development
initiatives

September 2020

Generating disability statistics

Models of disability measurement, history of disability statistics and the Washington Group Questions

background paper

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Introduction

This report presents research that was undertaken as part of Development Initiatives' work on data to support disability inclusion.

In 2015, 193 countries agreed to the 2030 Agenda for Sustainable Development and its Sustainable Development Goals which included a commitment to, where possible, disaggregate the statistics they generate by disability.

Disability statistics and data disaggregated by disability can provide important insights about the extent to which persons with disabilities are being included in society, benefit from government programmes, or are included in the workforce. They can also provide a useful evidence base to inform the development of disability-inclusive policies and programmes by government, civil society and the private sector at the local, national or global level.

However, generating accurate, comparable and disaggregated statistics on disability is challenging. Disability can be categorised in many different ways, measured using different data collection processes, and contextualised within differing environments and legal frameworks. Over the past century, the global statistics and disability communities have tested and refined a range of approaches to disability measurement, making significant progress towards creating a more harmonised approach.

This paper provides an overview of progress towards the creation of accurate and comparable disability statistics, the critical issues that impact on the measurement of disability, and discusses one of the most prominent international efforts to improve data on disabilities – the Washington Group on Disability Statistics.

The Washington Group is a multi-party, multi-stakeholder exercise established by the United Nations Statistical Commission.[1] It is the largest international effort to develop a tool to expand the collection of data on disability that is internationally comparable. Its approach is particularly well suited to disaggregating household survey data by disability.

As persons with disabilities are particularly vulnerable to the health risks of Covid-19 and the secondary effects of the pandemic, generating disaggregated data by disability has taken on added importance in the current climate. Improved data disaggregation by disability can provide insights into the extent to which the rights of persons with disabilities are being respected and the extent to which responses are reaching them.

As the consequences of the Covid-19 pandemic will likely have a significant impact for several years, understanding the extent to which the experiences of persons with disability compare to the rest of the population will be critical to ensuring that recovery is inclusive. Many household surveys and censuses have been interrupted or shifted to mobile-based phone surveys which requires special considerations. The Washington Group has produced some notes on factors to consider if administering the questions via phone surveys.[2] Some reports have included the Washington Group Questions to track the impact of Covid-19 pandemic.[3]

Models of disability measurement

Data collection on disability is shaped by ideas about definitions of disability and the frameworks from which they are built. In 2006, the Convention on the Rights of Persons with Disabilities (CRPD)[4] was adopted by the United Nations and entered into force in 2008.

The convention is a human rights treaty with a social development dimension, and was ratified by 163 signatories and 181 entities. The CRPD is rooted in a belief that the rights of persons with disabilities are fundamental. Countries have an obligation to eliminate social, legal and political barriers that prevent persons with disabilities from being fully included in societies. Furthermore, persons with disabilities must not be treated as 'subjects' and persons deserving respect and equality rather than as 'objects' or a 'problem'.

Over the years, different models of disability measurement have defined how questions on disability have been asked in surveys, censuses and administrative systems and therefore who, in the statistics, is categorised as having a disability and on what basis.

The medical model

For some, disability is considered to be a medical issue. This view focuses on the physical or psychological aspects of a disability. It generally frames a disability as a 'problem', 'deviation' or loss from a physical or psychological 'norm'. In a clinical setting, the medical model of measuring disability may be seen as particularly useful for the prevention of impairments and medical treatments, although it is generally not considered as useful for rehabilitation. However, this model feeds into a narrative that undermines the dignity, rights and opportunities of persons with disabilities, which does not provide a solid foundation for acceptable policymaking. By focusing on the medical characteristics of disability, the medical model centres on the extent to which a person with a disability is different from society rather than focusing on the rights and changes that may be required in society to ensure equal opportunity and rights of persons with disabilities.

The charity model

The charity model of disability sees persons with disabilities as recipients of charity: disempowered, without agency or objects of pity. Like the medical model, the charity model also frames disability in terms of a 'problem' and generally focuses on adapting persons with disabilities to a society rather than ensuring that society adapts to the needs

of persons with disabilities. Both the charity model and the medical model fail to acknowledge the human rights of persons with disabilities.

The social model

The social model of disability provides a view of disabilities in line with a rights-based approach by emphasising that much of the challenges of disability are due to social and environmental factors. In this model, disabilities are considered a challenge because of the social and environmental barriers that exist for persons with disabilities. The social model aims to ensure that the rights of persons with disabilities are respected and that they are provided equal participation with others in workplaces, schools and all aspects of life. As a rights-based approach to measuring disability, the social model can support the appropriate design of policies, programmes and services that support inclusion.

The identity model

Another major model for understanding disability is the identity model. This view emphasises that the common experiences of persons with disabilities create a common identity. As with any other social identities, persons with disabilities are a diverse group with different views. However, the fundamental principle of this model emphasises the potential for radical acceptance of disabilities.

This model rejects the idea of disability as a problem to be solved and asserts that it is an identity to be celebrated. Persons with a strong sense of disability identity are not seeking a 'cure' for their disability but are seeking full acceptance for persons with disabilities.[5] In this view, a person is not 'bound' to a wheelchair or does not 'suffer from' a disability, they use a wheelchair and have a disability.

History of disability statistics

The first disability statistics – The US and India Census

The 1840 US Census is the first known national survey or census to include questions about disabilities. The questions were added to the census at the request of reformers who wanted to provide data to encourage the government to build institutions to confining persons with disabilities. This approach was drawing on models that view disability as a problem.[6]

The 1840 Census included significant inaccuracies in disability measurement because of biases among the enumerators, including racism and ableism. The enumerators were also inconsistent in their classification. A further substantial bias was introduced as some enumerators received bonuses based on the number of people they identified as having disabilities.[7]

In India, the 1881 Census included questions about disabilities and questions were included in a census every ten years until 1931. These censuses, too, were biased for many of the same reasons as the earlier US Census. In addition, a bias was introduced due to the prejudices of the colonial administrators overseeing data collection in India during this period.[8]

A human rights-based approach in the early 20th century

Generally, questions on disability in censuses fell out of favour among disability rights activists in the early 20th century. Increasing demands for more rigorous data collection practices also weakened the support for these questions among official statisticians.

Over the next few decades, several international human rights declarations built an international framework for a human rights based approach to disability – particularly the Universal Declaration of Human Rights (1948), the International Covenant on Civil and Political Rights (1976), and the International Covenant on Economic, Social and Cultural Rights (1976).

At the same time that these international human rights frameworks and standards were being developed, national statistics offices – many from newly independent countries – were conducting their first independent censuses and surveys.

In 1962, Paraguay included questions about disability in its census with a question about whether household members had a 'permanent disability' with a follow up question asking if they were 'blind', 'deaf', 'deaf-mute' or 'unknown'. [9]

In the 1970s, Libya, Togo, Syria, the Republic of Congo, Egypt and Iraq included questions about disabilities on household surveys or censuses.[10] These questions tended to follow the same framework – a brief list of medical conditions with a 'yes/no' option for each disability. In short, these questions generally used a medical model.

The International Classification of Functioning, Disability and Health

In 1980, the World Health Organization introduced the International Classification of Functioning, Disability and Health (ICF). The ICF was created to challenge the conceptualisation of disability as binary. It suggested that a framework needed to show that disability is not simply a case of a small fraction of the population that clearly has a disability while the rest of the population does not. The ICF combines both a medical and social approach to considering disability and focuses on a person's functional abilities. The ICF is a distinct but related concept to the WHO's International Classification of Diseases (ICD) which is the internationally recognised method for classifying diseases, injuries and causes of death.

The ICF is a complex disability classification system which can be used for medical diagnosis as well as for statistics, social work, rehabilitation services, electronic health records and other uses. The ICF model says that disability is linked to a health condition, but the extent to which it affects a person's functioning depends on external factors. Consequently, two people with the same medical diagnosis may have very different experiences in the workplace due to social, environmental and personal factors.[11]

The ICF includes a series of codes for body functions (such as the ability to see and distinguish colour), body structures (such as eyes), activity (such as seeing), environmental factors and personal factors. Each of these elements has a series of hierarchies and a code for the intensity of the difficulty associated with each element.

Adequately addressing all these dimensions of disability requires a substantial number of questions. It would therefore require specialised disability surveys, so it would be impractical to cover all dimensions on a population census or a household survey. However, many surveys on disabilities are influenced by the ICF.

The World Programme of Action Concerning Disabled Persons

In 1981, the 'International Year of Disabled Persons' laid the groundwork for the 'World Programme of Action Concerning Disabled Persons' (WPA) which was adopted by the UN General Assembly in 1982. The WPA further strengthened the human rights approach to disability by a commitment to the equalisation of opportunities and full participation of persons with disabilities in social life. The WPA called for more analysis of the situation of persons with disabilities.[12]

The Standard Rules

This was followed by the Standard Rules on the Equalization of Opportunities for Persons with Disabilities which was adopted by the UN General Assembly in 1993. The Standard Rules called for increased monitoring of obstacles to inclusion and the development of suggested measures to ensure progress.[13] These measures and the expansion of recommendations to increase the measurement of disabilities helped prepare the groundwork for further international agreements on disabilities embedded within the human rights framework.

The Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD), adopted by the UN in 2006, has a separate treaty known as the Optional Protocol. Ratified by 94 countries, it allows citizens of states that had signed the Optional Protocol to report a violation of disability rights, which a committee can then investigate.

The CRPD embraces the social and human rights models of disability, rather than the medical and charity models. Consequently, any statistical activity that wishes to fully respect the CRPD should embrace elements of the social and human rights models. Articles 4 and 31 of the CRPD call for States to carry out their responsibility to collect more statistics on disability, efforts to protect the rights of persons with disabilities in statistics, and more disaggregation of data by disability.[14]

The Sustainable Development Goals

In 2013, one of the first documents on the Sustainable Development Goals (SDGs), published by the High-Level Panel of Eminent Persons, included several references to the need for improved disability data. The report called for a "data revolution" and stated that: "Disaggregation of data by disability, age group and gender should be part of all targets" generated to monitor progress towards the SDGs.[15]

In 2016, countries agreed to the SDGs providing a commitment to disaggregation by disability. The guiding principle of 'Leave No One Behind' also supports the need to improve data disaggregation to assess inequality by gender, age, and disability and other factors.

The Washington Group

In 2001, the United Nations Statistics Division, Unicef, the Statistical Office of the European Communities, and the United States' Centers for Disease Control and Prevention gathered national statisticians and government officials from around the world to discuss the need for regular, internationally comparable measures of disabilities.[16] One result from this meeting was the creation of the Washington City Group on Disability Statistics.

The purpose and formation of a city group

When the United Nations Statistical Commission identifies a challenge to producing comparable statistics, a 'city group' can be established.[17] They are named in reference to the place where they hold their first meeting. While the country hosting the city group has an obligation to the success of the city group, the city groups are meant to serve the objectives of the United Nations Statistical Commission.

Such city groups generally create steering committees, working groups, communication channels and other features that may be necessary. City groups should serve the interests of the international community and should seek to ensure that their activities address issues of concern for all regions of the world.

In the case of the Washington Group, voting members are appointed representatives from national statistical offices, but adjunct members include representatives from international agencies, researchers and organisations of persons with disabilities (OPDs). The Washington Group currently has more than 135 members and reports that it sends semi-annual membership invitations to national statistical offices to further expand participation.

Current working groups for the Washington Group are on Child Functioning and Inclusive Education, Mental Health, Employment, Environment, Participation and Analysis of the Extended Set.[18] City groups are typically required to report on their activities to the United Nations Statistical Commission every year or two and provide recommendations[19] for consideration to the United Nations Statistical Commission.

City groups have focused on many different issues, such as the Ulaanbaatar City Group on Statistics for Economies Based on Natural Resources (which completed its work in 2018 with the publication of a handbook on best practices) and the Praia City Group on Governance Statistics (which was created in 2015 and is still operating).

The most recently formed City Group was the Titchfield City Group on Ageing and Age Disaggregated Statistics[20] which is managed by the United Kingdom's Office of National

Statistics. The Washington Group has provided guidance to the Titchfield City Group on several occasions.[21]

The Praia City Group, the Titchfield City Group and the Washington City Group have some participation from civil society – and importantly for the Washington Group, the role of OPDs has been critical. However, city groups are meant to primarily be led by national statistical offices. The Washington City Group is unusual among the city groups in terms of its duration and level of continued support.

Nevertheless, the Washington Group's guidance has not been universally adopted. Some of the barriers to adoption of the Washington Group Questions are described in greater depth below. However, typically they can be attributed to official statisticians being directed to favour legal definitions of disability over the Washington Group's approach, a lack of understanding of the work of the Washington Group, concerns about the limited focus of the Short Set of questions, and concerns about the validity of the Extended Set of questions.

The Washington Group approach

Early on, the Washington Group had significant contributions on the collection of data on persons with disabilities from a variety of countries as well as OPD participation in meetings. For instance, the Kenyan organisation, International Development Project, chaired the working group on Implementation from 2005 to 2006. The Uganda Bureau of Statistics (UBOS) participated in meetings from the beginning and hosted the annual meetings in 2006. As the questions were developed, there was extensive cognitive testing in 2005 by the national statistical offices of 15 countries.[22]

The Washington Group aims to provide a tool for disaggregation rather than a diagnostic tool or a legal framework. Disaggregating by disability requires the ability to adopt a definition of disability which is distinct from environmental factors. For instance, if a researcher wishes to compare poverty rates between persons with disabilities and the rest of the population, it will be critical to understand if a person would be identified as having a disability regardless of whether or not they fall below the poverty line.

Wealthier people are more likely to afford assistive devices that may increase their apparent ability to function in an environment and decrease the likelihood that they would be identified as having a disability. With the Washington Group approach, it should be possible to meaningfully identify what percentage of persons with disabilities live below the poverty line without worrying that definitions of who has a disability is linked to their wealth. The Washington Group Questions identify persons with activity limitations that put them at risk of exclusion if there are barriers in the environment. For instance, if a person responds that they have some difficulty hearing even when using hearing aids, further questions on a survey could measure the extent to which respondents are unemployed or are in poverty or other dimensions of poverty.

The Washington Group approach asserts that the purpose of disaggregating data is to compare outcomes between persons with disabilities and the rest of the population. A

tool that is appropriate for this purpose would have different features than a tool that seeks to understand the broad contexts or detailed elements of the experience of disability.

A blog from the Washington Group illustrates this point in a discussion of a survey from the European Union. The Global Activity Limitation Indicator (GALI), asks: "For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do?"

This question calls for a subjective judgement from respondents. Respondents must determine what people usually do and if their activities are different because of health problems or other factors. The response to this question is also closely linked with the environment. If an environment has been adapted to increase accessibility, the results would look very different from an environment where many people are excluded. It does not help you understand the effects of barriers for persons with disabilities because you cannot be certain how many people are able to participate in an activity and how many are not.[23]

The Washington Group Questions

The Washington Group has developed several sets of questions. The most widely used is known as the Short Set, which were developed after significant testing and feedback from national statisticians. The Short Set is a short module that can be added to household surveys to allow results to be disaggregated by disability, and are meant to provide a quick and low-cost method for disaggregating by disability.

The Short Set Enhanced provides some additional questions, including questions on depression and anxiety. An additional module is the Child Functioning Set which is meant to better measure disabilities among younger respondents. Another set of questions is the Extended Set which aims to address some of the key gaps left by the Short Set, particularly by including some questions around mental health.

The Short Set

The Washington Group's Short Set has six questions. It was designed to capture a broad range of activity limitations across a wide range of contexts that can be uniformly understood and compared. The questions are as follows:

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?

For each question respondents can choose:

a) No – no difficulty
b) Yes – some difficulty
c) Yes – a lot of difficulty
d) Cannot do at all

The use of a four-point scale on difficulty of doing activities allows for the conceptualisation of disability as on a continuum. However, to try to assess the prevalence of disability or to make comparisons with the rest of the population, analysts must decide at what point someone can be considered to have a disability. The general practice with the Washington Group Questions has been to classify people who report that they have great difficulty or cannot do one of the six domains at all as having a disability. In most countries where the Washington Group Questions have been asked, 6–12% of the population have been classified as having a disability using this cut off.[24]

Limitations of the Short Set

The questions very deliberately do not use the terms 'disability' or 'suffering'. These terms have significant stigma in some countries which might discourage people from disclosing their impairments. The Short Set of questions can be asked by an enumerator without the need for significant training, although there are some problems that countries have encountered when administering the survey. In some cases, survey enumerators have moved from one part of the survey to the Washington Group Questions by saying, "Now I will ask you some questions about disability".

In other cases, the forms being filled by enumerators have had the word 'disability' printed on them. Survey respondents may be biased by the term 'disability' and may answer questions differently when they hear the term 'disability' than when they are asked indirectly about disability. The Washington Group asserts that avoiding the term provides a more accurate form of identifying persons with disabilities.

Other potential problems arise around translations, interviewers making assumptions and not asking the questions as written, respondents detecting discomfort from inadequately trained interviewers, and other factors. The Washington Group is actively working to address and minimise the impact of these factors. However, they are not yet fully addressed.

Two particular limitations of the Washington Group Short Set are that they often miss persons with psychosocial disabilities, and that they are not appropriate for children.[25] The Short Set should not be used on children under five, and for those over age five the questions will under-identify children with developmental and intellectual disabilities. The Child Functioning questions have been developed by Unicef and the Washington Group to address this issue.

Modifications to the Washington Group Questions should be limited, as they can reduce the international comparability of the questions. For instance, the Washington Group

Extended Set (discussed in further detail below) has a set of questions about depression separate from a set of questions about anxiety. Survey designers may be tempted to combine these two questions to save time but that can create confusion among respondents who have a very different response to one part of the question (such as depression) as opposed to another part of the question (such as anxiety).

Another common modification is to add a question to the Washington Group Short Set, such as on albinism or autism. Such questions can serve a valuable purpose. However, if a question from the Short Set were to be dropped in favour of a different question, the questions will no longer be comparable to international data, may not be as useful for disaggregation, or may be incomparable across time.

A good practice would be to ask the Washington Group Questions followed by any additional questions that may be particularly relevant. By placing additional questions at the end of the Washington Group Questions, the survey will be less likely to influence responses to the Washington Group Questions.

The Extended Set

The Washington Group Extended Set is meant to provide richer data on disability, primarily by increasing the domains of disability considered but it also includes questions on devices (such as glasses or wheelchairs), the age at onset and environmental factors. The Extended Set has not been as widely endorsed as the Short Set.

The Extended Set includes the following functional domains:

- vision
- hearing
- mobility
- cognition
- affect (anxiety and depression)
- pain
- fatigue
- communication
- upper body functioning.

The Child Functioning Module

Unicef has developed a Child Functioning Module in collaboration with the Washington Group to better address shortcomings in identifying disability among children. This is appropriate for children aged two to seventeen with some questions developed for children ages two to four and a separate set of questions for children ages five to seventeen.[26] As with the Short Set, it draws on the concepts found in the International Classification of Functioning, Disability and Health (ICF). Questions focus on hearing, vision, communication/ comprehension, mobility and emotions. The module has been

added to the latest round of Unicef's Multiple Indicators Cluster Survey (MICS),[27] significantly increasing the likelihood that the Washington Group Questions will be used.

Use of the Washington Group Questions

The Short Set questionnaire has been used in at least 80 countries. It has been frequently used in household surveys, in some censuses, in administrative data systems and in crisis settings. In addition to use by governments, there have been some use cases by civil society groups. More than 100 countries have participated in Washington Group meetings, and many organisations have championed their use, including Leonard Cheshire, Sightsavers and CBM.

In addition, groups such as the Stakeholder Group of Persons with Disabilities, International Disability Alliance, and International Disability and Development Consortium have worked closely with Washington Group, especially advocating for the use of the Short Set of questions in the global Sustainable Development Goal (SDG) indicator framework. Furthermore, nearly all United Nations agencies are using the Washington Group Questions.

The United States, Australia, Uganda and South Africa were among the countries to adopt the questions early on. Since 2017, Unicef's Multiple Indicators Cluster Survey (MICS) has incorporated a Child Functioning Module as part of the standard surveys administered and as a result, the Washington Group approach will likely be adopted more widely.

The World Bank's Living Standards Measurement Survey (LSMS) survey has included the Washington Group Short Set questions as a module in some countries for several years. The LSMS presents an interesting use case because it frequently uses a panel data set where the survey is administered to the same household more than once over the course of several years. This allows for the analysis of time trends and the possibility to examine trends in cases where a person has different responses to the Washington Group Questions over time – allowing for an examination of indicators before and after someone indicates a change in disability status.

Umbrella groups of OPDs, such as the International Disability Alliance and the International Disability and Development Consortium, along with several UN Agencies and the UK's Foreign, Commonwealth & Development Office (FCDO) and Australia's Department of Foreign Affairs and Trade (DFAT), have issued joint statements formally endorsing the Washington Group Short Set and the Unicef/Washington Group Child Functioning modules as key contributors to the monitoring of SDGs.[28]

Another new area for adaptation of the Washington Group Questions is Labour Force Surveys. The Washington Group first announced work with the International Labour Organization (ILO) in 2016, to develop and promote a module on employment and disability. This module was published in July 2020. [29] Labour Force Surveys are meant to be conducted annually in most countries and monthly in many other countries, increasing the potential use of the Washington Group Questions.

As of 2018, the Washington Group reported that 24 countries and territories had reported employment status disaggregated by disability in their SDG reporting.[30] Ten of these – Afghanistan, Canada, Israel, Mexico, New Zealand, Palestine, Trinidad and Tobago, Turkey, the United States and Yemen – had used the Washington Group Questions.

Reasons countries do not use Washington Group Questions

There are many reasons why some countries do not use Washington Group modules. In many cases, countries may not be familiar with the approach or may not see demand for the questions. The Washington Group Short Set questions may not cover a specific type of disability in a way that is politically salient in a certain context. For instance, in some countries it is not appropriate for a male interviewer to ask a woman if she has difficulty with washing or dressing. In such contexts, the self-care questions have generally been dropped from the Short Set.

Additionally, countries may prefer to ask questions in a manner that is similar to the way that disabilities are legally defined in their particular context.[31] For instance, the UK's Office of National Statistics recommends the following questions in surveys and administrative data, linked to certain UK legal definitions of disability.[32]

- Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more? (Yes / No)
- Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry out day-to-day activities? (Yes, a lot; Yes, a little).

These questions may not be as internationally comparable because of cultural factors that may create different interpretations about what constitutes a health condition or illness – particularly for mental illnesses.

Another example of different approaches is the Benin Republic's 2013 Housing and Population Census which asks if people have one of twelve disabilities falling under the categories of motor, visual, audio/verbal, intellectual and mental disabilities.[33] These questions are modelled after legislation that defines eligibility for protections and services from the government.

Of course, many countries currently using the Washington Group Questions have legal definitions of disability and still ask the questions, suggesting that legal barriers are not the sole determinant of how disability questions are asked. In any case, questions should always avoid stigmatising language and should be developed in consultation with OPDs at all stages.

Use in the Model Disability Survey

The Washington Group Questions have also been used as part of other surveys. The World Health Organization and World Bank have created a Model Disability Survey (MDS). The survey is meant to provide a comprehensive view of "all aspects of functioning" in a society. It was developed following a mapping of over 170 surveys to the

ICF framework.[34] The full survey is extensive and would require significant costs to field. The Washington Group Short Set is included within the survey. A shorter version of the survey includes 40 questions. This survey is a good option for countries seeking a comprehensive disability survey.

Much like the questions used in the World Health Survey, the Model Disability Survey can be a powerful tool for countries seeking a more in-depth approach to disability statistics. Many countries do not regularly conduct such studies. By contrast, the Washington Group Questions can feasibly be added to ongoing data collection activities in many countries – albeit with a far more limited view of disabilities than would be possible with a long survey.

Testing has shown that the MDS takes an average of 120–150 minutes, the Washington Group Short Set takes an average of 1.5 minutes to administer and the Washington Group Extended Set takes an average of 10–12 minutes.[35] The marginal costs of adding the Washington Group modules are negligible for most national household surveys.

Use in the World Report on Disability

The World Report on Disability which was published by the World Health Organization and World Bank in 2011 used the Model Disability Survey. This survey drew on the World Health Survey which was administered between 2002 and 2004. In 59 countries, questions on disability were included, drawing on the conceptual framework of the ICF.

These questions covered the domains of affect, cognition, interpersonal relationships, mobility, pain, sleep and energy, self-care and vision. Hearing was included but dropped from the analysis. People were asked to identify levels of difficulty along five points – no difficulty, mild difficulty, moderate difficulty, severe difficulty and extreme difficulty. A score ranging from 0 (no disability) to 100 (severe disability) was calculated.

After extrapolating the results from the surveyed countries to the global level, the report estimated that 15.6% of the global population would be classified as having a disability with a threshold set at 40 points on the 100-point scale.[36] The approach used by the World Report on Disability is considerably more complicated than the Washington Group Questions. It also sets a lower threshold for what is considered 'a disability' than is typically done using the Washington Group Questions.

Use in humanitarian contexts

Another interesting use of the Washington Group Questions is being led by the organisation Humanity & Inclusion (formerly known as Handicap International). This project is piloting the use of the Washington Group Questions in humanitarian contexts. In Jordan, the Democratic Republic of the Congo and the Philippines, intake forms for participants in humanitarian programmes include the Washington Group Questions.

The UN High Commissioner for Refugees (UNHCR) found a disability prevalence of 2.4% in Jordan using its standard form, while the Washington Group Short Set found a

prevalence of 27.6%.[37] This difference suggests that the Washington Group Questions can identify a certain fraction of persons with disabilities that otherwise may have been categorised differently.

Limitations, concerns and benefits

The Washington Group Questions have been developed primarily with a focus on disaggregating household surveys and censuses, not as a tool for project-based work or administrative data. There is value in using the tool for disaggregating populations for which data are collected for programmatic work or administrative data. However, the data should not be expected to be representative of the general population and will be more dependent on reporting from people who are not data collection specialists.

When OPDs or NGOs collect Washington Group Questions as part of their data collection activities, they may have concerns that their data will indicate that some of their members do not have a disability despite the organisation clearly affirming that they do have a disability. It is important to recognise that the thresholds that the Washington Group typically uses are not diagnostic – they should not replace official legal or organisational definitions. Rather, the Washington Group Questions are useful for disaggregating and providing some international comparison.

It is also worth mentioning that the Washington Group Questions may serve different purposes depending on the populations to which they are asked. For instance, if a national statistical system administers the module as part of a population census, it will produce different numbers than if a civil society organisation uses their questions among their clients.

Some OPDs or other actors have expressed concern with the Washington Group Questions because they worry that it will not correctly identify the prevalence of disabilities. However, this concern may obscure the primary benefit of the Washington Groups questions – its ability to make comparisons of other variables measured between a significant subset of those with disabilities and the rest of a certain populations being used for comparisons. In other words, the primary purpose of the Washington Group Questions is to disaggregate other data by disability. Such comparisons may not need the level of precision that is needed for highly accurate prevalence estimates.

The level of disaggregation and comparability across contexts enabled by the Washington Group Questions have allowed for more detailed analysis by think tanks and research groups of persons with disabilities against other metrics – for example, the share of the population with a disability who are in the poorest 20% of a population.[38] OPDs also collect data on the populations they serve. While their data collection efforts will have different objectives and occur in a different context than data collected through national surveys and population census, the Washington Group guidance can help inform stakeholders as they explore opportunities to improve and harmonise their data.

Table 1: Use of Washington Group Questions in countries involved in Inclusion Works

Country	Use of Washington Group Questions
Bangladesh	The 2019 Multiple Indicator Clusters Survey (MICS) for Bangladesh asked the Washington Group Short Set questions to women ages 18–49 and reported that 3.1% of this population has a disability. They note that 0.5% of women in that age group were not asked any survey questions because they were 'incapacitated'. While this would presumably indicate that these respondents have a disability, MICS data collection procedures differ from Washington Group recommendations and does not include questions to a proxy about this group of women. It is also worth noting that the age cut-off could exclude older populations which may be much more likely to have disabilities.

Kenya	The 2019 Population and Housing Census included the Washington Group Short Set followed by the question, "Does [NAME] have albinism?". For people over age five, this question was followed by:
	
	• "Because of the disability does [NAME] have difficulties engaging in any economic activities?"
	
	    o "Yes"
	    o "No"
	    o "Don't know"
	    o "N/A"
	
	There are some concerns about the accuracy of the results as the Census reported that 2.2% of the population had a disability. This low number may be due to several different factors including stigma, translations, the question about albinism and other factors.[39]

Nigeria	Nigeria has used the Washington Group Short Set on a panel survey funded through the World Bank's Living Standards Measurement Survey (LSMS) programme.
Uganda	Uganda has used the Washington Group Short Set in the 2016 Demographic and Health Survey. It also used a modified version of the questions in the 2014 Population Census.

Source: Development Initiatives review of Bangladesh Multiple Indicators Clusters Survey 2019, Kenya 2019 Population and Housing Census, Nigeria Living Standards Measurement Survey 2015-16, Uganda Demographic and Health Survey 2016, Uganda 2018 Population Census.

Conclusion

The Washington Group Questions are currently the most tested, widely used comparable tool for disaggregating indicators by disability. This comes with the support of many national statistical offices and the United Nations Statistical Commission and there is considerable potential for further adoption by civil society, in population censuses and in administrative data systems.

Despite this, there is still significant room for guidance to help national statistical systems, organisations of persons with disabilities (OPDs), civil society organisations and international organisations further advance the generation of disability statistics. Specific support that can be given ranges from the informing of OPDs, CSOs and national statistical offices about the merits of the Washington Group Questions, to detailed research on how the Washington Group extended questions compare to the Model Disability Survey when surveys are carried out.

Furthermore, it may be worthwhile to collect further information to the challenges to the use of the Washington Group Questions by relevant stakeholders for learning and development purposes. The measurement of these issues is complex. However, making disability statistics a part of statistical systems provides opportunities to highlight the barriers persons with disabilities experience in society.

Notes

[1] The Washington Group on Disability Statistics published a primer on their questions sets in 2020. Available at: https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Primer.pdf. This paper seeks to build on that work and to provide additional context.

[2] The Washington Group on Disability Statistics, 2020. Using the Washington Group Short Set in a telephone survey. Available at: https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Using_the_Washington_Group_Short_Set_in_a_Telephone_Survey.pdf

[3] See for instance: Save the Children, 2020. The hidden impact of Covid-19 on children. Available at: https://resourcecentre.savethechildren.net/library/hidden-impact-covid-19-children-global-research-series

[4] United Nations, Convention on the rights of persons with disabilities, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (accessed 25 September 2020)

[5] Dana Dunn and Shane Burcaw, 2013. Thinking about disability identity. American Psychological Association Spotlight on Disability Newsletter. Available at: https://www.apa.org/pi/disability/resources/publications/newsletter/2013/11/disability-identity

[6] Sarah F. Rose, No Right to Be Idle: The invention of disability, 1840s–1930s, University of North Carolina Press, 2017. Available at: https://uncpress.org/book/9781469624891/no-right-to-be-idle/

[7] David L. Braddock and Susan L Parish, 'An institutional history of disability', in Handbook of disability studies, Thousand Oaks, Sage Publications, 2015, p.35.

[8] VM Tamhane, Office of the Registrar General and Census Commissioner, India, 2013. Disability, https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwj3rY2l5IPsAhUFlnIEHQB1D0oQFjACegQIBBAB&url=https%3A%2F%2Fwww.censusindia.gov.in%2FDigitalLibrary%2Fdata%2FCensus_2011%2FPresentation%2FIndia%2FDisability.pptx&usg=AOvVaw1bXt-bjByxEqcNC83p1vpi

[9] Paraguay 1962 Census in International Public Use Microdata Series (IPUMS), https://international.ipums.org/international-action/variables/PY1962A_0439#codes_section (accessed 25 September 2020)

[10] Human functioning and disability, Recensement general de la population du Congo, 1974, in UN Statistics Division, https://unstats.un.org/unsd/demographic/sconcerns/disability/disform.asp?studyid=163 (accessed 25 September 2020)

[11] World Health Organization, 2002. Towards a common language for functioning, disability and health: ICF. Available at: https://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1

[12] United Nations Department of Economic and Social Affairs, World programme of action concerning disabled persons https://www.un.org/development/desa/disabilities/resources/world-programme-of-action-concerning-disabled-persons.html (accessed 25 September 2020)

[13] United Nations Department of Economic and Social Affairs, Standard rules on the equalization of opportunities for persons with disabilities, https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html (accessed 25 September 2020)

[14] United Nations Department of Economic and Social Affairs, Convention on the Rights of Persons with Disabilities (CRPS) Article 31 – Statistics and data collection, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html (accessed 25 September 2020)

[15] United Nations High-Level Panel of Eminent Persons on a Post-2015 Development Agenda, 2013. A new global partnership: Eradicate poverty and transform economies through sustainable development. Available at: https://www.un.org/sg/sites/www.un.org.sg/files/files/HLP_P2015_Report.pdf

[16] United Nations Statistical Division, International Seminar on measurement of disability, 2001. https://unstats.un.org/unsd/disability/Seminar%202001.html (accessed 25 September 2020)

[17] Another possibility is that the Chair of the UN Statistical Commission can create a 'Friends of the Chair' committee, to carry out similar activities. A recent example of this is the Friends of the Chair's committee on Open Data for which civil society and governmental actors convene and provide recommendations.

[18] The Washington Group on Disability Statistics, 2020. http://www.washingtongroup-disability.com/about/the-secretariat/ (accessed 18 March 2020)

[19] United Nations Statistical Division, Washington Group on disability statistics, https://unstats.un.org/unsd/methodology/citygroups/washington.cshtml (accessed 25 September 2020)

[20] Titchfield is officially classified as a village – not a city. However, the name, "Titchfield City Group" has been adopted to show consistency with the naming conventions for other UN City Groups.

[21] General Statistical Services, Titchfield City Group on ageing statistics, https://gss.civilservice.gov.uk/user-facing-pages/ageing-statistics/ (accessed 25 September 2020)

[22] Argentina, Brazil, the Democratic Republic of the Congo, Egypt, the Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, the Philippines, Uganda and Vietnam. See http://www.washingtongroup-disability.com/meetings/past-meetings/sixth-meeting/

[23] Mont D. Why global health and functioning indicators like GALI are not suitable for disaggregation, Washington Group on disability statistics blog, 10 March 2018. https://www.washingtongroup-disability.com/wg-blog/why-global-health-and-functioning-indicators-like-the-gali-are-not-suitable-for-disaggregation-98/

[24] Mont D., Differences in reported disability prevalence rates: Is something wrong if I didn't get 15? Washington Group on disability statistics blog, 25 February 2020, http://www.washingtongroup-disability.com/differences-reported-disability-prevalence-rates-something-wrong-i-dont-get-15-2

[25] The Washington Group on Disability Statistics, 28 May 2020. An Introduction to the Washington Group on Disability Statistics Question Sets. Available at: https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Primer.pdf

[26] The Washington Group on Disability Statistics, 28 May 2020, An Introduction to the Washington Group on Disability Statistics Question Sets. Available at: https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Primer.pdf

[27] There are currently 70 surveys at some stage of development in this round of surveys, covering more than 60 unique countries according to Development Initiative's count of surveys listed at: http://mics.unicef.org/surveys (accessed 2 March 2020)

[28] Disability data disaggregation joint statement by the disability sector, 2016. Available at: http://www.internationaldisabilityalliance.org/sites/default/files/joint_statement_on_disaggregation_of_data_by_disability_final.docx

[29] International Labour Organization, Labour Force Survey (LFS) Resources, https://ilostat.ilo.org/resources/lfs-resources/ (accessed 25 September 2020)

[30] Washington Group, 30 October 2018. 2030 Agenda for Sustainable Development Goals: Selected SDG indicators disaggregated by disability. Available at: http://www.washingtongroup-disability.com/wp-content/uploads/2018/11/Disagregation-Data-Report_F4.pdf

[31] Many countries have legal definitions of disabilities which are often tied to social protection programmes or access to other sorts of government resources.

[32] Government Statistical Service, 2019. Measuring Disability for the Equality Act 2010 Harmonisation Guidance, https://gss.civilservice.gov.uk/policy-store/measuring-disability-for-the-equality-act-2010/#further-links (accessed 25 September 2020)

[33] Institut National de la Statistique et de l'Analyse Economique (INSAE) Benin, 2011. Recensement General de la Population de l'Habitat, https://insae-bj.org/images/docs/insae-statistiques/enquetes-recensements/RGPH/1.RGPH_4/Questionnaire-RGPH-Edition-2013/QUESTIONNAIRE%20RGPH4%20Final%20Mardi%2026%20MARS%202013.xls

[34] WHO, no date. Model Disability Survey: Providing Evidence for Accountability and Decision-Making. Available at: https://www.who.int/disabilities/data/mds_v4.pdf?ua=1 (accessed 18 March 2020)

[35] Nora Groce, no date. Which one to use?: The Washington Group Questions or The Model Disability Survey. Available at: https://www.ucl.ac.uk/epidemiology-health-care/which-one-use-washington-group-questions-or-model-disability-survey-0 (accessed 18 March 2020)

[36] WHO and World Bank, 2011. World report on disability. Available at: https://www.who.int/disabilities/world_report/2011/report.pdf

[37] International Federation of the Red Cross, 2018. World disaster report 2018, p.99. Available at: https://media.ifrc.org/ifrc/wp-content/uploads/sites/5/2018/10/C-04-WDR-2018-4-loop.pdf

[38] Zach Christensen, 2017. Data to leave no one behind and the Washington Group, Washington Group on disability blog. Available at: http://www.washingtongroup-disability.com/data-leave-no-one-behind-washington-group/ (accessed 3 March 2020)

[39] Development Initiatives, 2020. The status of disability in Kenya: Statistics from the 2019 census. Available at: https://devinit.org/resources/status-disability-kenya-statistics-2019-census/

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