation of inequality and extreme difference between the richest and the poorest. The analysis identified some dynamics in regional trends: 1. The target aimed at reducing the mortality rate of children under 5 years of age to fewer than 25 for every 1,000 live births (target 3.2) has already been achieved. 2. The target aimed at achieving universal and equitable access to drinking water at a price that is affordable to all (target 6.1) will not be reached. In addition, the trend on access to secondary education is not enough for all children to be able to complete this level in a timely way by 2030 (target 4.1), and the positive trend seen on reducing the percentage marking the prevalence of undernourishment (target 2.1) came to a halt. Meanwhile, the recent economic and distributive performance is insufficient for eliminating extreme poverty: in the last 10 years, Latin America's GDP has grown by less than 2% annually (1.7%). At the same time, the coefficient measuring income distribution has declined 0.9% annually over a period of 10 years. Without a change in the development pattern, the targets of various SDGs will not be achieved. Here, policies for equality and growth are indispensable. An environmental push with policies on industry, investment and innovation was requested for progressive structural change. It was also acknowledged that the political consensus achieved around the 2030 Agenda is in danger, and countries were urged to defend it. Governments declared the need of the appropriation of the Sustainable Development Goals (SDGs) by the citizens. They denounced the lack of integration of the SDGs with the climate goals and corruption at all levels present in the countries of Latin America and the Caribbean are some of the critical links of the implementation of the 2030 Agenda in the region. They also welcome the ongoing process to strengthen and adapt the United Nations development system to better support Member States in the implementation of the 2030 Agenda for Sustainable Development, avoiding a one-size-fits-all model for the regional approach, being necessary to consider the specifics of each region and the strengths of its regional mechanisms. On the other hand, the general conclusion of the civil society was that Governments do not open spaces for participation of CSOs. Thus, the reading of the Declaration of Civil Society Organisations from Latin America and the Caribbean at the Forum of States Parties was criticised as two Monologues do not make a dialogue. The main conclusion of the CSOs is to demand governments to open opportunities for participation to these organisations. They highlighted the importance of two documents: the Montevideo Consensus on Population and Development and the Regional Agreement on Access to Information, Public Participation and Justice in Environmental Matters in Latin America and the Caribbean, also called Escazu Agreement.

Information: https://inclusion-international.org/third-meeting-of-the-forum-of-the-countries-of-latin-america-and-the-caribbean-on-sustainable-development/; https://foroalc2030.cepal.org/2019/es/documentos/informe-avance-cuatrienal-progreso-desafios-regionales-la-agenda-2030-desarrollo.

Inclusion Works! Employment Workshop Kenya

In December 2018, Inclusion International became part of a consortium led programme, called Inclusion Works! The programme is funded by UK Aid (DfiD) and will create and test innovative approaches to improve the long-term economic empowerment and inclusion of people with disabilities. The programme will be delivered in four countries (Bangladesh, Kenya, Nigeria and Uganda) over three years. Self-advocates will play a leading role in the project and working with the employers, policymakers and DPOs to understand the barriers that people with intellectual disabilities face in accessing employment. KAIH, UPPID and Inclusion Uganda took part in the first *Inclusion Works! Development Workshop* in Nairobi, Kenya on 19th to 21st March 2019 in partnership with Inclusion Africa. Across three days, the existing attitudes towards employment of people with intellectual disabilities and potential strategies to improve access to employment in participants' countries were discussed. Additionally, participants reviewed the implementation of the Convention on the Rights of Persons with Disabilities on national level with specific attention to Article 27. People with intellectual disabilities are disadvantaged in the labour market due to attitudes and stigmatisation of wider society. Changing attitudes of employers and the public towards people with intellectual disabilities can be achieved by their inclusion in the wider labour market. Whilst the adjustment of the physical environment can help some people, the barriers that people with intellectual disabilities face often go beyond. This project aims to develop the

capacities of Inclusion International's members in countries to work with employers, policy makers and other DPOs to help develop their understanding of how to include people with intellectual disabilities when developing policies and implementing inclusive practices. Inclusion International will also work with our members to develop advocacy strategies to ensure that people with intellectual disabilities are not left behind.

Information: https://inclusion-international.org/inclusion-works-employment-workshop/.

Statement on the Right to Family

The International Disability Alliance and Partners have endorsed a "statement and key recommendations on the Right to Family", recognised under international law. All children have the need and the right to live and grow up with a family. The preamble of the Convention on the Rights of the Child (CRC) recognises that for their "full and harmonious development", all children "should grow up in a family environment." Reflecting the CRC standards, the UN Convention on the Rights of Persons with Disabilities (CRPD) sets out that the best interests of the child are the paramount consideration in all decisions affecting them (Article 7(2)), and places clear obligations on States to protect the right to family life (Article 23) and to live and be included in the community (Article 19). As such, the above signed disability rights, child rights and human rights organisations call on the UN General Assembly to include a number of recommendations in its forthcoming resolution on the rights of children without parental care.

Information: http://www.internationaldisabilityalliance.org/right-to-family-statement; http://www.internationaldisabilityalliance.org/sites/default/files/unga_right_to_family_2019_06_20.pdf.

Global Survey to Track DPO Participation in Development Programmes and Policies

In recent years, new commitments to include persons with disabilities have been taken by governments, UN and funding agencies through the 2030 Agenda, the 2018 Global Disability Summit and the recent UN Disability Inclusive Strategy. With these commitments comes the urgency to ensure that persons with disabilities are represented in decision-making, in line with a rights-based approach, to guide strategies in line with article 4.3 of the CRPD. With these commitments comes a new phase of advocacy for the disability rights movement to monitor that the pledge to leave no one behind effectively translates into laws, policies and programmes advancing the rights of persons with disability. The IDA Global Survey is a tool to measure the reality of consultation of DPOs: how do governments, UN or funding agencies engage them and at which stages of the policy or programme cycle? The International Disability Alliance launched on December 2018 a global survey by and for the disability rights movement to measure DPO's perceptions on their participation in the shaping of development policies and programmes. 573 DPOs across 165 countries responded to a questionnaire developed in English plain language disseminated online in Arabic, Chinese, English, French, Russian, Spanish and International Sign. Respondent DPOs represented a wide range of constituencies among persons with disabilities, with a majority of them being active at the national or local level. While IDA is still analysing the data, preliminary findings from the report provide new evidence to characterise participation of DPOs: When asked to compare with one year ago, respondents perceive that their involvement and influence is improving, which suggests that the global momentum on inclusion of persons with disabilities is somewhat impacting levels of participation of representative organisations. However, overall DPOs are more displeased (45.6%) than pleased (31.0%) with their engagement with their government. Preliminary analysis also suggests that some groups are less represented than others in consultations with government, UN and funding agencies. Persons with visual impairments, physical impairments and hearing impairments are considered to have more access than persons with intellectual disabilities, persons with deafblindness or indigenous persons with disabilities. A majority of DPOs also reports that they are never invited to take part in influential stages of the policy or programme cycle such as budget decisions. Barriers remain significant to ensure persons with disabilities can take part with their government, with only 25% of DPOs reporting they mobilise resources to ensure DPOs can participate, less than 17% reporting that attitudes and knowledge are fully supportive of their participation, and about 8% reporting full accessibility of venues and of information and communication. With further analysis underway, IDA will establish with this initial Global Survey a baseline of evidence against which progress will be measured every two years.

Information: http://www.internationaldisabilityalliance.org/global-survey-preliminary-results-2019; http://

www.internationaldisabilityalliance.org/sites/default/files/ida_global_survey_initial_report_final_draft_.docx.

Multi-Stakeholder Forum on Science, Technology and Innovation for the Sustainable Development Goals (STI Forum) 2019

The fourth annual Multi-Stakeholder Forum on Science, Technology and Innovation for the Sustainable Development Goals (STI Forum) took place on the 14th and 15th of May 2019 at UN Headquarters in New York. The theme of the 2019 STI Forum was STI for Ensuring Inclusiveness and Equality, with a Special Focus on SDGs 4, 8, 10, 13, and 16. The forum was enriched with interactive dialogues about emerging technologies, STI for education and decent work, gender and STI for the SDGs, STI for inclusive and equitable societies, STI to combat climate change, and linkages between STI and indigenous peoples, culture and traditional knowledge. The forum also included a ministerial segment which discussed strengthening capacity and policy for the development of STI roadmaps. The Stakeholder Group of Persons with Disabilities was invited to be a panelist on the second day of the forum during Session 6: STI for Inclusive and Equitable Societies (SDG 10 and SDG 16). The key message of the Stakeholder Group of Persons with Disabilities was that to achieve truly inclusive and equitable societies, persons with disabilities must be meaningfully included in all discussions related to emerging technologies and considered in all stages of the development process. The statement promoted the key findings of the European Disability Forum's *Plug and Pray?* report.

Information: http://www.internationaldisabilityalliance.org/sti-2019; http://www.edf-feph.org/sites/default/files/edf-emerging-tech-report-accessible.pdf.

Sendai Global Platform for Disaster Risk Reduction 2019

The sixth session of the Global Platform for Disaster Risk Reduction (GP2019) took place in Geneva, Switzerland from 15th to 17th May 2019. Established as a biennial multi-stakeholder forum by the UN General Assembly, the Global Platform is a critical component of the monitoring and implementation process of the Sendai Framework for Disaster Risk Reduction (2015-2030). The aim of the Global Platform is to review progress, share knowledge and discuss the latest developments and trends in reducing disaster risk. The outcomes of the Global Platform inform the deliberations of the High-Level Political Forum on Sustainable Development and the UN 2019 Climate Summit from a disaster risk reduction perspective. The Stakeholder Group of Persons with Disabilities: Thematic Group on Disaster Risk Reduction actively engaged in advance of and during the GP2019, with the aim to bring a strong message that disaster risk reduction must be inclusive of persons with disabilities. The Global Platform 2019 saw the highest number of participants with disabilities and their representative organisations in the conference to date. However, the Co-Chair's Summary (the conference outcome document) reflected that implementation of the Framework for persons with disabilities requires greater consideration, specifically that: Data disaggregated by disability, sex and age on persons is lacking to a large extent (paragraph 11) and commitments towards the engagement of persons with disabilities in the development of inclusive DRR strategies have not been transformed into action (paragraph 12). While recommendations on moving the Framework's implementation forward did not explicitly include persons with disabilities and their representative organisations, States were encouraged to target drivers of inequality and exclusion in their DRR policies, strategies and programmes, which should be informed by a rights-based approach. This outcome largely mirrors the Stakeholder Group's reflection on the aspirations of the Sendai Framework: commitments without action will not achieve disaster risk reduction strategies inclusive of persons with disabilities. The Stakeholder Group presented a joint statement in the plenary session of the final day of the conference. The Summary also reflected a shift from the perception of persons with disabilities and others as *vulnerable* populations to *at-risk* groups--i.e. from recipients of aid and beneficiaries of charity, to actors for change. As a result of the Stakeholder Group's advocacy, the NGO joint statement to the GP2019 also included persons with disabilities, highlighting the importance of: Participation and role of persons with disabilities in local DRR action, and a recognition of the barriers faced; DRR strategies inclusive of persons with disabilities, in order to leave no-one behind; data disaggregated by disability, gender and age.

Information: http://www.internationaldisabilityalliance.org/GP2019; https://www.unisdr.org/conference/2019/globalplatform/home.

UN Women Regional Office of Arab States Staff Disability and Gender Inclusivity Training

From 21st to 23rd April 2019, UN Women Offices of Arab States partnered with IDA and its regional member, the Arab Organisation of Persons with Disabilities to pilot the first UN Women Staff Disability and Gender Inclusivity Training. The programme was developed through the results of a survey disseminated to staff in UN Women country offices across the region. The responses, which were collected from the UN Women staff from a diversity of offices, highlighted that there is limited disability inclusive programming in the country and regional offices, and when there is disability-focused programming it addresses rehabilitation and the distribution of mobility equipment. Many staff members at the same time noted that the integration of disability in the country team strategic frameworks has started. However, there is a lack of technical capacity to fully realise disability inclusion as it is highlighted in their strategies. In order to respond to the gaps indicated by the UN Women staff and the increased enthusiasm to ensure inclusivity, the pilot disability and gender inclusivity training was launched. The training brought together women leaders with disabilities from grassroots communities to global leaders, to share their experience in creating a disability and gender inclusivity at the national and regional levels. During the interactive discussions, participants and speakers examined the multi-dimensional nature of gender inclusivity in regard to the principle of *Leave No One Behind*. Women leaders with disabilities from grassroots communities shared how inclusivity and intersectionality are experienced by women and girls with disabilities. The objectives of the training were two-fold: A) Provide the Arab State Region's personnel with tools on disability inclusivity for their operations and programme work to increase collective and individual capacity; B) To provide an interactive knowledge exchange amongst UN Women offices and with external partners.

Information: http://www.internationaldisabilityalliance.org/UN-Women-IDA-AOPD.

Fourth Financing for Development (FfD) Forum

The fourth Financing for Development (FfD) Forum took place from 15th to 18th April 2019 at the United Nations Headquarters in New York. The event brings together ministers, high-level officials from ministries of finance, foreign affairs and development cooperation, Executive Directors of the World Bank and IMF, as well as senior officials from the UN system, including the other stakeholders, such as the Stakeholder Group of Persons with Disabilities. Mr. Jose Viera, permanent representative of the Stakeholder Group of Persons with Disabilities and CEO of World Blind Union was a lead discussant on domestic public resources in the context of persons with disabilities on 17th April. This was the first time that a person with a disability was an official presenter at a Financing for Development Forum. The annual FfD Forum results in inter-governmentally agreed conclusions and recommendations that are fed into the overall follow-up and review of the implementation of the 2030 Agenda for Sustainable Development in the High-level Political Forum (HLPF) on Sustainable Development. This year the agreed conclusions and recommendations were adopted on 18th April. For the first time in an FfD Forum, persons with disabilities have five explicit references as well as three inexplicit references. Explicit references are included in areas of inclusive infrastructure, disability-led businesses, access to markets at all levels, underrepresentation in science, technology, engineering and mathematics (STEM) education and jobs, and disaggregation of disability data to achieve the 2030 Agenda. Inexplicit references include: accessibilty, ensuring no country or person is left behind, and inclusive and equitable quality education. This increased inclusion and engagement means that Member States recognise and acknowledge persons with disabilities in the financing for development dialogue. In addition, this is particularly powerful since this year's agreed conclusions and recommendations will feed into the High-level Dialogue on Financing for Development on 26 September, which will be turned into actionable figures.

Information: http://www.internationaldisabilityalliance.org/ffd-2019; https://undocs.org/E/FFDF/2019/L.1.

Workshop for Revision of the Draft of the Regional Report in Bolivia

On March 11th and 12th, the Latin American Network of Non-Governmental Organisations of Persons with Disabilities and their Families (RIADIS) organised a workshop for the revision of the draft of the SDG-CRPD regional report in Cochabamba, Bolivia. This workshop was intended to discuss and analyse the draft of the report in order to receive contributions from DPOs representatives, government officials, non-governmental organisations and other stakeholders. One of the main challenges

of RIADIS for this report was to ensure the participation of the most underrepresented groups such as deafblind persons, persons with autism and persons with intellectual disabilities. Although the draft of the regional report was focused on eight thematic areas such as inclusive education, employment, women with disabilities, indigenous persons with disabilities, accessibility, Disaster risk reduction, data collection and participation of the organisations of persons with disabilities, the participants in the workshop, particularly the representative of the autism movement in Brazil, requested to include two additional topics such as the access to justice and the right to live independently in the community. During these two days the participants were working in groups to give their contributions in each of the eight thematic areas and at the same time one group was working in the structure of the additional thematic areas. The final regional report will include these contributions and RIADIS will release this report in different accessible formats such as sign language videos, easy to read format, digital accessible format and braille.

Information: http://www.internationaldisabilityalliance.org/blog/workshop-riadis-sdg-crpd.

Third Technical Workshop on Amplifying Voices of Persons with Psychosocial Disabilities

From 24th to 27th March 2019, the third World Network of Users and Survivors of Psychiatry (WNUSP) Technical workshop took place in Nairobi Kenya. The workshop was a call to action for the full inclusion and participation of persons with psychosocial disabilities in determining their life journeys and for the end of discrimination and human rights violations perpetrated against them both in institutions and also within community-based settings. Participants are all individuals with psychosocial disabilities representing youth, men and women, from different regions in the country. The main agenda of the workshop was to empower and promote the social, economic and political inclusion of persons with psychosocial disabilities on an equal basis with others. The participants were introduced to the Convention on the Rights of Persons with Disabilities (CRPD) and Agenda 2030 and the Sustainable Development Goals (SDGs) in day one and two. On the third day the participants had the opportunity to participate in an interactive session with various partners including government Ministries, Departments and Agencies and development stakeholders. The sessions had roundtable discussions on CRDP compliant mental health laws and on Employment and Sustainable Entrepreneurship for youth with psychosocial disabilities by exploring opportunities and challenges. The CRPD emphasises the important role of persons with disabilities in all aspects of society and development, respecting their rights and dignity. In line with Article 4(3) of the CRPD, States parties should closely consult and actively involve persons with disabilities, through their own organisations, in legal and regulatory frameworks and procedures across all levels and branches of Government. This is also emphasised by Article 33(3) of the CRPD on National Implementation and monitoring. Kenya as a State party to the CRPD must take appropriate measures to ensure that all persons with disabilities, without any form of exclusion based on the type of impairment, such as persons with psychosocial disabilities or intellectual disabilities, can effectively and fully participate without discrimination on an equal basis with others. In the implementation of the 2030 Agenda, persons with psychosocial disabilities must be recognised for whom they are - effective agents of change whose contributions will bring enormous benefit to the global community. There is a global consensus on the importance of empowerment and equality for persons with disabilities in sustainable development. The commitment to *leave no one behind* is a key feature of Agenda 2030 and the Sustainable Development Goals (SDGs). The idea that no goal should be met unless it is met for everyone is well established in the SDGs. Therefore, the workshop is intended to strengthen development policies and practice to ensure that they are inclusive of persons with psychosocial disabilities.

Information: http://www.internationaldisabilityalliance.org/WNUSP-Workshop-Kenya.

UN-Behindertenrechtskonvention: Inklusive Entwicklungspolitik muss zum Standard werden

Zum 10. Jahrestag der Inkraftsetzung der UN-Behindertenrechtskonvention in Deutschland fordert der Verband Entwicklungspolitik und Humanitäre Hilfe (VENRO), diese auch in der Entwicklungszusammenarbeit konsequent umzusetzen. Eine neue, ressortübergreifende Inklusionsstrategie ist dafür das entscheidende Instrument. Menschen mit Behinderungen machen rund 15 Prozent der Weltbevölkerung aus, das ist fast jeder siebte Mensch. Mit 80 Prozent leben überdurchschnittlich viele von ihnen in Armut. In Entwicklungsländern ist ihr Armutsrisiko besonders hoch. Menschen

mit Behinderungen fänden dabei noch zu wenig Beachtung in der Entwicklungszusammenarbeit, so Vorstandsvorsitzender Dr. Bernd Bornhorst. Die Umsetzung der UN-Behindertenrechtskonvention beziehe sich auch auf eine inklusive Entwicklungspolitik, die Menschen mit Behinderungen in Entwicklungsländern gezielter fördert als bisher und im Sinne des Mainstreamings deren Rechte bei allen Vorhaben in den Blick nimmt. Bereits für Mitte 2018 hatte das Bundesentwicklungsministerium eine neue Inklusionsstrategie angekündigt. Das Versprechen der Agenda 2030, niemanden zurückzulassen, könne nur erfüllt werden, wenn auch die Rechte von Menschen mit Behinderung verwirklicht werden. Dabei seien ebenso die zivilgesellschaftlichen Akteure und Akteurinnen in der Pflicht, ihre Projekte und Programme inklusiv zu gestalten. VENRO hat eine praxisnahe Handreichung für eine inklusive Projektarbeit entwickelt.

Information: https://venro.org/presse/detail/un-behindertenrechtskonvention-inklusive-entwicklungspolitik-muss-zum-standard-werden/; https://venro.org/publikationen/detail/handreichung-fuer-inklusive-projektarbeit/.

Literatur

Venro

Handreichung für inklusive Projektarbeit

Neben der Bundesregierung sind auch zivilgesellschaftliche AkteurInnen in der Pflicht, ihre Projekte und Programme inklusiv zu gestalten. Hierzu hat Venro eine praxisnahe Handreichung entwickelt.

Bezug: https://venro.org/fileadmin/user_upload/Dateien/Daten/Publikationen/Diskussionspapiere/Handreichnung_Inklusive_Projektarbeit_DE_Barrierefrei_DIGTAL_2019_01.pdf; https://venro.org/publikationen/detail/handreichung-fuer-inklusive-projektarbeit/.

Holoboff Radford/Anastasia et al.

Women and Young Persons with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights

This publication aims to provide practical and concrete guidelines for making Gender-Based Violence (GBV) and Sexual and Reproductive Health and Rights (SRHR) services more inclusive of and accessible to women and young persons with disabilities and for targeting interventions to meet their disability-specific needs. Fundamental SRHR services for women and young persons—with and without disabilities— include comprehensive sexuality education; information, goods, and services for the full range of modern contraceptive methods, including emergency contraception; maternal/newborn healthcare (including antenatal care, skilled attendance at delivery, emergency obstetric care, post-partum care, and newborn care); prevention, diagnosis, and treatment for sexual and reproductive health issues (e.g. sexually transmitted infections, including HIV, syphilis, and HPV, cancers of the reproductive system and breast cancer, and infertility); safe and accessible abortion, where it is not against the law; and post-abortion care to treat complications from unsafe abortion. While the primary audience of these Guidelines is GBV and SRHR service providers and support staff, these Guidelines are also intended as a valuable resource for all stakeholders – including those in government, international organisations, and non-governmental organisations – involved in designing, developing, implementing, or advocating for GBV or SRHR services for women and young persons with disabilities.

Bezug: https://www.womenenabled.org/wei-unfpa-guidelines.html; https://asksource.info/resources/women-and-young-persons-disabilities-guidelines-providing-rights-based-and-gender.

Humanity & Inclusion/CAMID/ The Employers' Federation of Ceylon

Local Economic and Inclusive Development; A Toolkit for Replication

This replication guidebook is a tool that aims to highlight the link between social exclusion and poverty and is based on the premise that a country cannot achieve its development targets, if a section of its people is left behind. This guidebook aims to show practitioners practical ways of working on economic development inclusive of socially excluded groups such as women, people with disabilities, people living in poverty, etc. It provides corresponding concepts, explains the steps and suggests tools that may help practitioners use and adapt to their context. The context of this book is based on field level experience of the project team of the Inclusive Economic Development project.

Bezug: https://asksource.info/resources/local-economic-and-inclusive-development-a-toolkit-replication.

Elizabeth Presler-Marshall/ Nicola Jones/Workneh Yadete/ Kassahun Tilahun

Leave No One Behind: An Agenda for Action to Enhance the Full Capabilities of Adolescents with Disabilities in Ethiopia

The government of Ethiopia has made multiple commitments aimed at supporting the rights of persons with disabilities, beginning with the country's 1995 constitution, its 2010 ratification of the UN Convention on the Rights of Persons with Disabilities, and further strengthened by its 2018 commitments to inclusive education at the world's first disability summit. However, much work remains to be done if the inclusive society envisioned by the 2012 National Plan of Action of Persons with Disabilities is to achieve its goals. This policy note summarises key findings from Gender and Adolescence: Global Evidence's (GAGE) baseline work with adolescents with disabilities in Ethiopia. The mixed-methods research involved approximately 350 adolescents – with physical, visual, hearing or intellectual impairments – as well as their caregivers and service providers and policy actors. It draws attention to the multiple and intersecting capabilities that need to be supported for adolescents

with disabilities in Ethiopia to reach their full potential, including education and learning, health and nutrition, and economic empowerment and social protection.

Bezug: https://www.odi.org/publications/11318-leave-no-one-behind-agenda-action-enhance-full-capabilities-adolescents-disabilities-ethiopia; https://www.gage.odi.org/publication/leave-no-one-behind-an-agenda-for-action-to-enhance-the-full-capabilities-of-adolescents-with-disabilities-in-ethiopia/.

TAP Network

SDG Accountability Handbook: A Practical Guide for Civil Society

This handbook is a capacity development resource that seeks to support national-level civil society to hold their government accountable for 2030 Agenda promises, better understand specific approaches to hold governments accountable for the SDGs, and guide them through the practical steps they can take to improve accountability for the 2030 Agenda in their country. The handbook includes ways in which civil society can monitor and follow-up on SDG implementation.

Bezug: https://sdgaccountability.org/sdg-accountability-handbook/; https://sdgaccountability.org/.

Colleen Howell/Theresa Lorenzo/Siphokazi Sompeta-Gcaza

Reimagining Personal and Collective Experiences of Disability in Africa

This paper explores understandings of disability in Africa through the personal and collective experiences of a group of postgraduate students at the University of Cape Town in South Africa. The students, as disabled people themselves or practitioners working in the field across Africa, were required to capture their understanding of disability on the continent in a poster, set as a summative assessment task. What emerges from the students' posters provides valuable insights into the complex social, political and economic factors that influence and shape the experience of disability in Africa. The paper argues that these insights are especially important to existing conceptual thinking around disability and its importance to discussions on Africa and its development. It suggests that grappling more carefully with the experience of disability in Africa brings much needed voices from Africa and the global South into the field of Disability Studies and deepens these debates in valuable and necessary ways.

Bezug: https://disabilityglobalsouth.files.wordpress.com/2019/07/06_02_02.pdf.

Nathan Grills/Jacob Devabhaktula/Nicole Butcher/Sarojitha Arokiaraj/Prottoy Kumar Das/Pam Anderson

Inclusive Education in India Largely Exclusive of Children with a Disability

Exclusion of children with a disability from education negatively affects national economic growth. Education is important for children with a disability to acquire skills that allow them to gain employment, and thus address a key driver of poverty. A cross-sectional study was conducted in 2015 to better understand the relationship between disability, education and health among children in India. Across 17 states in India, the study sample included 39,723 households with a child aged 0-59 months (163,400 individual cases in total), based on randomised cluster sampling methodology. Key outcomes of interest were school attendance, completion of early childhood education and highest level of education. The study found one percent prevalence of disability, nearly double among boys (1.38%) compared to girls (0.77%), and linked disability to lower level access to education and highest level of education. This study confirms the negative relationship between disability and educational exposure among children, and highlights that India's efforts to make education a fundamental right of every child have not yet translated to benefits for children with a disability. There remains a pressing need for well-designed longitudinal studies that capture the barriers and protective factors of school attendance at every transition between stages of schooling in children with a disability.

Bezug: https://disabilityglobalsouth.files.wordpress.com/2019/07/06_02_04.pdf.

Behinderung und Entwicklungszusammenarbeit e.V.

Inklusiv begleitet! - Handbuch zur inklusiven pädagogischen Begleitung im (Auslands-) Freiwilligendienst

In den letzten Jahren haben zahlreiche Träger *bezev* um Ideen gebeten, wie sie ihre pädagogische Begleitung von Freiwilligen in internationalen Austauschdiensten inklusiver gestalten können. Das vorliegende Handbuch konzeptualisiert die gemachten Erfahrungen der letzten zehn Jahre und teilt sie mit allen Interessierten. Im Handbuch werden, neben einem einführenden Kapitel über die Konzepte Inklusion und Beeinträchtigung/Behinderung, Themen wie Kommunikation, Elternarbeit, Freizeit, Finanzierung, Fortbildung und Evaluation behandelt, aber auch Konzepte wie Peer-to-Peer und inklusive Didaktik vorgestellt. Zusammen mit der Vorstellung von Adaptionsmöglichkeiten von Seminarmethoden und ausgewählten Beispielen wird das Handbuch zu einem praktischen Ratgeber der alltäglichen Arbeit von Pädagogen und Bildungspersonal, das sich anerkannten wissenschaftlichen Konzepten bedient und so einen wichtigen Beitrag zur inklusiven Arbeit in internationalen Austauschdiensten leistet.

Bezug: https://www.bezev.de/de/home/service-und-bestellungen/inklusiv-begleitet/

Veranstaltungen/Events

04. - 05.11.2019

Fit for Inclusion

Information: https://www.bezev.de/de/institut-fuer-inklusive-entwicklung/fort-und-weiterbildung/fit-for-inclusion/.

Kontakt: Gabriele Weigt, E-Mail: weigt@bezev.de.

24. - 25.11.2019

Belonging - The international conference of AKIM Israel & Inclusion International, Tel Aviv, Israel.

Information: http://akim2019.org.

Kontakt: Conference Secretariat: Tel.: +972(03)5767716; E-Mail: torkabi@paragong.com.

07. - 08.11.2019

4th World Disability & Rehabilitation Conference 2019 (WDRC 2019), Bangkok, Thailand.

Information: https://disabilityconference.co/.

Kontakt: The International Institute of Knowledge Management, #531/18, Kotte road, Pitakotte; Tel.: +94 11 20 444 80/ Ext. 6105; Hotline: +94 76 573 37 37; E-Mail: secretariat@disabilityconference.co.

02. - 03.03.2020

PacRim2020, Honolulu, Hawaii.

Information: http://www.pacrim.hawaii.edu/.

Kontakt: Tel.: 808-956-8816; Fax 808-956-4437; E-Mail: prreg@hawaii.edu.

Schwerpunktthemen kommender Ausgaben der Zeitschrift
Focal Topics of Upcoming Issues

3/2019: Frauen mit Behinderung
Woman with Disabilities
verantwortlich/responsible: Prof. Dr. Michael Boecker

1/2020: Inklusive Bildung
Inclusive Education
verantwortlich/responsible: Prof. Dr. Sabine Schäper

2/2020: Inklusion in Freiwilligendiensten
Inclusion in Voluntary Services
verantwortlich/responsible: Jelena Auracher/Franziska Koch

Interessierte Autorinnen und Autoren mögen sich für nähere Informationen und unseren *Leitfaden für AutorInnen* bitte an die oben genannten Verantwortlichen wenden.
Darüber hinaus sind Vorschläge für weitere Schwerpunktthemen willkommen unter info@inie-inid.org.
If you are interested in contributing, please contact the respective member of the editorial board mentioned above for more information and our *Guidelines for Submissions*.
Moreover, we welcome ideas and suggestions for future focal topics which you can submit to our editorship at info@inie-inid.org.

Redaktionsschluss für zukünftige Ausgaben
Deadlines for the upcoming issues

	3/2019	1/2020	2/2020
Hauptbeiträge/Focal articles	31.07.2019	31.10.2019	30.04.2020
Kurzbeiträge/Other contributions	31.07.2019	31.10.2019	30.04.2020

Liebe Leserinnen und Leser,
bitte informieren Sie uns unter info@inie-inid.org über eine Adressänderung bzw. wenn Sie die Zeitschrift nicht mehr beziehen möchten oder falls Ihnen die Zeitschrift nicht zugestellt worden ist.
Dear Reader!
Please notify any changes of address, if you wish to end your subscription or have not received the print edition to info@inie-inid.org.

Behinderung und Entwicklungszusammenarbeit e.V.
Institut für inklusive Entwicklung
Altenessener Strasse 394-398
45329 Essen
Germany
Tel.: +49-(0)201/17 89 123
Fax: +49-(0)201/17 89 026
info@inie-inid.org
www.inie-inid.org

Behinderung und internationale Entwicklung

Die Zeitschrift Behinderung und internationale Entwicklung erscheint seit 1990 dreimal jährlich mit Beiträgen sowohl in deutscher als auch englischer Sprache. Ihr Anspruch ist es, ein Medium für einen grenzüberschreitenden Informationsaustausch zur Thematik zu bieten sowie die fachliche Diskussion zu pädagogischen, sozial- und entwicklungspolitischen sowie interkulturellen Fragen im Zusammenhang mit Behinderung in Entwicklungsländern weiterzuentwickeln. Jede Ausgabe ist einem Schwerpunktthema gewidmet, das durch Einzelbeiträge und einen aktuellen Informationsteil ergänzt wird.

Bezugsmöglichkeiten:

KOSTENFREIER VERSAND DER AUSGABE IM PDF-FORMAT per E-Mail für die Aufnahme in den Verteiler: info@inie-inid.org

KOSTENPFLICHTIGER BEZUG DER PRINTAUSGABEN für 18 €/Jahr 3 Ausgaben, innerhalb Deutschlands und 27 € im europäischen Ausland: info@inie-inid.org

DARÜBER HINAUS kostenlos im Internet unter www.zeitschrift.bezev.de

Disability and International Development

The journal Disability and International Development is published three times a year since 1990, featuring contributions in both English and German. Its objective is the scholarly and practice-oriented discourse on disability in low-income countries. The journal aims at providing a platform for a cross-border dialogue and promoting the professional discussion of related development policy, pedagogical/educational, socio-political and intercultural questions. Each issue is dedicated to a focal topic, complemented by single contributions on other subjects and up-to-date information.

Subscription:

FREE PDF VERSION via e-mail:
info@inie-inid.org for subscription

PRINT VERSION at a rate of 18 €/year, 3 issues, within Germany and 27 € to other European countries:
info@inie-inid.org for subscription

IN ADDITION, a free online version is available at
www.zeitschrift.bezev.de

Die Zeitschrift wird unterstützt durch | The journal is supported by:

bezev wird gefördert aus Mitteln des Kirchlichen Entwicklungsdienstes
Brot für die Welt – Evangelischer Entwicklungsdienst