Disability Data Lab learning paper: a practical guide to disability data

By Bond's Disability and Development Group

Contents

About Bond

Bond is the civil society network for global change. We connect, strengthen and champion a dynamic network of diverse civil society organisations to help eradicate global poverty, inequality and injustice. To learn more about Bond, visit www.bond.org.uk.

Acknowledgements

Background and introduction

The Bond Disability and Development Group (DDG) has commissioned this learning paper to summarise discussions which took place at the DDG's Data Lab workshop, held in London on 22 October 2019, and to be used as a reference document going forward. The Data Lab workshop was the first in a series of learning events funded by the National Lottery Community Fund to support the mainstreaming of disability within international development programmes.

This first workshop focused on why organisations need to collect disability data; what tools are available and practical ways in which these can be used. This learning paper provides a summary of these discussions and can act as a guide and reference tool for organisations looking to be more inclusive in their programming, generally, and in their data collection practices, specifically.

This is not a definitive or exhaustive guide, but is rather intended to be a helpful starting point and signpost for readers to available resources.

1. Why collect data on disability?

1.1 Ensuring inclusive programming and advocacy work

People with disabilities[1][2] make up around 15 per cent of the global population[i]. An estimated 80 per cent of people with disabilities live in developing countries, and one in five of the world's poorest people have a disability. Despite this, people with disabilities have rarely been the focus of development. This oversight means that, historically, data collection on people with disabilities and their experiences has been largely overlooked. Furthermore, as disability is a complex and multi-dimensional process which is defined and interpreted differently across societies, it has been seen as extremely challenging to collect and analyse information on people with disabilities[ii].

In recent years, there has been heightened recognition of the fundamental rights of people with disabilities and the need to ensure that they are included in all interventions. Furthermore, there is a greater understanding that, without collecting data disability, development and humanitarian programmes cannot meet the needs of the most marginalised. Qualitative and quantitative data on disability is essential to inform all phases of programming, and to support advocacy work. This increased awareness of the need for disability data has been catalysed by data collection requirements called for in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the inclusion of disability within the 2030 Agenda and Sustainable Development Goals (SDGs), with their call to 'leave no one behind'. This was reinforced through the commitments made in the Inclusive Data Charter and during the Global Disability Summit 2018. As a result, there has been a considerable increase in efforts to collect and analyse data on people with disabilities – globally and at national levels, with more governments including questions on disability in national censuses and surveys.

1.2 The United Nations Convention on the Rights of Persons with Disabilities

The UNCRPD[iii] is a legally-binding human rights treaty which has been ratified by 178 countries. It was a milestone treaty for the disability movement as it marked a shift away from models of disability where people with disabilities were considered 'problems' who required medical and charitable interventions, to a model where people with disabilities had rights. Article 31 of the UNCRPD requires States Parties "…to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention".

Resource box

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):
https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

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[1] The UN Convention on the Rights of Persons with Disabilities (UNCRPD) describes people with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others". Based on this definition, 'disability' can be defined as the relationship between a person's impairment and their environment.

[2] Note that the term 'people with disabilities' is used throughout this document, rather than 'disabled people', as person-first language is preferred by the UNCRPD and many of the NGOs which make up Bond's membership. This should not be seen as at odds with the social model of disability and the preferred term used by the UK disability movement 'disabled people.'

1.3 The Sustainable Development Goals and leave no one behind

People with disabilities are explicitly referenced in five of 17 SDGs enshrined in the 2030 Agenda (SGD 4 on education, 8 on employment, 10 on reducing inequalities, 11 on sustainable and inclusive cities, and 16 on peaceful and inclusive societies). In addition, there is an underlying guiding principle to 'leave no one behind', and many references to reaching the most vulnerable, meaning that, in effect, all goals apply to people with disabilities. Without disaggregated data, governments will not be able to meaningfully include people with disabilities in national plans for implementation and monitoring of the SDGs.

Resource box

The Sustainable Development Goals: https://sustainabledevelopment.un.org

1.4 Mapping the UNCRPD onto the SDGs[iv]

There is a great deal of overlap between the principles enshrined in the UNCRPD and the SDGs. For instance, SDG Goal 8 on productive employment and decent work, maps very well onto the UNCRPD's Article 27 on access to work without discrimination. Furthermore, many of the UNCRPD's articles are cross-cutting in nature and can be applied to the implementation of all of the SDGs. Many organisations are therefore capitalising on the momentum created by the SDGs to reinforce their campaigning to governments to uphold the rights of people with disabilities, as outlined in the UNCRPD.

Resource box

CBM infographic which maps specific UNCRPD articles onto individual SDGs. Available from: https://www.cbm.org/get-involved/search-resources-publications/

1.5 Inclusive Data CharterIn 2018, the Global Partnership for Sustainable Development Data[3] developed the Inclusive Data Charter (IDC)[v].

Their aim was to further mobilise political commitments made through the 2030 Agenda, and accelerate and increase uptake of the data disaggregation. The Inclusive Data Charter presents a shared vision of improving the quality, quantity, financing, and availability of inclusive and disaggregated data, as well as the capacity and capability to produce and use it. Signatories to the IDC develop and publish their own tailored action plan (see the resource box below for examples), outlining practical steps that they are

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[3] The Global Partnership for Sustainable Development Data was established to help stakeholders across countries and sectors fully harness the data revolution for sustainable development, using this new knowledge to improve lives and protect the planet. For more information, please visit: http://www.data4sdgs.org/

going to take to achieve the vision and principles outlined in the Charter over the short, medium, and long term.

Resource box

Inclusive Data Charter: http://www.data4sdgs.org/sites/default/files/2018-08/IDC_onepager_Final.pdf

DFID's Inclusive Data Charter Action Plan:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/783756/Inclusive-Data-Charter-_Action-Plan-March.2019.pdf

Sightsavers' Inclusive Data Charter Action Plan:
http://www.data4sdgs.org/sites/default/files/2018-07/Sightsavers%20IDC%20Action%20Plan.pdf

Sierra Leone's Ministry of Basic and Senior Secondary Education's Inclusive Data Charter Action Plan: http://www.data4sdgs.org/sites/default/files/2019-03/IDC%20action%20plan%20Sierra%20Leone.pdf

UNICEF's Inclusive Data Charter Action Plan: http://www.data4sdgs.org/sites/default/files/2018-07/UNICEF%20IDC%20Action%20Plan.pdf

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1.6 The Global Disability Summit

In 2018, the UK Department for International Development (DFID), the International Disability Alliance[4] (IDA) and the Government of Kenya co-hosted the Global Disability Summit (GDS) to galvanise support to implement the UNCRPD. During the event, representatives from over 300 governments, UN agencies, NGOs, private sector organisations and the disability movement signed up to the Summit's Charter for Change. Furthermore, 170 sets of commitments were made on core Global Disability Summit themes, which included disaggregated data collection. For instance, 10 governments committed to use the Washington Group Questions (WGQs) (see section 4.1) in national censuses or surveys, and four governments committed to undertake a national disability survey or similar study on the situation of people with disabilities.[vi]

1.7 Increasing demand from donors for disability data

Due to the growing recognition of the rights of people with disabilities and the different commitments made outlined above, many donors now require evidence of the inclusion of people with disabilities in the development and humanitarian programmes they are funding. They increasingly want to see indicators disaggregated by disability. For example, DFID's Strategy for Disability Inclusive Development 2018-2023 committed to ensuring that all new programmes collect, use and analyse disability disaggregated data for relevant indicators[vii]. Many donors want to see more in-depth situational analysis using regional level data as part of project planning. For instance, DFID now require UN country teams

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[4] The International Disability Alliance is a global consortia of disabled people's organisations, whose mission is to advance the human rights of persons with disabilities as a united voice, utilising the CRPD and other human rights instruments. For more information, please visit: http://www.internationaldisabilityalliance.org

to include disability data in their humanitarian response plans and humanitarian needs overviews[viii]. It has also been recognised that inclusive programmes based on evidence offer better value for money[ix], which is also important to many donors.

This learning paper seeks to support organisations trying to respond to this growing demand for disability data by signposting available resources and providing case studies of approaches taken by others operating in this sector.

Resource box – The Disability Data Portal

The significant push for more data on disability over the last 20 years has started to yield a lot of material. However, it is not always easy to find. Furthermore, to be able to assess how reliable the data is, organisations need to understand how it has been collected, for example: what terms were used, what level of training was provided to the data collectors, whether people with disabilities were consulted directly.

In 2018, Leonard Cheshire Disability designed the Disability Data Portal to provide a snapshot of globally-available data on people with disabilities in 40 countries. It offers a useful source of individual, anonymised, ethics-compliant data. The portal was initially developed for the Global Disability Summit and focuses on data relating to the summit's four thematic areas: inclusive education, stigma and discrimination, technology and innovation, and economic empowerment. It is open source and can be used by international agencies, governments, civil society and researchers. The portal is updated when new data sources are identified and generated, and is being expanded to include more countries and indicators. It also highlights where there are gaps in the current body of data. There are a number of limitations which users need to be aware of when interpreting and comparing the data on the portal. These include lack of available data, outdated data, methodological issues, comparability and limited verification. These are outlined on the website.

Disability Data Portal: https://www.disabilitydataportal.com

2. Elements to consider when collecting data on disability

This section outlines some of the general principles and practicalities that need to be considered when collecting data on disability, such as training required, engaging with people with disabilities and Disabled People's Organisations (DPOs), and adaptations that need to be made to existing data collection practices.

2.1 Importance of taking a rights-based approach and creating a culture of disability awareness

Before any data collection takes place, organisations should commit to a rights-based approach to disability inclusion, and develop an internal understanding on disability rights and perspectives. Putting internal policies and guidance in place can help embed these. This is an important step to consider before data collection takes place, as it ensures that the complexity of disability inclusion is better understood and that appropriate research questions are set and methodologies implemented.

As well as understanding disability inclusion, organisations should also ensure that specific contextual dynamics are understood so that they do no harm. For example, identification attempts can actually increase stigma and discrimination for people with disabilities in some instances. Organisations also need to ensure that data collectors themselves have had adequate training and sensitisation, as prevailing beliefs and attitudes can lead to people with disabilities being infantilised, dehumanised or patronised during data collection. This is extremely harmful to the individual involved and reinforces negative belief systems.

2.2 Including the people with disabilities in data collection

To be truly inclusive, organisations should include people with disabilities throughout programming and data collection – from setting research questions and indicators, and identifying methodology, to data collection, analysis, validation and dissemination[x]. While this might not always be possible or practical, as an absolute minimum, data collectors should consult people with disabilities directly, rather than relying on proxy respondents. People with disabilities' feedback is the most accurate reflection of their lived experience and will provide a far more compelling case for change than statistics on their own, particularly when informing an organisation's advocacy work or campaigns.

Due to the stigma they face, people with disabilities are often not visible in their communities, and data collectors can assume that they are not there. Another erroneous assumption often made is that people with disabilities will not have anything to say. While some people with disabilities may struggle to respond, as often they are not used to being consulted or may have hearing, speech, and/or cognitive impairments, with some adaptations they can provide valuable insights. Finally, data collectors should be aware that, in some instances, the issue that people with disabilities see as the most important, might have nothing to do with their disability and may be linked to a different aspect of their lives or identity altogether.

2.3 Working with Disabled People's Organisations

Any organisation seeking to gather more information on people with disabilities should engage with local DPOs. This is mandated under Article 33 of the UNCRPD, which calls for the inclusion of DPOs in monitoring and accountability processes. Furthermore, DPOs have an understanding of the context and any specific challenges that data collectors may face, or risks to people with disabilities that sharing information may cause. In most instances, DPOs can help identify participants, and advise on accessibility and support with the validation of findings. Furthermore, any data an organisation collects relating to people with disabilities in the DPO's catchment could support their programming and advocacy activities, thereby further empowering the disability community.

2.4 Building on existing data collection practices

Organisations wishing to gather qualitative and quantitative data relating to disability should not feel that they need significant additional training in a range of new methodologies, or have to develop a new portfolio of data collection tools. Existing tools and approaches can usually be adapted and made accessible, with the right planning and resourcing. There are some practical considerations:

- **Using a mixture of qualitative and quantitative approaches:** it is important to carefully consider what approaches will generate the information required. Qualitative approaches allow for a more exploratory approach to data collection and the co-construction of knowledge based on individuals' experience and perspectives. They provide more in-depth information on the 'how' and the 'why' of the 'what', which tends to come through more quantitative data collection methodologies. Qualitative approaches can be more effective at gathering feedback from the most marginalised. For instance, because the numbers of people with the most severe and complex impairments are relatively small, the experience of these individuals tends to be excluded from quantitative data collection. However, qualitative data collection methodologies can reveal the nature of and reasons for their exclusion, more clearly.

- **Be flexible:** collecting disability data will require flexibility and the use of a range of methodologies to capture the experiences of people with disabilities. These could include focus group discussions, surveys, key informant interviews, audio-visual tools, participatory methodologies (such as mapping, storytelling or drawing) and observations.

- **Accessibility:** comprehensive accessibility ensures that physical, communication, policy and attitudinal barriers are identified and addressed. A common misconception is that accessibility is only about physical access, which overlooks the different access requirements of many people with disabilities[xi]. It is also essential to consider local contexts, and analyse barriers and cultural practice, technologies and materials. See the resource box at the end of this section for some references on mainstreaming and accessibility.

- **Inclusive approaches versus disability-specific methodologies:** organisations need to consider whether they want to use inclusive methodologies that consult with all members of their target groups (including people with disabilities), or disability-specific methodologies that separate individuals into groups with and without disabilities. Inclusive approaches are preferable, where possible, as they do not deepen or validate the social exclusion these individuals already experience; but existing power dynamics may impact the information produced.

- **Safeguarding:** adults and children with disabilities are at greater risk of abuse, so rigorous safeguarding processes need to be implemented, ethical best-practices[xii] adhered to, and risk assessments carried out. Safeguarding procedures may need to be adjusted for people with different impairment types. Reporting mechanisms also need to be in place in case an issue arises or incidents are uncovered during discussions.

- **Additional investment:** being fully inclusive will cost more money, so there is a need to invest in this. There are some adjustments to the way data collection activities are carried out that can result in the inclusion of many people with disabilities, if designed in from the outset. For instance: booking sign language interpreters; providing participants with information ahead of meetings; taking a bit of extra time at meetings to allow for more breaks; producing information in simplified language forms (braille, Easy Read, picture-based); checking for a venue's physical accessibility[xiii]. Some organisations are also exploring more cost-effective methods for data collection, such as the Key Informant Method, instead of population-based surveys to establish prevalence where appropriate (see section 6.1). However, fundamentally, all organisations do need to budget to be able to carry out inclusive

data collection. World Vision recommended including a standard line for disability access/inclusion within all budgets as a fixed percentage (two to five per cent) of activities or overall costs to cover costs, such as interpreters, guides, transport, and the production of material in alternative formats[xiv].

- **Including the voice of those most marginalised:** organisations need to take into account the intersectionality of discrimination and existing power dynamics. For instance, in focus group discussions, data collectors need to consider the age, gender, ethnicity, education and wealth status of the different participants. Furthermore, even within the category of disability, impairments and conditions range widely, as do levels of severity. Data collectors therefore also need to be aware of the dynamics between people with different impairments, so that all involved are given an equal opportunity to express themselves.

- **Informed consent:** many organisations struggle with how to get informed consent from people with disabilities, especially from people with psychosocial or intellectual disabilities. This often leads to their exclusion from these processes. While there is no easy answer to this challenge, some organisations have found ways to adapt the consent process so that they can gather the experiences of these particularly marginalised individuals. These adaptations include using picture consent or verbal consent. Part of ethical practice involves also ensuring that any participant can withdraw their consent at any point. The data collectors need to be aware of individual needs and sensitive to non-verbal behaviour, such as changes in body language suggesting that a person might no longer feel comfortable participating in a discussion.

- **Carers or assistants:** data collectors need to be mindful of carers and assistants as they have often been used to speaking for the person with disabilities and can find it difficult to step back. If they do act as a proxy and speak for the person, this should be clear in the records, as it may not accurately represent what the person would have said if they could.

- **Do not separate respondents by impairments:** it is not in compliance with UNCRPD to segregate people with disabilities by impairment or disability. It can be done for specific reasons, such as part of a disability-specific intervention, but should not be done simply because it is cheaper or easier, for example, bringing all people with hearing impairments together so that organisations only need to get a sign language interpreter once.

- **Sharing data:** data sharing helps to deliver better programmes and strengthen data collection practices. Many organisations that gather data on disability have shared not only their findings, but also the methodologies used and the strengths and weaknesses of these approaches. An example of this is the report drafted by Leonard Cheshire[5] and Humanity & Inclusion[6], in which they shared learnings on the use of the WGQs in the development and humanitarian contexts (see the resource box in Section 4.1).

Case study 1: ADD – child-led peer research on modelling inclusive education in Tanzania

Action on Disability and Development (ADD)[7] used an inclusive participatory approach and empowered children with disabilities to be at the heart of a research process to improve outcomes for themselves and their peers in Tanzania[xv].

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[5] Leonard Cheshire support individuals to live, learn and work as independently as they choose, whatever their ability. For more information, please visit: https://www.leonardcheshire.org/

[6] Humanity & Inclusion works in situations of poverty and exclusion, conflict and disaster, alongside people with disabilities and vulnerable populations, taking action and bearing witness in order to respond to their essential needs, improve their living conditions and promote respect for their dignity and fundamental rights. For more information, please visit: https://hi.org/en/index

[7] Action for Disability and Development (ADD) partners with disability activists in Africa and Asia to help them access the tools, resources and support they need to build powerful movements for change. For more information, please visit: https://www.add.org.uk

ADD trained 12 children, aged 8-17 years, as researchers. The group was gender mixed with 6 boys and 6 girls, as well a mix of abilities, including: albinism (3), mild visual (3) hearing (4), physical (4), learning (2), with some children falling into more than one category. ADD ran a three-day workshop to help the children get to know each other, learn about research ethics, practice a variety of data collection games/tasks, develop questions to ask other children, and practice interviewing and running focus group discussions. ADD then supported the children to gather information and evidence from peers. Twelve focus groups were run with children with and without disabilities to understand: how do children perceive and experience school and inclusion within their community? The child researchers led and facilitated the running of four key activities in each focus group session, as well as warm-up games and motivational songs and dances. ADD guided the child researchers through a three-day review and analysis process, during which they collated and summarised the data collected. They produced a research poster to present their findings and developed role plays informed by their experiences and those they had heard about during the focus groups. These were presented to the child researchers' schools and communities, as well as DPO leaders and the Ministry of Education.

Overall, the child researchers (and many of the group participants) demonstrated and expressed positive attitudes about themselves and others, high self-esteem and aspirational ideas about their futures. They had a strong sense of the importance of education and had a range of ambitions in relation to their future lives. Importantly, this pioneering approach challenged perceptions about what children with disabilities can achieve.

Resource box – Mainstreaming toolkits and case studies

CBM's Disability-Inclusive Development Toolkit 2018: https://www.cbm.org/get-involved/search-resources-publications/

ADD's The Value of Mainstreaming: Why disability-inclusive programming is good for development: https://www.add.org.uk/research

World Vision's Travelling Together: How to include disabled people on the main road to development: https://www.wvi.org/disability-inclusion/publication/travelling-together

CBM, Humanity & Inclusion and the International Disability Alliance's Inclusion of persons with disabilities in humanitarian action: http://blog.handicap-international.org/influenceandethics/wp-content/uploads/sites/4/2019/11/Case-studies_Inclusion-of-persons-with-disabilities-in-humanitarian-action_CBM_HI_IDA.pdf

3. Internationally-validated tools

There are a number of internationally-validated tools which can be used in different ways to collect data on disability. This section focuses on the WGQs, which are widely used to establish prevalence and access, and the Model Disability Survey (MDS), used to gather more detailed information on how people with disabilities conduct their lives and the difficulties they encounter.

3.1 The Washington Group Question Sets

In 2001, the UN Statistical Commission authorised the formation of a Washington Group on Disability Statistics to address the gap in measurement and comparison data on disability, globally. This group has spent 18 years developing and testing tools which can offer a simple and effective means of measuring and obtaining comparative data on the prevalence of disability across countries.

The WGQ Sets were designed with a functional approach, based on the social model of disability[8]. They were developed in line with the WHO's International Classification of Functioning, Disability, and Health (ICF), purposefully avoiding the term 'disability' itself. They were also an intentional move away from binary 'yes/no' questions on disability, which generated far lower prevalence rates. There are multiple reasons for this. People can often be reluctant to admit that someone in the household has a disability, due to stigma and prejudice that can be attached to this label in many societies. Furthermore, the term disability is often interpreted as resulting from a severe impairment, so people with more moderate impairments, who still might face significant risks of exclusion, are missed. Finally, older people often consider their functional limitations not to be associated with 'disability' but only with age, when age in fact may simply be a cause of their disability.

Since 2001, a number of different sets of questions have been released:

- Washington Group Short Set: the most widely used; intentionally kept to only six questions to be suitable for censuses and surveys. They are not designed to measure all aspects of difficulty in functioning that people may experience, but rather those domains of functioning that are likely to identify a majority of people at risk of participation restrictions.

- Washington Group Short Set Enhanced: includes the Short Set questions and four questions on upper body functioning, anxiety and depression (10 questions in total).

- Washington Group Extended Section Functioning: expands on the Short Set, to look at the use of assistive devices/aids, functioning with and without the use of devices/aids, where applicable, and additional domains of functioning, such as upper body, anxiety and depression, fatigue and pain (38 questions in total).

- Washington Group/UNICEF Module on Child Functioning: specific to the needs of children aged 2-4 and 5-17 developed in conjunction with UNICEF. These were developed as the Washington Group Short Set is not appropriate for children under the age of five, and misses some children with developmental issues, aged 5-18.

- The Washington Group and the International Labour Organisation (ILO) are developing a draft module on disability and employment for inclusion in Labour Force Surveys. For more information, contact the Washington Group Secretariat.

The WGQs have been endorsed by a number of organisations, including the ILO, UNICEF, the WHO and the Office of the High Commissioner for Human Rights, as the questions most suitable to disaggregate data by disability, and are the designated methodology for the Sustainable Development Goals. They have been promoted by DFID and the Australian Department for Foreign Affairs and Trade (DFAT), and are currently being used in over 78 countries. They have also been tested by a number of organisations to understand their viability and utility for the non-governmental sector (see the resource box at the

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[8] The social model of disability states that disability is caused by the barriers to opportunities and participation erected by society, rather than by a person's physical or mental impairment or difference itself. It recognises that people with disabilities can live as equal members of society once these barriers to inclusion are removed.

end of section 3.2 for the Leonard Cheshire and Humanity & Inclusion report, and Case study 4 on Sightsavers' experience of using the WGQs).

The Washington Group is continuing to develop these resources with the upcoming launch of a new website, more translations of the Question Sets and new modules on civil participation and environment. They are also in the testing phase for a UNICEF/Washington Group survey Module on Environment and School Participation, which will aim to measure the barriers/facilitators to accessing education for children with and without disabilities. The Secretariat is always willing to respond to queries relating to usage and translations of the Question Sets, and analysis and interpretation of the data produced. There is a contact form on the website (see the resource box at the end of this section for a link to the site).

3.2 Considerations when using the Washington Group Questions

- The WGQs are not a diagnostic tool, but are rather designed to identify people who experience functional difficulties and are therefore at risk of exclusion.

- The WGQs have been extensively tested in a range of contexts, including looking at changes both in the introductory section and in the questions. Even minor changes in wording produced less accurate results. Using the existing wording accurately is therefore encouraged, and if more information is needed, additional questions should be added after the WGQs have been asked.

- Research shows that only half of people with psychosocial disabilities are captured by the Washington Group Short Set of Questions (those whose psychosocial issues affect communication, cognition or self-care)[xvi]. To be able to identify more people with psychosocial disabilities and identify them as such, it is necessary to add the questions on anxiety and depression from the Extended Question Set.

- The WGQs do not capture certain disabilities, such as albinism. While there is no specific question relating to albinism (as visual impairment is a key feature in all types of albinisms), the majority of people with albinism are expected to report difficulty seeing[xvii]. However, people who do not have much difficulty seeing will therefore not be included.

- The accuracy of the translation of the WGQs has been found to affect the validity and quality of the data. For instance, 'concentrating' has often been misinterpreted as 'memory'[xviii]. This is why, where possible, validated translations which consider the contextual and conceptual meaning, should be used. Please contact the Washington Group Secretariat with questions on translation.

- Context has an impact on the validity of the data collected. For example, male data collectors asking women about washing and dressing was problematic in many settings. Humanity & Inclusion found that 'Do you have difficulty seeing, even if wearing glasses?' and 'Do you have any difficulty hearing, even if using a hearing aid?' caused issues in some parts of the Democratic Republic of the Congo (DRC), as many interviewees had no access to glasses or hearing aids[xix]. There are not yet solutions identified for all these issues. However, it is important to have skilled data collectors, who are able to respond appropriately to the needs of the context and adapt questions, while remaining true to their design.

- Asking the WGQs can raise expectations for support[xx]. This was particularly the case with the issue of glasses and hearing aids. It is therefore important to be clear with respondents how the data collected will be used, and to manage expectations.

- Sample sizes of several hundred are required when using the WGQs to accurately establish the prevalence of disability in the general population. However, there are still many uses for the WGQs

for organisations working with smaller sample sizes. For example, the Short Set could be included as part of baseline and end line surveys for a project, to understand impact.

- The WGQs do not provide information on when or how impairments may have been acquired – which can be a gap for humanitarian organisations operating in conflict zones or following natural disasters. Additional questions such as 'What age did you acquire your disability?' or 'What was the cause of your disability?' can be added. However, any additional questions should be asked after the original questions – which explicitly do not mention disability. Any additional questions which ask specifically about disability should be considered with caution.

- The Washington Group Short Question Set does not capture use of assistive devices (such as wheelchairs, hearing aids, spectacles). This can be addressed either by including additional questions relating to assistive devices (after the six questions have been asked), or by using the Extended Set of questions which do cover access to assistive devices.

- The WGQs are intended to be incorporated into other surveys or censuses being used, so there may be instances when there will be differences in responses depending on whether the questions are addressed to heads of households and/or all the individuals in a household. However, when they are included in large surveys, the Washington Group Secretariat have found that these differences tend not to be statistically significant.

- The WGQs alone are not enough to develop inclusive programmes, as they do not provide information on the experience of people with disabilities. When analysed alongside other information, they can provide additional data on the prevalence of different types of disabilities and some of the barriers they may face. However, more qualitative data is required to better understand the experience of people with disabilities, and so inform programme design.

Case study 2: Sightsavers – using the Washington Group Questions in development programmes

Since 2014, Sightsavers[9] has conducted a number of studies to understand how the WGQs could be used to measure disability inclusion, and strengthen programming in different settings, including Bangladesh, Cameroon, Ghana, India, Malawi, Mozambique, Pakistan, Tanzania and Senegal[xxi]. Collecting disability disaggregated data has revealed a number of interesting findings:

- Sightsavers' qualitative data showed that training and sensitisation had a positive influence on data collectors' and health providers' attitudes and perceptions towards people with disabilities.

- Collecting disability data alongside other measures helped to explore the intersectionality of marginalisation. Sightsavers' surveys in Cameroon, India, Mozambique, Pakistan and Tanzania found that access to health services differed by sex, disability and wealth status in different settings, and that it is important to understand the different factors at play in any particular setting.

- How questions on disability are asked makes a difference. Sightsavers found that women were more likely to report disabilities than men when using the Washington Group Short Set of Questions assessing functionality, but were less likely to self-identify as 'disabled' when directly asked about disability using the binary (yes-no) measure. In their pilot Urban Eye Health Project in Bhopal, India, Sightsavers found that 17.5 per cent of female respondents reported disabilities when using the WGQs, but only 0.4 per cent self-defined as disabled[xxii].

- Collecting data disaggregated by disability helped Sightsavers understand how people were accessing services. The continued data collection in their post-pilot Urban Eye Health project in Bhopal, India,

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[9] Sightsavers is an international charity working to prevent avoidable blindness, support equality for people with disabilities and advocate for change. For more information, please visit: https://www.sightsavers.org/

revealed that people with disabilities were more likely to attend community-based services (outreach camps and vision centres), but less likely to go to the hospital. This suggested that people with disabilities may experience problems with accessing hospital services.

- Sightsavers also found that, for these tools to be effectively implemented and produce quality, valid data, they had to invest in training the data collectors, and ensure that the tools were linguistically and culturally appropriate through testing of initial translations.

Resource box

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

Leonard Cheshire and Humanity & Inclusion, Disability Data Collection: A summary review of the use of the WGQs by development and humanitarian actors: https://reliefweb.int/sites/reliefweb.int/files/resources/Disability%20Data%20Collection%20DIGI .PDF

Sightsavers' publications, reports and presentations on using the WGQs: https://www.sightsavers.org/programmes/everybody-counts/

3.3 Model Disability Survey

The WHO and the World Bank have been developing the Model Disability Survey to provide a more comprehensive tool for collecting data on disability[xxiii]. This is a general population survey that provides detailed and nuanced information about how people with and without disabilities conduct their lives, and the difficulties they encounter, regardless of any underlying health condition or impairment. As with the WGQs, the Model Disability Survey is grounded in the International Classification of Functioning, Disability and Health (ICF), and explores disability as an outcome of interactions between a person with a health condition or impairment and various environmental and personal factors, rather than focusing only on a person's health or impairments. This gives a more complete understanding of the lived experience of people with disabilities. The Model Disability Survey provides both a comprehensive, general population survey (294 questions), and a brief survey (40 questions), intended as a set of supplementary questions to be added to a survey on any other topic.

Resource box

Model Disability Survey: https://www.who.int/disabilities/data/mds/en/

4. Disability data in humanitarian contexts

The Inter-Agency Standing Committee (IASC)[10] stated that quality humanitarian programming is built on an understanding of the requirements and priorities of persons with disabilities during a crisis[xxiv]. This understanding is generated by: (1) identifying the population of persons with disabilities; (2) analysing the risks that persons with disabilities face and the factors that contribute to those risks; (3) identifying barriers that impede persons with disabilities from accessing humanitarian assistance; and (4) understanding the roles and capacities of persons with disabilities in the humanitarian response. This need for disability data in humanitarian contexts has been endorsed by a number of global agencies. For instance, the Charter on the Inclusion of Persons with disabilities in Humanitarian Action[11] has data as one of its five commitments[xxv]. However, disability-inclusive data collection can be seen as challenging in times of humanitarian crises, when the situation is changing fast; there are significant time constraints; current data systems have not been adapted to include people with disabilities; and levels of stigma and discrimination can be more prevalent than ever. This section offers some examples of approaches and tools that organisations have used to overcome some of these challenges.

Case study 3: International Rescue Committee – learnings from mainstreaming disability data collection within a humanitarian organisation

The International Rescue Committee (IRC)[12] has been looking at inclusion for a number of years, and started engaging in disability data in 2018. The IRC's entry points for disability data collection were individual projects rather than organisational level. It also started by training disability and data champions to support this initiative. The IRC has had a number of successes at project level, including using the WGQs to determine whether people with disabilities were accessing economic wellbeing and livelihood programmes across all population groups, to ensure that formative and operational research was targeting people with disabilities. There is now an institutional commitment at the IRC to use the WGQs, which is a significant success for an organisation of this size.

Some of the IRC's key lessons during this process were:

- Organisations have to invest in training, monitoring, and evaluating staff, otherwise they may struggle to analyse data and the resulting data disaggregation may be poor. IRC initially found that the data was not being viewed through an intersectional lens, which led to errors like double counting.

- Organisations need to sensitise staff and partners, otherwise they may face resistance and attitudinal barriers, as inclusive data collection is perceived to be harder to plan and implement.

- The IRC encountered a real fear of 'doing the wrong thing' (for instance, issues around informed consent in research protocols), and had to spend time discussing these sensitive issues.

- Organisations need to consider what they will do with the findings. How will the learnings from the data collection be translated into meaningful action?

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[10] The Inter-Agency Standing Committee (IASC) is an inter-agency forum of UN and non-UN humanitarian partners, founded in 1992 to strengthen humanitarian assistance. The overall objective of the IASC is to improve the delivery of humanitarian assistance to affected populations. For more information, please visit: https://interagencystandingcommittee.org/

[11] This Charter on Inclusion of Persons with Disabilities in Humanitarian Action was developed in advance of the World Humanitarian Summit 2016, by over 70 stakeholders from states, UN agencies, the international civil society community and global, regional and national organisations of persons with disabilities.

[12] The International Rescue Committee (IRC) responds to the world's worst humanitarian crises and helps people whose lives and livelihoods are shattered by conflict and disaster to survive, recover, and gain control of their future. For more information, please visit: https://www.rescue-uk.org/

Resource box – The Humanitarian Innovation and Evidence Programme (HIEP) toolkit

From 2016 to 2018, Humanity & Inclusion ran a Humanitarian Innovation and Evidence Programme (HIEP)-funded programme to test whether the WGQs could be used in a humanitarian context. This was a three-phase project, with an initial action-research phase to establish whether the WGQs could be used; a second phase to focus on developing accessible training tools; and a third phase for the dissemination of the learning and publication of the tools.

The action-research phase was carried out in Jordan, the Philippines and the DRC. Humanity & Inclusion trained 30 partner organisations to use the WGQs, and monitored how they were used. They found that proper training in the use of the WGQs was essential as without it, there were a number of common errors and misconceptions. However, with additional investment in training, Humanity & Inclusion found that they were getting better data, more effective collection and evidence of staff challenging attitudinal barriers.

Working with Leonard Cheshire, Humanity & Inclusion published a report of their learning, as well as fact sheets. They have also developed a learning toolkit (e-learning). This two-hour course has been designed to support humanitarian programme staff understand, plan for and use the WGQs to identify peoples with disabilities in humanitarian action. It includes case studies, practical examples and a number of supporting resources (see the link below). These resources are currently available in English, French and Arabic, and will soon be available in Spanish.

Learning toolkit on the use of the WGQs in humanitarian action: https://humanity-inclusion.org.uk/en/projects/disability-data-in-humanitarian-action

Case study 4: Islamic Relief Worldwide - disability data analysis to inform programming in Gaza

Islamic Relief Worldwide[13] is committed to implementing inclusive programmes which consider all factors resulting in protection risks and inequality. Over the last three years, it has been making concerted efforts to develop internal capacity to be sensitive and responsive to intersectional discrimination. The collection, analysis and use of programme data, as well as survey data on access and control over resources, disaggregated by sex, age, and disability, is a fundamental pillar of Islamic Relief Worldwide's Protection & Inclusion Framework[xxvi]. Disability-focused training and mentoring is essential to further develop the technical understanding of Islamic Relief's HQ and country office staff, to ensure systematic and effective collection, analysis, and use of disability data to inform programmatic decision making.

In Gaza, the Islamic Relief Palestine team used age, gender and diversity analysis to separately consult with people with disabilities, older people, abandoned women, and internally-displaced groups[xxvii]. Analysing data disaggregated by these groups enabled the Islamic Relief Palestine team to refine their targeting criteria and provide adapted assistance. It also changed staff's outlook on the design and delivery of humanitarian programmes. The new approach empowered staff to critically reflect on gaps in their procedures, and to identify solutions so that services on the ground can become more inclusive. For example, insights gained from the new programming approach have prompted Islamic Relief Palestine to work alongside local partners to overcome barriers related to social acceptance of men and women with disabilities in livelihood projects. They have also sought technical advice and support from

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[13] Inspired by their Islamic faith and guided by their values, Islamic Relief Worldwide is a humanitarian and development organisation which works towards their vision of a world where communities are empowered, social obligations are fulfilled, and people respond as one to the suffering of others. For more information, please visit https://www.islamic-relief.org

disability organisations to better integrate the needs of men and women with disabilities into their projects. Changes made included developing accessible cash-for-work resources and training materials, and selecting accessible training venues. One of their key learnings was that local staff must also be trained to raise awareness of the importance of providing men and women with disabilities with safe and dignified access to humanitarian interventions.

"We used focus group discussions before, but it was just two separate groups, one for men and one for women. When we consulted with men and women with disabilities separately, we were able to appreciate the difference, as often the ones who are discriminating against us are the ones living alongside us. The groups were more open and forthcoming in sharing not only their challenges, but also advice with possible solutions. That helped us to better integrate their needs into our project." Islamic Relief Palestine[xxviii].

Resource box

IASC Guidelines, Inclusion of Persons with Disabilities in Humanitarian Action: https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines

Charter on Inclusion of Persons with Disabilities in Humanitarian Action: http://humanitariandisabilitycharter.org/

DFID's Guidance on strengthening disability inclusion in Humanitarian Response Plans: https://reliefweb.int/report/world/guidance-strengthening-disability-inclusion-humanitarian-response-plans

Islamic Relief Worldwide, Learning paper 1, Leave no one behind in humanitarian programming: An approach to understanding intersectional programming. Available from: https://www.islamic-relief.org/publications/

CBM, Humanity & Inclusion and the International Disability Alliance's Inclusion of persons with disabilities in humanitarian action: http://blog.handicap-international.org/influenceandethics/wp-content/uploads/sites/4/2019/11/Case-studies_Inclusion-of-persons-with-disabilities-in-humanitarian-action_CBM_HI_IDA.pdf

5. Child-focused disability data

When starting any programme which is likely to impact children, organisations should be seeking to understand the prevalence of child disability, as well as trying to document their experiences. Population-based surveys used by government agencies are considered the most accurate approach to collecting robust and representative data on child disability prevalence. For instance, the WGQ/UNICEF Module on Child Functioning has been extensively tested and reviewed, and is considered to be the gold standard tool for identifying child disability prevalence. However, as with any tool, it is not perfect. There are some limitations in terms of accuracy[xxix], and, as the prevalence of child disability is comparatively low, a large sample is required, which makes it an expensive and time-consuming exercise. They also exclude children in residential homes and can lead to under-reporting in areas where

stigma against disability means that parents feel that they have to deny the presence of a child with disabilities in their home. Another tool for identifying prevalence is the Malawi Developmental Assessment Tool, which has been created for use in African settings and shows good reliability, validity, and sensitivity for identification of children with neurodisabilities[xxx]. Sightsavers has been using this tool as part of a multi-method research project to identify children with developmental delays in Malawi (see the resource box at the end of this section for more information)[xxxi].

Due to perceived challenges, many organisations have not historically attempted to collect data from children with disabilities, and focused instead on collecting data about them. However, without consulting children with disabilities, organisations will only ever get half the story and will not fully understand the impact of their programmes. The act of including children with disabilities is also an effective way of demonstrating to their community that their voice is as important as that of other children, and is a powerful form of indirect advocacy. Furthermore, consulting children with disabilities can be incredibly empowering for them as it can increase their confidence and allow them to self-advocate and interact with change- and decision-makers. Where possible, this should be done as part of inclusive data collection methodologies, rather than through disability-specific data collection activities which may reinforce the social exclusion that these children already face. Finally, collecting data directly from children with disabilities ensures quality and offers an important perspective, as they have the best understanding of how organisations' interventions have affected them; plus, children are less susceptible to social desirability bias[14]. While it is challenging and does require more planning, it is possible, and important, to collect data from children with disabilities.

Case study 5: Chance for Childhood – Leveraging Global Disability Summit commitments to strengthen disability data collection in Rwanda

As part of the 'Education, Equality and Empowerment' (EEE) project, from 2013 to 2015 Chance for Childhood[15] administered a multi-disciplinary questionnaire in three districts of Rwanda to map out all people with disabilities, including children with disabilities. One of the key findings from this survey was that out of the 37,895 people with disabilities identified, 38 per cent were children in the age category of 0-3 who were likely not accessing Early Childhood Development (ECD) services. As Rwanda currently has limited ECD screening and referral services, these children and their families were not being identified through existing channels, or receiving vital support services – further compounding their marginalisation.

Based on this evidence, and capitalising on the Government of Rwanda's commitment made at the Global Disability Summit 2018[xxxii], Chance for Childhood (with Inclusion and Disability) developed standardised national early risk screening and disability identification tools. Based on WHO guidance on developmental difficulties in early childhood[xxxiii] and WGQ/UNICEF Modules on Child Functioning, they developed new, context-appropriate screening tools to identify 0-2 year olds who might be experiencing developmental delays. They also adapted the WGQ/UNICEF Modules on Child Functioning for children aged 3-17 years.

In partnership with UNICEF and the Ministry of Gender and Family Promotion in Rwanda (under their National Early Childhood Development Programme), Chance for Childhood took an inclusive approach from the design all the way through to the validation phase, involving a broad range of stakeholders that included central, regional and local government staff, multi-laterals, technical experts such as physiotherapists and Community Health Workers, and families of children with disabilities. Practical

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[14] Social desirability bias is the tendency of survey respondents to answer questions in a way that they believe will be viewed favourably by others, instead of choosing responses that are reflective of their true feelings.

[15] Chance for Childhood is an award-winning charity working in Africa to support the most vulnerable children, such as street children, children with disabilities, children affected by conflict and kids behind bars. For more information, please visit: https://chanceforchildhood.org/

considerations were addressed from the outset, such as who should be administrating these tools? How often? How should the data be stored? This consultative approach, although causing some challenges around planning and input, meant that the tools developed were appropriate to the context and easy to use, and that their uptake was well supported. Chance for Childhood is now working with the Government to have these new tools rolled out nationally. It is also ensuring that national ECD Master Trainers under the National ECD Programme will be trained across Rwanda to support the identification of children with disabilities and/or developmental delays. This is essential as referral structures within communities need to be strengthened to ensure that services can be accessed once these children have been identified.

Chance for Childhood is also planning to support the National Council of Persons with Disabilities in Rwanda to take ownership of the data collection and storage, as well as to develop a joint action plan with representatives from all sectors, including health, education, family promotion and justice.

Case study 6: International Centre for Evidence in Disability – using a Key Informant Methodology to gather data on the prevalence of children with disabilities

To overcome some of the challenges and cost of gathering prevalence data, researchers from the International Centre for Evidence in Disability (ICED), based at the London School of Hygiene and Tropical Medicine[16],piloted the use of the Key Informant Method[17], using community volunteers to identify children with disabilities[xxxiv]. Key informants were trained to identify impairments visually and through the use of short question sets, and refer children who met a certain criteria for assessment. Key informants were also encouraged to spread messages through community networks and visit households of all children believed to have impairments meeting the agreed criteria. A 2008-2012 study on visual impairments in Bangladesh showed that this methodology is valid to identifying prevalence of disability, as it produced a prevalence that was comparable to a population-based study. Critically, it did so at 10 per cent of the cost. Another advantage of this approach was that these key informants can become advocates for children with disabilities in their communities.

ICED has continued to use this approach and have found that is can be used to effectively identify almost 100 per cent of children with targeted moderate or more severe impairments in vision, muscular-skeletal system, epilepsy and cognition. It provides not only robust estimates of prevalence, but also more in-depth information on children with disabilities. Finally, the Key Informant Method can also assist in service planning and costing.

There are some limitations and considerations that organisations need to be aware of when using this approach. Firstly, ICED found that the Key Informant Method was less effective at identifying children with hearing impairments. Furthermore, it has not been validated for identifying children with mild impairments, which may affect their participation. In addition, good training of key informants and coordination of assessment process and referrals is crucial to the success of this approach. Finally, extensive barriers to service uptake exist across many development settings and must be eliminated to fully support the children with disabilities identified.

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[16] Based at the London School of Hygiene and Tropical Medicine, the International Centre for Evidence in Disability's mission is to provide evidence to improve the health and wellbeing of people with disabilities, globally. For more information, please visit: https://www.lshtm.ac.uk/research/centres/international-centre-evidence-disability

[17] The Key Informant Method has been used across the health sector to identify prevalence of illness or disease. It uses community members (key informants) to identify prevalence, in this case, children with disabilities and refer them for assessment.

Case study 7: AbleChildAfrica – lessons learned from collection data from children with disabilities

AbleChildAfrica[18] has tried a range of approaches to gather information directly from children with disabilities for a number of years. Here are some of their key learnings and recommendations:

- Identity existing, well thought-through child-participatory data collection tools, such as charts, diagrams, cards and open-ended stories and adapt them for accessibility.

- Employ data collectors that understand how to collect data from children with disabilities. These do not need to be trained data collectors but could be people who have worked with children with disabilities and understand their needs.

- Ensure that those collecting data from children with disabilities understand their needs. For instance, children with disabilities may have never been asked questions about their experiences before so may need time to reflect before they can respond. Data collectors might also need to use approaches that allow a question to be asked and answered in multiple ways. They will need to be flexible during data collection as there is no one way of collecting data and including all children.

- Empower and protect – during the design of the process and the data collection, organisations should think of approaches that minimise people speaking on behalf of children with disabilities.

- Ask the extent to which children with disabilities' self-reported feelings are similar to that of their peers without disabilities.

- Ensure that the data collection environment is also inclusive – do not segregate children with disabilities during data collection.

- Think about safeguarding – collecting data from children with disabilities is likely to uncover issues so organisations need to have identified how they will respond to this information.

- Using the Washington Group/UNICEF Module on Child Functioning to gather data from children can be challenging, as they can struggle to answer the questions when they are not used to being asked. Furthermore, children tend to speak more localised dialects than adults, so tested translations may not be available (although it is worth contacting the Washington Group to check). AbleChildAfrica has persevered with this tool as they find the data critical to supporting their advocacy work.

Resource box – child-focused disability data collection tools and resources

World Health Organisation (WHO) guidance on developmental difficulties in early childhood: https://www.who.int/maternal_child_adolescent/documents/development_difficulties_early_childhood/en/

Washington Group/UNICEF Child Functioning Module: http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/

Using the Key Informant Method to identify children with disabilities: A working guide: https://www.lshtm.ac.uk/media/23601

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[18] AbleChildAfrica's mission is to promote the realisation of equal rights for children with disabilities and their families in Africa, and to facilitate their meaningful inclusion in all aspects of life. For more information, please visit: https://www.ablechildafrica.org

Example of a multi-method research study on children with disabilities: Sightsavers multi-method research study: https://research.sightsavers.org/project/a-multi-method-research-study-to-improve-curriculum-and-teaching-methods-to-influence-policy-and-increase-the-quality-of-early-childhood-development-and-education-provision-for-children-with-disabilit/

6. Disability data collection in mental health programming

6.1 Why we should be collecting data on mental health and psychosocial disabilities

Mental health[19] has moved up the agenda in recent years, and is becoming a key part of international development efforts[xxxv]. While addressing mental health is implicit to achieving all the SDGs, it is also explicitly referenced in Goal 3 on Good health and wellbeing[xxxvi]. Despite this, those with mental health conditions or psychosocial disabilities[20] are among the most marginalised. Compared to other diseases, mental health is significantly underfunded. For instance, mental health accounts for 183.9 million healthy years lost, compared to 81.5 million years lost due to HIV, globally, yet receives much less funding ($136.12 million global development assistance compared with $6.8billion on HIV)[xxxvii]. The 2019 Lancet Commission on Global Mental Health and Sustainable Development advocates for a dramatic reframing of mental health as an essential part of everything done in development[xxxviii]. However, the data that is currently available is weak and more research evaluation is needed.

6.2 Monitoring the inclusion of people with psychosocial disabilities

One of the actions organisations can take to address this gap is to monitor the inclusion of people with psychosocial disabilities in their programmes. The Washington Group Short Question Set can be used to monitor the inclusion of people with disabilities, including those with psychosocial disabilities, as many people with psychosocial disabilities have difficulties with remembering, concentrating and self-care, meaning they are mostly being counted. However, not all will be captured and the Short Set do not allow for disaggregation to determine who has psychosocial disabilities versus other disabilities. This is because, as outlined in section 4, the WGQs are not intended to be diagnostic tools and will only identify people who experience functional difficulties, and therefore are at risk of exclusion.

The Washington Group Extended Question Set on functioning includes a module on 'Affect', which targets anxiety and depression. While these questions will still not capture everyone with a psychosocial disability, they will include more people than the Short Set alone. However, the Extended Set may not be practical in all settings and can be more time consuming and expensive to administer.

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[19] The WHO defines mental health as "a state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community."

[20] The Independent Commission for Aid Impact uses the term psychosocial disability to "describe people who have or are perceived to have mental health support needs and who have experienced discrimination (including but not limited to infringements on their liberty, autonomy, and effective participation) based on their needs or presumptions about their needs". Because the concept of psychosocial disabilities is rooted in a social approach, this term focuses on barriers to participation rather than on symptoms or diagnosis.

The compromise option is to add the questions for "Affect" from the Washington Group Extended Question Set to the six questions in Short Set, to create an Enhanced Short Set. This is the option that DFID advocates. There are three questions under Depression and three under Anxiety. The Washington Group Secretariat is also currently working on a longer-term solution, so organisations interested in this should keep an eye on their website (see the resource box at the end of this section).

6.3 How to evaluate the mental health outcomes of a development programme

To understand the full impact of a programme, it may be helpful to measure mental health-related outcomes of non-mental health programmes. There is no one-size-fits-all approach to evaluating mental health outcomes, so organisations need to determine what is feasible for them. Here are some steps to consider when designing an evaluation of a programme's mental health outcomes:

a. Select an appropriate outcome:

- Something you can reasonably expect to change, within the timeframe available and with the interventions delivered through your programme.

- Something organisations can reasonably expect to measure, through self-reporting or with a tool administered by a non-specialist, and within cultural context and logistical constraints.

b. Choose a validated screening/outcome measurement tool, if possible:

- Locally developed or locally validated (if not available, it may be helpful to try to identify a tool which has been developed or validated in a similar context). See the resource box below for examples of tools which have been validated for low- and middle-income country settings.

- Short, simple and easy to use.

c. Identify a comparison/control group, if possible

- Before and after studies are not good enough for evaluating the impact of a programme on mental health outcomes, as they do not take into account the relapsing and remitting nature of many mental health conditions, and might make a programme look effective where, in fact, results are due to the natural mental health course.

Resource box – Examples of tools for low- and middle-income country settings

Measuring other aspects of quality of life and social circumstances – WHO Quality of Life (quality of life). Available from: https://www.who.int/mental_health/publications/whoqol/en/

Screening tools for common mental health conditions – Validated Screening Tools for Common Mental Disorders in Low and Middle-Income Countries: A Systematic Review (2016). Available from: https://www.mhinnovation.net/resources/validated-screening-tools-common-mental-disorders-low-and-middle-income-countries

Sci Dev Net's Better mental health in the global South: Key resources:
https://www.scidev.net/global/health/feature/mental-health-global-south-disoder.html

Mental Health Innovation Network and K4D will also be publishing a topic guide on mental health and development at the end of 2019. This will be available on www.mhinnovation.net

7. Checklist for collecting disability data

- ✓ Advocate for organisational commitment and develop a strategy to improve disability data collection. Start with one country/one project, develop a champion, and lobby for investment.

- ✓ Disaggregate all targets to incentivise data collection and create accountability mechanisms.

- ✓ Take into account the intersectionality of discrimination – people with disabilities will not only be informed by their impairment, but by other elements such as gender, age, ethnicity, caste, education or wealth status, religion or immigrant population, for instance.

- ✓ Do not treat people with disabilities as a homogenous group during data collection. People with different impairments will experience different barriers and challenges.

- ✓ Work with people with disabilities and disabled people's organisations (DPOs) when developing and implementing data collection and validating findings. Try to engage directly with adults and children with disabilities as much as possible, rather than relying on proxies.

- ✓ Choose carefully whether qualitative and quantitative data collection methodologies, or a combination of the two, will be most appropriate for your needs.

- ✓ Consider the WGQs. They are not a perfect tool, but they are useful for establishing prevalence and access, and are increasingly widely used. A lot of guidance and training is available on how to use them, and the Secretariat is willing to support with queries.

- ✓ Gather qualitative information from people with disabilities as, without it, organisations cannot understand their experience and what needs to be adapted to increase the inclusiveness of programmes, or develop effective advocacy campaigns.

- ✓ Train staff both in disability awareness and then in any data collection tools being used.

- ✓ Be flexible – there is no 'one' approach, so use a range of methodologies and ask questions in different ways to help people with disabilities to respond in a way that works for them.

- ✓ Keep people with disabilities in your programmes safe, and ensure ethical practice, robust safeguarding and reporting mechanisms are in place.

- ✓ Budget for inclusive data collection – this may mean spending more on accessible venues, sign language interpreters, publications in braille, and so on. It will be more cost-effective if budgeted for from the outset.

✓ Ensure that your disability data collection processes are fully accessible and will allow all people with disabilities to participate.

✓ Collect data on and from children with disabilities as part of the monitoring, evaluation, accountability and learning systems for any child-focused programmes.

✓ Try to monitor the inclusion of people with psychosocial disabilities, as they are some of the most marginalised people. Explore whether you could evaluate your programme's mental health outcomes.

✓ Research the ever-growing body of open-source, well-referenced, publications – full of useful guidance based on experience which can help inform the development of data collection plans (see the resource boxes in this report as a starting point, but there are many more).

✓ Share the disability data that your organisation collects, as well as your methodology – it's the best way for the sector to learn and improve. Think about disseminating the data that has been gathered in a variety of languages and accessible formats for different audiences.

✓ Plan what you will do with the data collected and what follow-up support will be provided.

References

i World Health Organisation and World Bank, World Report on Disability (2011). Available from: http://www.who.int/disabilities/world_report/2011/en; Groce et al, Poverty and disability– a critical review of the literature in Low and Middle-Income Countries (2011). Available from: http://www.ucl.ac.uk/ lc-ccr/centrepublications/workingpapers/WP16_Poverty_and_ Disability_review.pdf

ii Altman, B. M., International measurement of disability – Purpose, method and application (2016) Springer International Publishing, Cham

iii United Nations, UN Convention on the Rights of Persons with Disabilities (2006). Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

iv CBM, Disability, Human Rights and Sustainable Development infographic (2016). Available from: https://www.globaldisabilityrightsnow.org/infographics/link-between-sustainable-development-goals-and-crpd

v Global Partnership for Sustainable Develop, Inclusive Data Charter, Everybody Counts (2018). Available from http://www.data4sdgs.org/sites/default/files/2018-08/IDC_onepager_Final.pdf

vi The Global Disability Summit 2018, Summary of Commitments made (2018). Available from: https://www.gov.uk/government/publications/global-disability-summit-2018-summary-of-commitments

vii DFID, DFID's Strategy for Disability Inclusive Development 2018-2023 (2018). Available from: https://www.gov.uk/government/publications/dfids-disability-inclusion-strategy-2018-to-2023

viii DFID Humanitarian Investment Programme. Guidance on strengthening disability inclusion in Humanitarian Response Plans (2019). Available from: https://reliefweb.int/sites/reliefweb.int/files/resources/Guidance_on_strengthening_disability_inclusion_in_Humanitarian_Response_Plans.pdf_p. 25

ix Bond, Leaving no one behind: The value for money of disability-inclusive development (2016). Available from: https://www.bond.org.uk/resources/the-value-for-money-of-leaving-no-one-behind

x CBM, Humanity & Inclusion and the International Disability Alliance (IAD). Inclusion of persons with disabilities in humanitarian action. 39 examples of field practices, and learnings from 20 countries, for all phases of humanitarian response (2019). Available from: http://blog.handicap-international.org/influenceandethics/wp-content/uploads/sites/4/2019/11/Case-studies_Inclusion-of-persons-with-disabilities-in-humanitarian-action_CBM_HI_IDA.pdf_Chapter 3 p. 25-30

xi CBM, Disability Inclusive Development Toolkit (2017). Available from: https://www.cbm.org/get-involved/search-resources-publications/_p.53

xii Intrac Principles of Data Collection (2017). Available from: https://www.intrac.org/resources/prcinciples-data-collection/

xiii ADD, The Value of Mainstreaming Why disability-inclusive programming is good for development (2015). Available from: https://www.add.org.uk/research p.18

xiv World Vision, Travelling Together. How to include disabled people on the main road to development (2015). Available from: https://www.wvi.org/disability-inclusion/publication/travelling-together p.129

xv ADD, Modelling Inclusive Education. Child Led Research. A learning paper (2017). Available from: https://www.add.org.uk/file/2942/download?token=MPPNZFGL

xvi Leonard Cheshire and Humanity & Inclusion, Disability Data Collection: A summary review of the use of the WGQs by development and humanitarian actors (2018). Available from https://humanity-inclusion.org.uk/sn_uploads/document/2018-10-summary-review-wgg-development-humanitarian-actors.pdf p.26

xvii Mont, Daniel, Are people with albinism included in the WGQs? (2019) Blog available from: http://www.washingtongroup-disability.com/people-albinism-included-washington-group-questions/

xviii Leonard Cheshire and Humanity & Inclusion, Disability Data Collection: A summary review of the use of the WGQs by development and humanitarian actors (2018). Available from https://humanity-inclusion.org.uk/sn_uploads/document/2018-10-summary-review-wgg-development-humanitarian-actors.pdf p.21

xix Ibid p.22

xx Ibid p.22

xxi Sightsavers, Everybody Counts – Sightsavers' disability data disaggregation project June 2019 (2019). Available from: https://www.sightsavers.org/wp-content/uploads/2019/07/Everybody-Counts-–-Policy-brief-2019.pdf

xxii Sightsavers. Inclusive eye health in Bhopal, India: Assessing characteristics of patients and measuring equity of access to eye health services, 2014-2017. A summary report of data collected in the Madhya Pradesh Urban Eye Health Project – Bhopal, India (2018). Available from: https://research.sightsavers.org/wp-content/uploads/sites/8/2019/01/Summary-report-Assessing-characteristics-of-patients-and-measuring-equity-of-access-to-eye-health-services-July-2018.pdf

xxiii World Health Organisation Model Disability Survey (2017). Available from https://www.who.int/disabilities/data/mds/en/; World Health Organisation, Model Disability Survey: Providing evidence for accountability and decision-making (2017) Available from https://www.who.int/disabilities/data/mds.pdf

xxiv IASC Guidelines, Inclusion of Persons with Disabilities in Humanitarian Action, 2019. Available from: https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines

xxv Charter on Inclusion of Persons with Disabilities in Humanitarian Action. Available from: http://humanitariandisabilitycharter.org/

xxvi Islamic Relief Worldwide, Learning paper 1, Leave no one behind in humanitarian programming: An approach to understanding intersectional programming (2018). Available from: https://www.islamic-relief.org/publications/

xxvii Ibid Page 15

xxviii Ibid Page 11

xxix Sprunt B. , McPake B. and Marella M., The UNICEF/Washington Group Child Functioning Module—Accuracy, Inter-Rater Reliability and Cut-Off Level for Disability Disaggregation of Fiji's Education Management Information System, International Journal of Environmental Research and Public Health. Available from: https://www.mdpi.com/1660-4601/16/5/806/pdf

xxx Gladstone, M. ,Lancaster G. A., Umar, E., Nyirenda, M., Kayira, E., van den Broek, N. R. , Smyth, R. L. The Malawi Developmental Assessment Tool (MDAT): The Creation, Validation, and Reliability of a Tool to Assess Child Development in Rural African Settings (2015). Available from: https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000273

xxxi Sightsavers, University of Birmingham and University of Malawi, The impact caregiver training has on children with disabilities in Malawi – Baseline Report December 2017 (2017). Available from: https://research.sightsavers.org/project/a-multi-method-research-study-to-improve-curriculum-and-teaching-methods-to-influence-policy-and-increase-the-quality-of-early-childhood-development-and-education-provision-for-children-with-disabilit/ p. 11

xxxii Government of Rwanda, Form for submitting commitments for the Global Disability Summit 2018 (2018). Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/728143/National_Government_-_Government_of_Rwanda.pdf

xxxiii World Health Organisation, Developmental difficulties in early childhood: prevention, early identification, assessment and intervention in low- and middle-income countries: A review (2012). Available from: https://www.who.int/maternal_child_adolescent/documents/development_difficulties_early_childhood/en/

xxxiv International Centre for Evidence in Disability (ICED), Using the Key Informant Method to identify children with disabilities: A working guide, London School of Hygiene and Tropical Medicine 2015. Available from: https://www.lshtm.ac.uk/media/23601

xxxv WHO, Mental health: strengthening our response. Factsheet (2018). Available from: https://www.who.int/news-room/fact-sheets/detail/mental-health-strengthening-our-response

xxxvi ICAI, DFID's approach to disability in development: A rapid review (2018). Available from: https://icai.independent.gov.uk/wp-content/uploads/ICAI-Disability-Review.pdf (p. 6)

xxxvii Mackenzie, J., Kesner, C., Ball, L., Caddick, H. (2016). 10 Things to know about mental health. London: Overseas Development Institute. Available from: https://www.odi.org/publications/10424-10-things-know-about-mental-health

xxxviii Patel, V., Saxena, S., Lund, C, Thornicroft, G., Baingana, F., Bolton, P. et al., The Lancet Commission on global mental health and sustainable development (2018). Available from: https://globalmentalhealthcommission.org/