

Measuring Disability and Inclusion in relation to the 2030 Agenda on Sustainable Development

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This paper explores the development of disability measures for use in censuses and surveys that can serve to monitor the UN Convention on the Rights of Persons with Disability (UNCRPD) and to disaggregate indicators identified through the 2030 Agenda on Sustainable Development and implementing the Sustainable Development Goals (SDGs). The need for data to implement policies and the challenges to the collection of valid and reliable disability data are presented, and the work of the Washington Group on Disability Statistics (WG) is provided as a means to the collection of internationally comparable disability data. By standardizing data collection instruments used to identify the population with disabilities it will be possible to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources. The resulting data can be used to assess a country's compliance with the UN Convention and the 2030 Agenda for Sustainable Development and, over time, monitor their improvement in meeting the established requirements.

Keywords: UNCRPD, SDG, Washington Group, Disability, Disaggregation

Introduction: The UNRPD and the 2030 Agenda for Sustainable Development

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) establishes a policy framework for protecting the rights of persons with disability and ensuring their participation in all aspects of society on an equal basis with others. As stated in Article 1 of the Convention, 'the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'. Furthermore the UNCRPD clearly states the role and importance of data collection, analysis and dissemination, including statistics and research data in supporting that purpose.

The establishment of a human rights framework and principles for measurement and monitoring, however, omits the practical aspects of actualizing the de facto measurement of

disability in populations and the monitoring of compliance with the articles outlined in the UNCRPD. In September 2015, after several years of intergovernmental negotiations, United Nations Member States adopted the 2030 Agenda for Sustainable Development. The 2030 Agenda is comprehensive and has 17 goals for sustainable development, 169 targets and over 230 measurable indicators, and a number of these indicators relate specifically to disability. There are also 11 explicit references to persons with disabilities in the 2030 Agenda, and disaggregation of outcome data by disability status is a core principle. Guidelines are presented by which countries can measure disability in their populations and, with routine collection of important outcome indicators like education and employment, finally disaggregate these outcomes (sustainable development indicators) by disability status.

The 2030 Agenda and the Sustainable Development Goals (SDGs) will influence the direction of global and national policies relating to sustainable development for the next 15 years. If the 2030 Agenda is going to be successful all of the UN Member States - 193 countries - must include persons with disabilities in their national plans for implementation and monitoring.

The overriding principle of the SDGs is the global eradication of disadvantage through the improvement of situations for all people. To ensure that “no one is left behind”, the chapeau of the SDGs notes the importance of disaggregating data by characteristics associated with exclusion and vulnerability, including disability. Ample research (see for example Braithwaite and Mont, 2008; Loeb et al., 2008; WHO and World Bank, 2011; Trani and Loeb, 2012) has shown how people with disabilities disproportionately live in poverty and are excluded from social and economic activities. Without disaggregation by disability status, it is not possible to monitor the progress and outcomes of the implementation of the 2030 agenda activities in a way that documents if people with disabilities are indeed being left behind or not.

This paper addresses the different types of information that can be collected to support the implementation of the SDGs and thereby the monitoring of the UNCRPD.

Challenges in disability data collection

According to the UNCRPD, persons with disability are defined 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’ (UN, 2006). The definition, which reflects the evolution of the concept of disability, is broad, complex and comprehensive involving information about the person (their capacity), the environment in which that person lives, and the outcome of the interaction of these two factors (which are themselves complex) on participation in society. As disability is not a singular static state, there is no simple, singular way to collect disability data. There is also no gold standard by which to validate the data. To assure that appropriate and useful data are

collected, it is necessary to identify the purposes for which the data are needed, and then to identify the appropriate data collection approach. When reporting or using disability data, it is always necessary to be explicit about the objectives underlying the collection, which aspects of disability are being addressed, and how they relate to the overall conceptualization of disability. It is also necessary to be explicit about the data collection method being used, and how indicators are operationalized. This underscores the need to use standard data collection tools that have undergone thorough cognitive and field testing, and for which information on measurement properties is available.

The majority of disability data used to implement the SDGs and monitor the UNCRPD will be used by individual countries, suggesting that data collection should address the specific circumstances in that country. The prominent role of environmental factors (including the physical, social, cultural, political and civic environments) in the disablement process also suggests that data collection tools should be country specific rather than universal, as the environment varies greatly across geographical regions and even within national boundaries. However, the monitoring of major international initiatives usually includes components that apply to all countries. To achieve this objective, it is necessary to produce disability data that are internationally comparable. This has been a major challenge. The fact that disability is a complex and comprehensive concept has led to diverse data collection strategies that produce very different prevalence estimates, all of which have been labelled ‘disability’. This has led to confusion and a lack of trust in disability statistics. Much has been accomplished to rectify this situation so that information will be available to meet the SDGs and monitor the UNCRPD both within and across countries. The question remains as to which aspects of disability (individual functioning/capacity, performance/participation and environmental barriers and facilitators) can be measured in an internationally comparable way. Neither participation nor the environment (upon which participation is dependent) is uniform across countries, and it will, therefore, be difficult to develop standardised measures that are internationally comparable. Capacity (as measured through difficulty in functioning) is the aspect of the disablement process that, at its basic level, is most universally used and the main criterion for international comparability in measurement. Comparing patterns of associations between variables, for example, cause (difficulty function) and effect (participation) will also be important, but will not require the same rigour concerning universality at the level of single item measures. The data needed for the implementation of the SDGs and monitoring of the UNCRPD, must encompass both the universal and the place-specific aspects of disability.

Data to formulate and implement policies

Two major types of data are needed to formulate and implement policy: a status indicator (disability identifier); and an outcome indicator (a measure of participation e.g. employment status, education achievement etc.). With respect to the former, it is necessary to understand

the size and characteristics of the population of interest, i.e., those to whom policy is being directed. Disability, like many personal characteristics, exists as a continuum; it is not inherently a dichotomous yes/no phenomenon. However, the UNCRPD specifically addresses the rights of persons with disabilities (an identified subgroup of the population), and SDG indicators will be disaggregated by disability status. It is necessary, therefore, to create a disability indicator to identify those with and those without disability, and to obtain data on these groups for the purposes of monitoring the UNCRPD and implementing the SDGs. This is done by collecting data that describe the disability continuum from none to very severe, and then by identifying a point along the continuum that distinguishes between those with and without disabilities according to established criteria. In order to determine if those with a disability have achieved equalized opportunities (in selected outcomes like education or employment), it is necessary to compare that subgroup of the population with disabilities with that without disabilities (again, according to established criteria). The complexity of the disability paradigm allows for the identification of multiple subpopulations, each describing different levels of disability. For example, a more inclusive disability subpopulation could be identified by establishing inclusion criteria to include those individuals with milder as well as more severe impairments, which is a very heterogeneous group. Alternatively, a more restrictive disability subpopulation could be identified by establishing criteria that include only those with more severe limitations (a more homogeneous group of people with respect to functioning). One challenge is to ensure that inclusion criteria are consistent with the intent and requirements of the SDGs – and that can be replicated in data collections internationally.

It is important to remember that there is no single prevalence of disability in a population; prevalence is a function of the inclusion criteria selected, and different criteria are appropriate for different objectives. The choice of inclusion criteria (the selection of a cut point on the continuum) determines not only the percentage of the population with disabilities (prevalence) but also, consequently, the characteristics of that group. A cut point that identifies a subpopulation with more severe limitations might be used to estimate the population requiring more intensive and focused services while a cut point that includes a subpopulation with milder limitations might estimate those who would benefit from universal design. Both prevalence estimates would be valid and be useful for the associated intended purpose.

How the population with disabilities is defined will also impact the degree to which the defined subpopulation is fully participating in society. The population with more severe limitations in core functional domains (for example those whose inclusion is defined through the inability to do any one of a set of specific activities) will be a more homogeneous one and will be very different from the population without disabilities. The two groups will also likely differ considerably in their levels of participation. Expanding the population with disabilities to include those with more moderate or milder limitations will broaden the base, making this population more heterogeneous. The larger and more inclusive the subpopulation identified, the more similar it will be to the general population. There will, therefore, be considerable

variation among the members of this group in their functioning, and, consequently as a group, they will be more similar to the group without disabilities and thus will differ less in their levels of participation.

Once a disability identifier is selected, it will be possible to determine the characteristics of the population (those with and without disability) according to the selected SDG indicators. In order to meet SDG targets, countries will need to develop policies and programs that address the unmet needs of persons with disabilities, and evaluate whether, over time, these programs have been successful. The UNCRPD provides the framework for these policies and programs; but on a national basis, a set of programs will likely be needed, ranging from laws and regulations to actual changes in the physical, cultural and policy environments. Detailed information will be needed to develop strategies to meet these challenges, including first identifying the existing barriers to full inclusion, and then evaluating the success of the changes. The data required for the purpose of monitoring the success of individual programs, would present a significant data collection burden for countries, but it is usually not necessary for this information to be representative of the total population. More focused data collection in targeted areas is sometimes most useful. In addition, much of the information relates to the specific circumstances in a country. Internationally comparable data are generally not needed for this purpose, although similar information from countries with similar characteristics can be very useful.

Data to assess implementation

Assessing implementation can be accomplished in several ways. The policies, programs and changes instituted in order to meet the requirements of the UNCRPD and so that the SDGs can be directly monitored. For example, under Article 4, States Parties have an obligation to promote measures or modify or abolish laws, regulations, customs and practices that constitute discrimination against persons with disabilities. Information can be collected and reported on the creation of new measures or the modification or abolishment of existing discriminatory practices. Measures of this type are sometimes called process indicators. It is assumed that if these measures are enacted, they will have the intended effect of attaining the objectives of the UNCRPD and the SDGs. The validity of this assumption depends on how the process indicators are defined, and the nature of the relationship, whether direct, indirect or conditional, between the process indicator and outcome (full participation). Direct relationships provide the strongest evidence that the outcome has been affected. Conditional relationships are those where the process indicator's effect is dependent on another factor. For example, an increase in the use of wheelchairs, will have the largest effect on participation if accompanied by ramps, curb cuts, elevators or other appropriate environmental modifications.

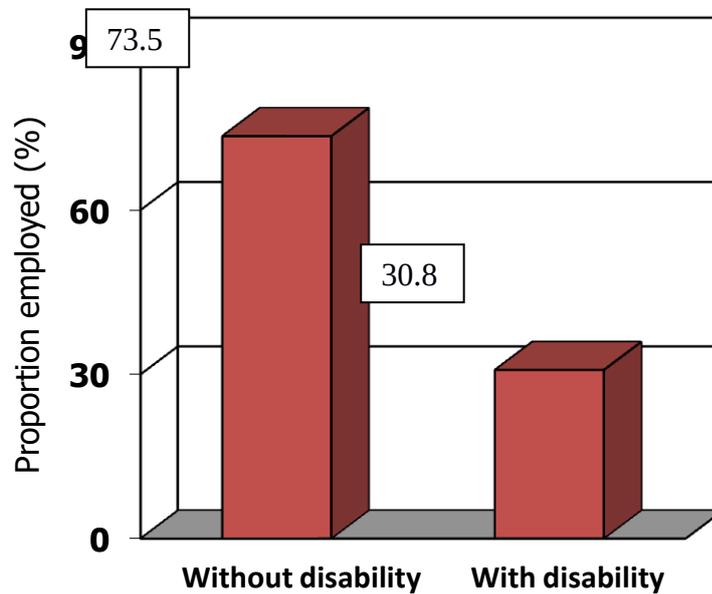
While process indicators are useful, it is preferable to directly measure a targeted outcome,

that is the extent to which participation in society is unimpeded by physical, mental, intellectual or sensory impairments due to the elimination of barriers. However, direct measurement of participation is extremely difficult. Attempts at using survey questions to determine if a person is limited in participation in their environment due to an impairment have not been successful due to the challenges of incorporating these multiple concepts into a single survey question. An example of such a question is: “Are you limited in any way because of an impairment or health problem?” The absence of a consistent standard that respondents can reference in making the determinations required by this question produces non-comparable data that does not adequately capture the concept of interest. While research exists on the measurement of participation and environmental barriers to successful participation in society (see for instance Gray et al. 2008), these measures are less applicable to the generation of internationally comparable data due to national and cultural variability of these constructs. A powerful alternative tool to assess participation in society is the disaggregation of outcome indicators (e.g. poverty status or employment) by disability status which is explicitly specified in Article 31 of the UNCRPD and in the SDGs Agenda. Disaggregation compares the levels of participation of those with and without disability. According to the UNCRPD and the SDG requirement to leave no one behind, these participation levels should be equal; those with disabilities should be participating equally in society compared to those without disabilities. If the levels are not equal, appropriate accommodations have not been made. Monitoring the difference in levels of participation over time provides evidence of progress, or lack thereof, in achieving the goals of both the Convention and the SDGs. This approach is also referred to as ‘equalization of opportunity’. In this case, environmental accommodations are not measured directly, and this greatly reduces the data collection burden. Additional data collection would be necessary to understand why progress has or has not been made or what needs to be done in terms of implementing necessary environmental and other accommodations in order to meet the requirements of the Convention and the SDGs. While disaggregation and comparison of outcome indicators should be based on (nationally) representative samples, this is not necessarily a requirement when analysing mechanisms explaining differences or progress/lack of progress in meeting international requirements.

In order to disaggregate outcome indicators by disability status, it is necessary to identify persons who, because of limitations in core functional domains, are at greater risk than those without functional limitations of experiencing limited participation in society. The creation of a disability status indicator which identifies those at greater risk, is subject to the same challenges discussed above in terms of the calculation of a disability prevalence. Risk of limited participation is a function of difficulties experienced in core functional domains without any accommodation or environmental effects. While it is impossible to completely eliminate the effects of the environment, the intent is to define disability in terms of abilities in universal functional domains that would apply internationally and are not culturally defined or delimited. This can be accomplished with the use of a short set of questions that focus on

difficulties in carrying out basic, universal domains of functioning as will be described below. When this derived disability indicator is coupled with other outcome information collected as part of the same data collection instrument such as employment, education, or family and social life, it is possible to disaggregate these outcomes by disability status to determine whether full participation has been achieved. The percentage of those employed, having achieved a specified level of education, or those involved in community life is calculated separately for those with and without disabilities (as measured by difficulty in the core functional domains) and the percentages are then compared. An example of disaggregation on an employment indicator (percent employed) is provided in Figure 1 below. Based on data from the National Health Interview Survey in the US, 73.5% of those aged 18-64 without disabilities (according to the definition used in this analysis) were employed compared to 30.8% of those with disabilities. Employment rates are higher among those without disabilities than those with disabilities, which suggests that policies and programs need to be instituted to increase employment among those with disabilities.

Figure 1: Disability disaggregation by Employment status (n=13404; ages 18-64) (NHIS, 2013)



Monitoring the difference in the percentage of those employed for those with and without disabilities over time will show if policy and program interventions initiated to enhance workplace accommodations are having the desired effect on the employment of persons with disabilities.

This approach is not limited to a single indicator of inclusion. Instead, inclusion is evaluated for multiple outcome indicators such as education, housing, transportation, social and health services and involvement in family, cultural and social life.

Monitoring the participation levels of those with and without disabilities can also suggest where further interventions are needed and data collections can be instituted to provide the information necessary to develop policies and programs to improve participation. In the example of employment, additional questions could be added to ongoing labour force surveys to determine the barriers to full employment for people with disabilities. More detailed and in-depth data collection can also be instituted to provide necessary information for program and policy implementation and evaluation.

Data collection tools to support monitoring

Historically, the quality of disability data has been poor (Loeb and Eide, 2006; Mont, 2007a; Loeb et al., 2008; Loeb, 2013). Estimates of disability prevalence have varied widely across time and place but also within the same place over the same time period. This reflects the complex nature of the topic, the lack of standardized disability measures, insufficient training directly affecting data quality, the stigma that has been associated with disability, and the cultural context within which the word ‘disability’ is interpreted. In the past, the population with disabilities has been identified using a single question similar to ‘Do you have a disability?’ Questions like this, assume that all respondents have the same understanding of disability, which is very problematic given that disability is a complex concept that relates to almost all aspects of life. How the term is understood and interpreted is also culturally specific, and in many cases is associated with stigma. Responses to a direct single question such as the one posed above, generally result in a very small percent of the population identifying as having a disability (Loeb, 2016). Over the past decade, a great deal of progress has however been made in disability data collection. The adoption of the International Classification of Functioning, Disability, and Health (ICF), approved by the WHO World Health Assembly in 2001, provides a common language and standardized framework for the conceptualization of disability (WHO, 2001). Previously, a medical model of disability placed disability within the individual and focused on medically based causes (e.g. diabetes) and subsequent impacts on the functioning of body system (e.g. vision and/or mobility) which in turn led to a focus on curing (eradicating the cause) and rehabilitating (restoring or substituting for the lost ability to function). While incorporating aspects of the medical model, the ICF describes a bio-psychosocial model whereby disability is conceptualized as the outcome of the interaction between a person with a functional limitation and an unaccommodating environment that results in the inability to fully participate in society. Disability is located outside of the individual, occurring as a result of environments that do not accommodate differences in peoples’ capacities to function.

Disability data collection now has a much stronger conceptual basis and standard, neutral language. The UN Statistical Commission created the Washington Group on Disability Statistics in 2001 to improve the state of disability statistics internationally. As a UN city group, the Washington Group is named after the site of its first meeting. The Washington Group was charged with addressing the need for population-based measures of disability, fostering international cooperation in the area of disability statistics, producing internationally tested measures to monitor the status of persons with disabilities, and incorporating disability into national statistical systems. At the onset, the Washington Group focused on obtaining information on ‘equalization of opportunity’, or the extent to which those with functional limitations in core domains were fully participating in society. This is also the goal of the UNCRPD and the SDGs. Thus, mainstreaming disability statistics into the ongoing national data collection systems would provide the information needed to monitor the implementation of the UNCRPD and the SDGs. For monitoring purposes, it is essential to have consistent measures at multiple time points. These can best be obtained when data collections are mainstreamed (Madans et al., 2011; Washington Group, n.d; Altman and Rasch, 2016).

The Washington Group has developed, tested and adopted a set of data collection tools which, because they obtain information on limitations in core, universal functional domains, can be used as the basis for the disability status indicator needed to disaggregate the outcome indicators used to monitor progress in implementing the UNCRPD and also achievement of the SDGs. The questions have been developed to assess functioning in core domains: a short set of only 6 questions designed originally to meet the requirements of a census format; and extended set of questions on functioning for adults designed for a survey format, and in collaboration with UNICEF, a question set for children aged 2-17. All question sets have undergone cognitive and field testing in multiple countries throughout the world to determine if the questions are interpreted in the same way irrespective of geography and culture, and if the questions are obtaining the information of interest. Test results provide the evidence that the data produced are valid and internationally comparable. The results of the cognitively testing done on the Washington Question sets are on the Washington Group web site (Washington Group, n.d) and in QBank (QBank, n.d.). The question sets were specifically developed for disaggregation of participation indicators such as the SDGs and the UNCRPD, and while they also provide information that can be used to understand disability more broadly, they cannot address all aspects of the disablement process. This would require more detailed data collection. As is the case for all data collection activities, the appropriateness of any data collection tool should be evaluated against the objectives for which the data are being collected.

Washington Group short set

The short set of questions were developed primarily for use in censuses, but are also appropriate for surveys focusing on other topics, and so can only devote very limited space to disability. The questions present minimal collection burden so they can easily be added to ongoing or special surveys that also obtain information on core participation indicators. The domains covered by the short set are seeing, hearing, walking, cognition, self-care and communication. The Washington Group short question set is provided below:

The next questions ask about difficulties you may have doing certain activities because of a ‘Health Problem’:

1. Do you have difficulty seeing, even if wearing glasses?¹
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 language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. The scaled responses allow space to capture the full spectrum of functioning from mild to severe, i.e. the continuum of disability.

The questions identify a population that is ‘at risk’ of a participation restriction due to limitation in these core domains. The population captured may or may not also experience restrictions in participation as actual participation levels will depend on the availability of assistive devices, a supportive environment and other resources. These accommodations can vary within the group identified as being at increased risk. The short set is used to create a disability indicator (described below) that when used in conjunction with other information on outcomes of interest also included in the data collection, will determine if the actual level of participation of those at higher risk (i.e. with a disability) is similar to that of those without disability. These observed differences in levels or degree of participation, reflect the need for societal accommodation to realize full inclusion. The need to keep the question set short so that it can be included in censuses and surveys, makes it impossible to include all aspects of functioning. One clear omission is the domain of psychological functioning. However, the domains included in the short set were selected to encompass core aspects of functioning and will identify a large proportion of the population at risk of experiencing participation restrictions. In addition, many of those who experience limitations in intellectual and/or psychological functioning may also experience difficulties with the domains included in the short set such as in communication or cognition.

Multiple disability status indicators can be derived from the 6 questions and 4 response options. (See section on data to formulate and implement policies above.) Analytic objectives should inform the development of the disability status indicators. Each disability status indicator will be associated with a prevalence measure that will vary in both the size and the composition of the group identified as having a disability. The Washington Group recommends that the following cut-off be used to define the populations with and without disabilities for the purpose of computing prevalence and differentials in participation for international reporting and cross-national comparability: the sub-population with disabilities includes those with at least one of the six domains coded as *a lot of difficulty* or *cannot do it at all*. However, it should be recalled that disability is complex and cannot be limited to a single static dichotomy. Countries should not feel restricted to producing data based solely on the above cut-off for their own use but, depending on the purpose for data collection and reporting, should take advantage of the information on functioning in the individual domains, and at several levels of severity from very mild (some difficulty) to very severe (unable to do at all) when analysing and disseminating their disability data.

Table 1 below, provides an example of the results when different definitions (cut-offs) are used to identify the population with disabilities using the same basic data set as we highlighted above. Data from the 2013 United States National Health Interview Survey shows that almost 41% of the population aged 18 and over had at least some difficulty in one of the six functional domains and 19% has at least some difficulty in at least 2 domains. Using the recommended definition of having at least a lot of difficulty in one domain, about 9.2% would be considered to have a disability. Limiting the population of persons with disabilities to those where the response to one domain is “unable to do” reduces the prevalence to 2.1%.

Table 1: Disability prevalence (n=17326; ages 18+) (NHIS: 2013)

Person with disability has at least:	Unweighted (n)	Weighted %
1 Domain that is at least ‘some difficulty’	7511	40.6
2 Domains that are at least ‘some difficulty’	3672	19.0
1 Domain that is at least ‘a lot of difficulty’*	1872	9.2
1 Domain is ‘unable to do it’	465	2.1

As noted above, using different cut-offs not only results in different prevalence estimates, but also produces populations that have different characteristics including those related to

participation in society. Again, using data from the US National Health Interview Survey, 60.2% of those with disabilities are employed when having difficulty in at least one domain is used as the definition of disability status, compared to 76.5% of those without disabilities using this same definition. When disability is defined as having at least some difficulty in at least two domains, 48% of those with disabilities are reported to be employed compared to 76.6% of those without disabilities. In comparison, 30.8 % of those with at least a lot of difficulty in one domain are employed compared to 73.5% of those without this level of difficulty. When disability is defined as being unable to do at least one domain, only 14.6 percent of those with disabilities are employed. As the criteria for defining disability become more restrictive (i.e. inclusion requiring more difficulty in these core domains), employment levels decrease for those with disability and the differences between those with and without disabilities increases.

Table 2: Employment status disaggregated by disability status: 18-64 years (n=13404) (NHIS: 2013)*

Person with disability has at least:	Weighted Percent Employed	
	Without disability	With disability
1 Domain that is at least ‘some difficulty’	76.5	60.2
2 Domains that are at least ‘some difficulty’	74.6	48.5
1 Domain that is at least ‘a lot of difficulty’	73.5	30.8
1 Domain is ‘unable to do it’	71.4	14.6

*NHIS questions: What was your employment status last week?

Washington Group extended Set

The Washington Group recognized that the short set of questions may not meet all needs for disability statistics, nor will it replicate question sets that can collect information across a wider range of disability domains. To meet the need for additional information on functional status, an Extended Set of questions for adults has been developed, tested and adopted. This set expands upon the Short Set by including additional questions for the domains covered by the Short Set and by including additional domains not included in the short set, that is upper body functioning, affect (anxiety and depression), pain and fatigue. Due to the constraints imposed by census formats, the short set was limited to one question per domain, but the extended set can include multiple questions per domain. Even though the extended set contains multiple questions per domain, the objective of parsimony was still an overarching

aim. A maximum of 30 questions covering 11 domains of functioning comprise the extended set. This set includes recommendations for combining the multiple questions per domain into domain-specific indicators. Recommendations are also provided on how to define the population with disabilities using the extended set data for use in international reporting. As the extended set includes more domains, the population with disabilities identified by this questions set will differ from that obtained by the short set. However, because the short set is embedded within the extended one, it is possible to crosswalk between the two. When presenting information on disability, it is always important to be explicit about the specific questions asked, and how disability was defined and operationalized using those questions. Finally, the extended set also includes questions that begin to explore the association between functioning and the environment. These questions address the use of assistive devices and aids for mobility and obtain information on functioning with and without the use of these aids.

Washington Group/UNICEF Module on Child Functioning

While the functional domains covered by the Washington Group Short Set are suitable for children five years and above, it was not possible to include domains in this set that are specific and relevant to child development; domains such as learning, focusing attention, and controlling behaviour. As a result, children with difficulties in these domains will not be explicitly identified by the short set questions, and as a result this set is not ideally suited for the child population. The Washington Group and UNICEF developed and tested a data collection tool specifically for use with children aged 2 to 17. The Washington Group/UNICEF Module on Child Functioning, including 8 domains of functioning for children 2-4 and 12 domains for children 5-17, will replace the Ten Question Screening Instrument (TQSI) (Durkin, 1991) as the standard tool to measure disability among children in the UNICEF-sponsored Multiple Indicator Cluster Surveys (MICS), and will more appropriately identify those children at a higher risk of limited participation because of difficulty functioning in domains more relevant to child development. As was the case for the short set and extended set for adults, the Child Functioning Module will include a set of recommendations for creating a disability indicator for identifying those children at greater risk than the general population for participation restrictions. This indicator can then be used to determine if children with functional limitations are participating in society, for example attending school to the same extent as children without these limitations.

Combining functioning and the environment

Full and effective participation and inclusion in society for persons with disabilities cannot be attained without addressing barriers to participation that exist in the environment. The combination of information on the functional status of the population with the characteristics

of the environment can help to explain why the goal of participation has or has not been met. Detailed information is needed on the intersection of person and environment in order to develop and implement policies and programs which will reduce barriers and maximize participation. Information on environmental barriers or facilitators can exist on several levels: the micro-environment which is defined in terms of personal and technical assistance (that which follows the person wherever they go, for example wheelchair, glasses, or personal attendant); the meso-environment which refers to the environment beyond the person (accessibility is facilitated or hindered based on, for example, transportation infrastructure, service provision at the local level, or attitudes of others), and the macro-environment which refers to regional, societal or national policies, legislation, or general societal attitudes and practices. In addition to including some aspects of the environment in the Extended Set on Functioning, the Washington Group is developing topic-specific modules that directly address the effect of the environment in different areas of participation. In collaboration with UNICEF, the Washington Group is working on a survey module on inclusive education that obtains information on the full range of barriers and facilitators that children face in obtaining a quality education. This information, in combination with information collected using the module on child functioning (described above), will allow for the disaggregation of data on education (participation and the environment) by disability status. A similar collaboration is underway between the Washington Group and the International Labour Organization (ILO) to develop a module on barriers to employment. The Washington Group is also developing modules that address the family, social and civic domains (see www.washingtongroup-disability.com).

Conclusion

To determine if the UNCRPD has been implemented and the SDGs met, it will be necessary for countries to demonstrate that persons with disabilities are enjoying the same rights as those without disabilities and are able to fully participate in society. There are several ways to document and monitor the implementation of the Convention and the SDGs, all of which will require that reliable and valid data be collected, analysed and reported. Data collection methods have and continue to be developed that can be used by countries to monitor their progress in meeting the objectives of the Convention and the SDGs. One of the most powerful approaches is the disaggregation of outcome indicators by disability status which will illustrate the extent to which persons with disabilities are fully participating in society.

Recently (November 2016), at the Fourth meeting of the Inter-Agency and Expert Group on Sustainable Development Goal Indicators (IAEG-SDG)², a plenary session attended by representatives from the international disability sector – UN agencies, organizations of persons with disabilities, civil society and independent experts – produced a Joint Statement calling on the IAEG-SDGs and the UN Statistical Commission to recommend that national

statistical offices move forward with the disaggregation of data by disability. Furthermore, the statement unanimously acknowledged that there are appropriate and broadly tested methodologies already in place to disaggregate data by disability:

...to ensure international comparability and comparability over time for the purposes of SDG data disaggregation for adults, we recommend the use of the Washington Group short set of questions. For disaggregation by disability among children the recommended tool is the UNICEF/Washington Group module on Child Functioning. Both instruments can be easily and cost effectively inserted in all national data collection efforts.

By standardizing data collection instruments used to identify the population with disabilities, it will be possible to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources. The resulting data can be used to assess a country's compliance with the UN Convention and the 2030 Agenda for Sustainable Development and, over time, monitor their improvement in meeting the established requirements.

Notes

¹ The inclusion of assistive devices was considered for two domains only, seeing and hearing, as limitations in these domains can often be overcome with the use of glasses or hearing aids and these aids are considered as 'within the skin'.

² The IAEG-SDG is comprised of representatives from 27 UN Member States.

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