

Self-care

Hearing

44

Mobility

%

Cognition

+

Communication

100%



Seeing

3248

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Regional Guidebook to Improve Disability Data Collection and Analysis in the Arab Countries

Implementing the Washington Group Questions on Functioning



UNITED NATIONS

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ESCWA

Washington
Group on
Disability
Statistics



Economic and Social Commission for Western Asia

Regional Guidebook to Improve Disability Data Collection and Analysis in the Arab Countries

Implementing the Washington Group Questions on Functioning

Prepared by the United Nations Economic and Social Commission for Western Asia
and the Washington Group on Disability Statistics



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Executive Summary

This regional guidebook explores the different approaches in design, implementation and analysis of disability data collection in the Arab countries, in view of improving the standardization and implementation of the Washington Group Short Set on Functioning and related indicators used to capture data on people with disabilities.

It considers the role of disability statistics in policy analysis, including how information on disability can assist in the design of inclusive policies, and in monitoring and evaluating their impact. In doing so, it presents the Washington Group data-collection tools, examines the implementation of the Washington Group questions and the best practices for data collection, and discusses measuring prevalence and analysing data on disabilities before presenting the recommendations to improve data collection methodologies that could lead to capturing data on the majority of people with disabilities.

Chapter 1 reviews the lack of reliable data and comparable statistics needed to mainstream disability-inclusive development programmes through evidence-based policymaking and programming decisions, and effective monitoring processes. It highlights the need for a deeper understanding of the scope of disability within a country and on how disability is distributed throughout the

population in order to calculate the differences in the rates of disability, demographically or by other characteristics.

Subsequent chapters explore the concept of disability and the importance of having a clear definition for data collection purposes, provide a historical overview of the Washington Group and the Short Set on Functioning, establish the best practices in data collection for comparability across different Arab countries, and identify the importance of comparing outcomes for people with and without disabilities disaggregated by characteristics such as sex, age, geographic location, and marital status, among others, and in development fields.

In conclusion, chapter 6 highlights the weaknesses and strengths of data collection and analysis in the region, and recognizes its experience in implementing the key principles and concepts of the Washington Group Short Set approach in a variety of survey types. However, the report suggests improvements needed in terms of moving forward in the implementation of the questions sets. Therefore, it presents the recommended Arab Washington Group Extended Short Set on Functioning (AWG-SS+), and puts forward two sets of recommendations to further produce and disseminate the harmonization and comparability of disability data on a number of levels region wide.

Contents

P. 3 Acknowledgements

P. 5 Executive Summary

P. 10 Acronyms

P. 11 Introduction

P. 13 1. Disability Statistics for Policy

P. 15 A. Equal participation

P. 15 B. Policies and mandates

P. 16 C. Statistics for evidence-based policy

P. 17 D. The WG approach to identifying persons with disabilities

P. 19 2. Disability Concepts and Data Collection Strategies

P. 21 A. The concept of disability

P. 21 B. The CRPD and ICF definitions of disability

P. 22 C. Past approaches to identifying people with disabilities

P. 23 D. The Washington Group definition of disability

P. 23 E. The objectives and use of a standardized measure of disability

P. 25 3. The Washington Group on Disability Statistics Data Collection Tools

P. 27 A. The history of the Washington Group

P. 27 B. The Washington Group Short Set on Functioning

P. 28 C. Domain definitions

P. 30 D. Use of assistive devices

P. 31 E. Time reference of a difficulty

P. 31 F. Advantages and limitations of the Washington Group Short Set

P. 32 G. The Washington Group Extended Set on Functioning

P. 32 H. The Module on Child Functioning

P. 35 4. Best Practices for Data Collection

P. 37 A. Implementing the Washington Group Short Set

P. 37 B. Translation

P. 39 C. Placement of the module in the questionnaire

P. 40 D. The screening question

P. 42 E. The introductory statement

P. 42 F. The term “difficulty” instead of “disability”

P. 42 G. Response categories

P. 43 H. Asking the questions

P. 44 I. Proxy respondents

P. 44 J. Adding or omitting domains

- P. 45 K. "Other," "multi-difficulties" and "main"
- P. 46 L. Causes
- P. 46 M. Age suitability
- P. 47 N. Interviewer training and instructions
- P. 47 O. Mainstreaming disability statistics

P. 49 5. Measuring the Prevalence of Disability

- P. 51 A. Importance of measuring disability
- P. 51 B. Prevalence and cut-off thresholds
- P. 52 C. Disaggregating disability
- P. 53 D. Cross-tabulations
- P. 54 E. Disability indicators for policy analysis

P. 59 6. Conclusion and Recommendations

- P. 61 A. Strengths and weaknesses
- P. 62 B. Recommendations for moving forward

P. 71 Endnotes

P. 73 References

List of Tables

- P. 38 Table 1. Selected national translations of domains in the Arabic language
- P. 39 Table 2. National translations of the four levels of difficulty
- P. 40 Table 3. Selected national practices of the placement of the disability questions
- P. 45 Table 4. Country practices in selecting the domain of disabilities
- P. 61 Table 5. Selected countries using the WG Short Set on Functioning in census and household surveys

List of Figures

- P. 53 Figure. Proportion of employed people with and without disabilities

List of Boxes

- P. 15 Box 1. Why information on disability is required?
- P. 21 Box 2. Transparency in defining disability
- P. 22 Box 3. Capturing data on persons with and without disabilities
- P. 24 Box 4. Discrepant national definitions
- P. 28 Box 5. The WG Short Set on Functioning
- P. 28 Box 6. Improving prevalence rates
- P. 29 Box 7. The difference between a disability and a diagnosis
- P. 29 Box 8. Cognition
- P. 30 Box 9. Use of assistive devices
- P. 30 Box 10. Accessibility to assistive devices in Arab countries
- P. 31 Box 11. Duration of difficulty
- P. 41 Box 12. The use of census to screen for disability and follow up with other surveys
- P. 41 Box 13. Avoid using the screening question

- P. 42 Box 14. Avoid using the word “disability”
- P. 43 Box 15. Question wording
- P. 44 Box 16. An example of a good format of a disability module in applying the WG-SS
- P. 44 Box 17. Sequence of domains
- P. 46 Box 18. Avoid using unspecified domains
- P. 46 Box 19. Avoid embedding the causes after each domain
- P. 47 Box 20. Multiple needs for disability data
- P. 48 Box 21. Registered and census/household data
- P. 51 Box 22. Cut-off thresholds of persons with disabilities
- P. 52 Box 23. WG classification of disability
- P. 52 Box 24. Heterogeneity in national disability estimates
- P. 53 Box 25. Access to safely managed drinking water
- P. 63 Box 26. Arab Washington Group Extended Short Set on Functioning

Acronyms

AWG-SS+	Arab Washington Group Extended Short Set on Functioning
CRPD	United Nations Convention on the Rights of Persons with Disability
DHS	Demographic and Health Survey
ESCAP	Economic and Social Commission for Asia and the Pacific
HBS	Household Budget Survey
ICF	International Classification of Functioning
ILO	International Labor Organization
I-PM	Integrated-Poverty and Maternal Mortality Survey
LFS	Labour Force Survey
SDGs	Sustainable Development Goals
UNDESA	United Nations Department of Economic and Social Affairs
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNESCWA	United Nations Economic and Social Commission for Western Asia
UNICEF	United Nations Children’s Fund
UNSC	United Nations Statistical Commission
UNSD	United Nations Statistical Division
WG	Washington Group on Disability Statistics
WG-ES	Washington Group Extended Set on Functioning
WG-SS	Washington Group Short Set on Functioning

Introduction

There is much to gain from the collection of data on people with disabilities. On the national and international level, collection results are crucial for both benchmarking and monitoring the impact of policies for people with disabilities and the implementation of the United Nations Convention on the Rights of Persons with Disability (CRPD).

Arguably, the methodologies used in the collection of data need to be applied consistently and tested cross-culturally in order to produce standardized, international comparisons. Accordingly, such methodologies rely on harmonized definitions of disabilities suitable for constructing well-designed questions for surveys and censuses.

Since its inception in 2001, the Washington Group on Disability Statistics (WG), formed under the auspices of the United Nations Statistical Commission (UNSC), has developed, tested and implemented methodologies for the collection and analysis of data on disabilities.

Three tools utilized by the WG – the Washington Group Short Set on Functioning (WG-SS), the Washington Group Extended Set on Functioning (WG-ES), and the Module on Child Functioning developed jointly with the United Nations Children’s Fund (UNICEF) – provide validated mechanisms using quantitative data instruments for identifying people with disabilities.

Data collected from national household surveys and population censuses using these existing tools in accordance with the WG guidelines provide internationally comparable

data on disability prevalence. Furthermore, outcome indicators, such as the Sustainable Development Goals (SDGs) outlined in the 2030 Agenda for Sustainable Development, can be disaggregated to determine the percentage of persons with disabilities who are fully participating in society.

Initiated by the Economic and Social Commission for Western Asia (ESCWA) in 2016, the Disability Statistics Programme implemented three interlinked activities in the region between 2016-2017. Beginning in June 2016, the first activity compiled national data on disabilities through the ESCWA Questionnaire on Disability Statistics. The data were used to assess implementation practices in different collection tools. The results provided a wealth of data on people with disabilities in areas such as demography, education, employment, occupation and industry, cross classified by sex, age and geographical area. In addition, it revealed a need for capacity-building efforts to address various national implementation practices.

The second activity organized was the Expert Group Meeting on Disability Measurement and Statistics in support of the 2030 Agenda for Sustainable Development and the 2020 World Population and Housing Census Programme, in Muscat, Oman, in March 2017. In collaboration with the United Nations Statistical Division (UNSD), the objectives were to assess good practices and enhance the understanding of disability concepts and definitions in different countries worldwide.

The third activity revolved around the Regional Workshop on Improving Disability Statistics in the Arab countries, which, in collaboration with the WG, was held in Casablanca, Morocco, in April 2017. The workshop focused on the best practices for implementing the WG-SS, reviewed the challenges encountered in collecting disability statistics, and made improvements to the implementation practices of the WG-SS.

The “Regional Guidebook to Improve Disability Data Collection and Analysis in the Arab Countries” herein is both the outcome of the three afore-mentioned activities and the collaboration with the national statistical offices in the Arab region.

The guidebook¹ aims to improve the collection, analysis and availability of data on persons with disabilities by providing guidance in standardizing the implementation of the WG questions and related indicators.

This guidebook is organized into six chapters as follows:

1. Discusses the role of disability statistics in policy analysis, including how information on disability can assist in the design of

inclusive policies, and monitoring and evaluating their impact

2. Explores the concept of disability, which has varied historically, as it is embodied in the CRPD and its implications in designing disability data collection efforts
3. Presents the WG disability data collection tools
4. Examines in more detail the implementation of the WG questions and the best practices for data collection
5. Discusses measuring prevalence and analyzing data on disabilities
6. Summarizes the Arab region’s experience of data collection and presents recommendations to improve data collection methodology to capture data on the majority of people with disabilities, including the Arab Washington Group Extended Short Set on Functioning (AWG-SS+).

The electronic version of this guidebook can be found at:


<https://www.unescwa.org/our-work/260170/resources>.



1

Disability Statistics for Policy

- | | |
|---|-------|
| A. Equal participation | P. 15 |
| B. Policies and mandates | P. 15 |
| C. Statistics for evidence-based policy | P. 16 |
| D. The WG approach to identifying persons with disabilities | P. 17 |



"For children with disabilities, these technologies help them see themselves, from an early age, as able – able to do the things they want to do. Move. Play. See. Hear. Interact. Learn. Communicate."

"Lack of mobility because of shattered infrastructure, difficulty fleeing harm and the prejudices that keep them from accessing the urgent assistance they need."

Henrietta H. Fore, Executive Director of the United Nations Children's Fund (UNICEF) at the first-ever United Nations-backed Global Disability Summit, London, 24 July 2018

1. Disability Statistics for Policy

A. Equal participation

A lack of reliable data and comparable statistics represents a critical obstacle in mainstreaming disability into disability-inclusive development programmes. Therefore, improvements in the collection, analysis and availability of disability statistics are crucial in promoting evidence-based policymaking, and programming decisions and effective monitoring processes.

The goal of the CRPD is to promote the equal participation of persons with disabilities in all aspects of life by removing the barriers faced by people with functional limitations. To pursue this goal, a deeper understanding of the scope of disability within a country and how disability is distributed throughout the population is needed in order to calculate the differences in the rates of disability by sex, age, ethnicity, region of residence or other characteristics (Box 1).

Countries need to benchmark the status of persons with disabilities and implement a mechanism to monitor status changes in order to understand whether policies aimed at reducing gaps in participation are working.

B. Policies and mandates

The importance of data for the design, implementation, monitoring and evaluation of more disabled-inclusive policies is encapsulated in article 31 of the CRPD and in the 2030 Development Agenda in its call for disaggregation of indicators by disability status.

CRPD: article 31¹ on statistics and data collection states:

1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.
2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Paragraph 48² of the 2030 Development Agenda Declaration states:

"Indicators are being developed to assist this work. Quality, accessible, timely and reliable disaggregated

Box 1. Why information on disability is required?

The first meeting of the United Nations Statistical Commission's Washington Group on Disability Statistics witnessed participating countries being asked why they wanted to collect information on disability.

The reasons fell into three main categories:

1. Providing services
2. Monitoring the functioning of the population
3. Assessing the equality of opportunities for persons with and without disabilities

data will be needed to help with the measurement of progress and to ensure that no one is left behind. Such data are key to decision-making. Data and information from existing reporting mechanisms should be used where possible. We agree to intensify our efforts to strengthen statistical capacities in developing countries, particularly African countries, least developed countries, landlocked developing countries, small island developing States and middle-income countries. We are committed to developing broader measures of progress to complement gross domestic product (GDP).”

The SDG indicators should be disaggregated, where relevant, by income, sex, age, race, ethnicity, migratory status, disability, geographic location or other characteristics, in accordance with the Fundamental Principles of Official Statistics (General Assembly resolution 68/261).

C. Statistics for evidence-based policy

Basic questions are often asked by programme managers when calling for statistical information on disability and rehabilitation related topics. The most commonly asked question is what is the number of disabled persons in the population? Few users of disability statistics, however, would be satisfied knowing only the total number of persons affected. Therefore, a host of additional questions would arise.

For example, rehabilitation programme planners would need to determine the kind and frequency of disability that occurs within the population. To target services appropriately, they would also need to determine how the prevalence of disability varies by age group, gender and geographical area.

Computing the prevalence of disability in different geographical areas of a country – using a unified definition of disability and standardized collection tools and computation of indicators – could reveal that prevalence rates are higher in some areas than others, and thus should be targeted

by rehabilitation programmes or prioritized when regarding building accessible infrastructure.

Health planners may want to determine the number of disabled persons who have no access to the needed special appliances or aids. However, the special appliances or aids must be defined, the population of interest (people with disabilities who need special appliances or aids) identified, and who within the population of interest do not have access to the needed appliances or aids determined.

Education planners may want to determine the percentage of school-age children with disabilities who are in school. However, more information would be needed regarding the total number of children with and without disabilities, both in and out of school. Thus, estimates can be created to compare the attendance rates of children with and without disabilities.

Planners within the ministries of labor may want to determine what percentage of adults with disabilities are economically active and how it compares with the percentage of non-disabled adults. Similarly, planners within the ministries or departments of social welfare may want to determine the number of persons with disabilities receiving social services who require full-time care from a family member or another person, which is critical to understanding the full economic impact of disability. However, this cannot be determined without systematic information on the number of people with disabilities in the population and the extent to which they depend on others for care.

The national council on disability in a country wishing to determine the barriers faced by persons with disabilities may ask if persons with disabilities are able to use public transport that is available to all. If a negative answer is given, the council will then need to determine the reasons for this. The answers to these types of questions go beyond the simple identification of people with disabilities, and therefore, must be addressed accordingly.

For example, the answers could determine how the environment must be further adapted to include persons with disabilities through modifications

such as providing ramps and elevators or including braille and tactile information, and alternative seating arrangements on public transportation.

It is important to recognize that most countries already collect this type of information regarding the general population and, therefore, indicators and data collection tools are already in place. Thus, all that is needed to make a comparison between people with and without disabilities is a straightforward way to accurately identify people with disabilities. This way the questions can be answered not only for the entire population, but for the population of people with and without disabilities.

D. The WG approach to identifying persons with disabilities

The WG has developed, tested and implemented methodologies for the collection and analysis of disability data, and has investigated ways to best identify persons with disability. For reporting and generating internationally comparable data purposes, the WG-SS approach identifies persons as having a disability if they have difficulty in undertaking at least one basic activity in core functional domains: seeing, hearing, mobility (walking or climbing steps), cognition (remembering or concentrating), communication, and self-care (washing all over or dressing). The exact questions used to identify such persons are discussed in the next chapter.

The reason behind this approach is to identify persons who have significant difficulties in basic activities arising from impairments that put them at risk of participation restrictions. The nature of those impairments is not important for identifying someone with a disability. For example, they may not be able to walk because they are paralyzed, missing a leg,

have a serious heart condition, are very frail, have a middle ear problem that affects balance or some other reason. What is important is that they have difficulties that could – in an unaccommodating environment – prevent them from participating in society to the same extent as able-bodied persons, in terms of education, employment, raising a family or participating in civic events, among others.

While the CRPD addresses the rights of persons with disabilities broadly, functional limitations exist along a continuum. Taking the ability to walk as an example, some people have no difficulties, some have a little difficulty, some a little more, some quite a lot, and some are unable to walk at all. Given that functioning (and disability) are continuous, the analytic challenge is how to identify a group with and without disabilities. While the WG has recommendations for creating the dichotomy between people with and without disabilities, the questions can also be used to place people along a continuum for more extensive analysis.

Estimates of disability prevalence and the impacts of disability have often not been comparable in the past because different definitions of disability, different cutoffs and different data collection methodologies were used. For these reasons, national studies show large variations in reported prevalence rates of disability ranging from 0.2 to 20.9 per cent. These differences could even arise within a single country using estimates produced by different agencies.


Thus, the WG questions have been designed to have a transparent, standard approach for making estimates that are comparable across countries and time. The concepts and strategies behind the WG approach are explained in the next two chapters.



2

Disability Concepts and Data Collection Strategies

A. The concept of disability	P. 21
B. The CRPD and ICF definitions of disability	P. 21
C. Past approaches to identifying people with disabilities	P. 22
D. The Washington Group definition of disability	P. 23
E. The objectives and use of a standardized measure of disability	P. 23



"To realize the promise of the 2030 Agenda – and its core pledge to leave no one behind – it is essential that all peoples, particularly those facing discrimination and exclusion, have access and voice and can participate equally in every aspect of life." This is a matter of justice, and equal opportunity, as well as economic growth. The costs of exclusion are simply too high." "Nothing about us without us' is the mantra of the disability movement."

Mr. Achim Steiner, Administrator of the United Nations Development Programme (UNDP), at the first-ever United Nations-backed Global Disability Summit, London, 24 July 2018

2. Disability Concepts and Data Collection Strategies

A. The concept of disability

Since disability has a different meaning for different people, it is critical to have a clear definition for data collection. Disability is heterogeneous, varying by type, severity, cause, age of onset, and how people with disabilities and long-term impairments interact with various environmental barriers that may hinder their full and effective participation in society on an equal basis with others. Therefore, any analysis or interpretation of data must take these factors into account (Box 2).

B. The CRPD and ICF definitions of disability

Article 1 of the CRPD states: “Persons with disabilities include 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.”

A long-term impairment is a personal characteristic that limits an individual’s functional capacity. One example of an impairment would be having paralyzed legs. Such impairment might prohibit basic functional activities such as standing, walking or climbing steps.

However, it is environmental barriers that render a person disabled by preventing (or limiting) those with functional limitations from exercising their rights to participate fully in society. Inaccessible buildings, roads and transport systems, and the lack of assistive devices, can pose barriers to participating in education and training,

employment, and family and community life, as can negative attitudes, low expectations, and laws and institutions that do not support inclusion. The CRPD approach¹ broadens the role of policy to create inclusive environments where people, regardless of their impairments, can fully participate in society, which is a basic human right.

The CRPD approach to disability is similar to that of the International Classification of Functioning, Disability and Health (ICF), the World Health Organization (WHO) framework for measuring health and disability at both individual and population levels. The ICF defines disability as “...an umbrella term for impairments, activity

Box 2. Transparency in defining disability

Because disability is a complex concept, it is necessary to adopt an explicit definition when developing census or survey questions that will be used to identify disability status. The recommended set of questions for censuses is based on such an explicit definition. It is essential that estimates or tabulations based on the recommended set be accompanied by information on how disability is defined and how the questions are asked. This information should be included as part of the metadata associated with the questions and data set, and it should be included as a footnote to the tables that include these estimates.

Principles and Recommendations for Population and Housing Censuses, Revision 3, (ST/ESA/STAT/SER.M/67/Rev.3), 2015, para 4.210.

Box 3. Capturing data on persons with and without disabilities

There is a difference between defining the number of persons with disabilities for statistical purposes, such as disaggregating the SDGs or monitoring the CRPD outcomes, and determining eligibility for a particular government programme. Not all people with disabilities will qualify for every type of programme and, moreover, programs are not the same in every country. Therefore, it is important to capture the number of people with disabilities and compare them to those with no disabilities in order to address the issue of social participation and equal rights from a policy perspective as illustrated by the CRPD and the requirements established in the 2030 Agenda on Sustainable Development.

limitations and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors)."² The ICF is not a measurement tool, but rather a guide to develop statistics and indicators in a way consistent with the CRPD approach.

Disability complexities have resulted in a proliferation of statistics, including, among others, for monitoring the CRPD or determining the need for services. With each purpose eliciting a different statistic, they are neither comparable nor easy to interpret. Even when the same concept is being measured, the actual questions used to gain information often differ in ways that severely limit comparability.

The conclusion, therefore, is not that some estimates are necessarily right or wrong, but that they are measuring different concepts. Furthermore, for measurement purposes, it is necessary to develop a clear definition of disability that can be operationalized for use in surveys and censuses (Box 3).

C. Past approaches to identifying people with disabilities

A common method for identifying people with disabilities via censuses and surveys is to ask the following yes/no screening question: Do you have a disability? Data from censuses and surveys that use this question produce very low rates of disability prevalence.³

This is because the term "disability" is often stigmatized and people do not wish to identify themselves or others in their households as having a "disability". Second, people often think disability refers only to the most serious limitations. Therefore, those with mild or moderate functional limitations will often respond in the negative. Third, functioning is related to age and, therefore, older people may not report a disability, believing it is a natural result of the ageing process.

For these reasons, people with disabilities can be missed. Generally, best practice would be not to use the term "disability" when attempting to identify people with disabilities.

Listing diagnoses such as epilepsy, leprosy, paralysis and cerebral palsy, among others, to detect respondents' disabilities can also lead to underreporting, since the list will be incomplete. Furthermore, this approach is biased, since those who had or have better access to education and health care are likely to have more knowledge about their diagnosis. Moreover, a diagnosis does not reveal much about a person's ability to function. For example, some people with cerebral palsy can speak with little or no problem, while others cannot speak at all.

Instead, the recommended approach for identifying persons with disabilities in quantitative data instruments is to focus on the level of difficulty that people have in undertaking various activities, such as walking or climbing steps or communicating. Regardless of the impairment, or the person's self-perception as to whether they have a "disability", the key is to identify persons who have difficulties with core and basic activities.

D. The Washington Group definition of disability

In June 2001, the United Nations International Seminar on the Measurement of Disability established the WG as a city group under the auspices of the United Nations Statistical Commission to:

- Address the need for population-based measures of disability;
- Foster international cooperation in health and disability statistics;
- Produce internationally tested measures to monitor the status of persons with disability;
- Incorporate disability into national statistical systems.

To meet these objectives, the WG first developed a clear link between the purpose of measurement and the operationalization of disability indicators. The equalization of opportunities was agreed upon and selected as the purpose for developing internationally comparable general measures of disability. The measures enable comparisons in outcomes between persons with and without disabilities in order to ascertain if they had the same participation rates in all aspects of society, including education, employment, health, and civic and family life. This purpose was chosen because:

1. It was relevant, in terms of being of high importance across countries with respect to policy;
2. It was feasible, since it is possible to collect the proposed information using a comparable general disability measure that includes a short set of questions suitable for census inclusion.

The WG defines persons with disabilities as those who are at greater risk than the general population of experiencing restrictions in completing specific tasks or activities due to limitations in their basic functioning, such as walking, seeing, hearing— even if such limitations

are ameliorated by the use of assistive devices, a supportive environment or plentiful resources. Such persons may not experience limitations in performing activities such as working or going shopping, because the necessary adaptations have been made at the person or environmental levels. These persons would still, however, be considered to be at greater risk of facing restrictions in undertaking activities and/or participating in society than the general population because of the presence of limitations in their basic functioning, and the absence of the necessary accommodation to them.

The definition of disability status requires identifying limitations in performing basic activities and functioning that would place a person at greater risk than the general public of restriction and participation in organized activities, including educational attendance or work participation. Considering the complexity of defining and measuring disability, and, in certain cultures, the sensitivity attached to people identifying as having a disability, it has been recommended that several functional activity domains be defined. Whereby people can respond to questions regarding their difficulty in performing certain activities rather than enquiries that directly address whether they have a particular disability.⁴

E. The objectives and use of a standardized measure of disability

A standardized measure of disability must meet the following tests:

- Be easily implemented on a global level in order that all national statistical offices can use it correctly, both technically and with respect to the amount of resources it requires;
- Identify the majority of persons with limitations in basic activities that put them at risk of restrictions in participation in society;

Box 4. Discrepant national definitions

Egypt	Mental, mobility or sensory difficulties that do not allow the individual to exercise their life normally and independently as a result of health problems that prevent them from participating effectively in society on an equal basis with others.
Iraq	Continuing difficulty, or a difficulty that is expected to last for six months or more.
Oman	Difficulty/disability in the practice of daily life.
State of Palestine	Difficulty/disability: persons with physical, mental or sensory disabilities for a long period, considered six months or more, and barriers, attitudes and different environments that prevent their participation in their society on an equal basis with others.
Saudi Arabia	Every person who has deficiencies in any of the functions or physical structures that lead to limited capacity to participate as a result of environmental and personal factors. Therefore, the term "difficulties" was used to reflect limitations in functions and physical structures. Avoid using the term "disability" because of the stigma that leads – most likely – to the denial of its existence.
United Arab Emirates (Abu Dhabi)	Disability is a physical, sensory or mental impairment that restricts a person's ability to perform certain activities when exposed to different attitudes or behavioral and environmental barriers or when they are fully engaged in society compared with others of the same age. The disability must be long-term, which means that it should last for six months or more.

- Identify persons with similar types and degrees of disabilities regardless of nationality and/or culture.

A measure meeting these criteria can be used to monitor prevalence trends for persons with activity limitations in basic domains. It can also be used to disaggregate data by disability status in order that comparisons of various outcome measures can be made between persons with and without disabilities. Finally, such a measure can be used to evaluate the effectiveness of programs and policies designed to promote full participation.


Arab countries have used different definition for people with disabilities. Box 4 shows an example of discrepancies in the definitions of disability used by some Arab countries. Such discrepancies would yield different results in measuring persons with and without disabilities. A standardized definition of persons with disabilities provides comparable information over time and among countries in this region and the world. Countries could use this information to compare the prevalence of disability at the national levels and the impact of policies and good practices that have been implemented.



3

The Washington Group on Disability Statistics Data Collection Tools

A. The history of the Washington Group	P. 27
B. The Washington Group Short Set on Functioning	P. 27
C. Domain definitions	P. 28
D. Use of assistive devices	P. 30
E. Time reference of a difficulty	P. 31
F. Advantages and limitations of the Washington Group Short Set	P. 31
G. The Washington Group Extended Set on Functioning	P. 32
H. The Module on Child Functioning	P. 32



"But too often, this political commitment has not translated into significant improvements in the lives of the 1.5 billion persons with disabilities across the world".

"...women and girls with disabilities suffer double discrimination based on sex and disability".

*Deputy Secretary-General Amina J. Mohammed,
at the first-ever United Nations-backed Global Disability Summit,
London, 24 July 2018*

3. The Washington Group on Disability Statistics Data Collection Tools

A. The history of the Washington Group

The Washington Group on Disability Statistics was formed in 2001 as a United Nations Statistical Commission city group with the major objective of providing basic and necessary information on disability that is comparable on the international level.

Membership of the WG comprises representatives from national statistical offices, and includes participation of United Nations agencies, disabled persons' organizations, non-governmental organizations and development agencies. The main purpose of the WG is the promotion and coordination of international cooperation in health statistics that focus on disability measures suitable for censuses and national surveys.

The WG – which has developed and tested several tools to be used for the collection of internationally comparable disability statistics – meets annually with representatives from national statistical offices, international statistical offices, non-governmental organizations and disabled persons' organizations. During the past 15 years, more than 135 countries have had representation within the WG.

The first priority of the WG was to develop a short set of questions suitable for a census or survey. The purpose of the resulting Washington Group Short Set on Functioning (WG-SS) is to disaggregate the population by disability status to ascertain if persons with disabilities are participating equally in all aspects of society. Thus far, more than 78 countries have implemented the WG-SS in censuses or surveys.

The WG-SS has been recommended by the United Nations Statistical Division (UNSD) and the United Nations Economic Commission for Europe Council of European Statisticians as the method for collecting information on disability in the 2020 round of population

census. Furthermore, the WG-SS has been endorsed by a disability data expert group under the auspices of the United Nations Department of Economic and Social Affairs (UNDESA) as the means to disaggregate the SDGs by disability status, and by multiple United Nations agencies, development bodies, non-governmental organizations and disabled persons' organizations.

To capture more extensive information on disability, a larger set of questions on functioning was developed for use in surveys and is called the Washington Group Extended Set on Functioning (WG-ES). Subsequently, and in collaboration with UNICEF, the Module on Child Functioning was developed. The ongoing work of the WG is now focusing on such issues as mental health, the environment and participation, inclusive education and employment.

B. The Washington Group Short Set on Functioning

The WG-SS asks whether people have difficulty completing basic universal activities due to a health problem in the six core functional domains of seeing, hearing, mobility (walking or climbing steps), cognition (remembering or concentrating), self-care, and communication. The questions have been designed to identify those who are at greater risk than the general population of experiencing restrictions in participation. Measurements intended to identify this “at risk” population who represent the most basic end on the spectrum of activities.

The ICF provides a detailed classification of health and health-related domains. However, for the purpose of disability identification in both a census and a standard household survey, it is necessary to focus on a few of the most important core domains that can be captured with a single question. As explained in Box 5, the WG

Box 5. The WG Short Set on Functioning

The next set of 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?
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?

Response categories for all questions:

1. No difficulty
2. Some difficulty
3. A lot of difficulty
4. Cannot do at all

has also developed a more extensive set of questions where space and time permit.

The six functional domains of seeing, hearing, mobility (walking or climbing steps), cognition (remembering or concentrating), self-care, and communication addressed by the WG-SS are based on two criteria: First, they cover most functional limitations that people might have; second, they are functional domains that can be adequately captured with a single question.

Box 6. Improving prevalence rates

It is important not to delete any of the six functional core domains, but rather add questions to yield accurate information and better reflect the prevalence of persons with disabilities in the country.

C. Domain definitions

‘Seeing’ refers to individuals using their eyes in terms of visual capacity to perceive or observe what is happening around them.

‘Hearing’ refers to individuals using their ears in terms of auditory (or hearing) capacity in knowing what is being said to them or the sounds of activity, including danger, within their immediate surroundings.

Furthermore, difficulty in seeing or hearing can result from structural or functional problems in the eyes or ears, but can also be caused by problems in other body systems such as in the brain.

‘Mobility (walking or climbing steps)’ refers to individuals using their legs in such a way as to propel themselves over the ground to get from point A to point B. The capacity to walk should be without assistance of any device or human. If such assistance is needed, the person has difficulty walking.

Box 7. The difference between a disability and a diagnosis

Mental illness is not a disability; it is a diagnosis; much the same way diabetes is.

Furthermore, difficulties in mobility can arise from wide-ranging impairments, such as paralysis, cerebral palsy, amputation, middle-ear issues, and significant cardio-pulmonary difficulties, among others. The kind of impairment from which any of the core domains can arise is inconsequential. The WG-SS is only interested in the activity limitation, not the impairment related to any of the functional domains.

‘Cognition (remembering or concentrating)’ refers to individuals using their memory capacity to recall facts, events, experiences or what has happened in their immediate surroundings. Individuals can recall or think again about something that has taken place in the past (either the recent past or further back). With younger people, remembering is often associated with storing facts learned in school and being able to retrieve them when needed.

Furthermore, ‘concentrating’ refers to individuals using their mental ability to accomplish such tasks as reading, calculating or learning something new, and focusing on the task at hand in order to complete it. Concentrating is the act of directing one’s full attention on one subject or focusing without distraction on one thing.

Testing results from various forms of a cognition question revealed the importance of asking about remembering and concentrating in the same question. This signaled to the respondent that the intent of the question was to focus on significant difficulties, and not common everyday problems like forgetting where keys have been placed or getting to the end of a task that was considered boring or unpleasant.

‘Self-care’ refers to ‘washing all over’ and represents the process of self-cleaning the entire body (usually with soap and water) in a culture-specific manner. The activity includes washing hair and feet, and gathering the items necessary for bathing, such as soap or shampoo, a washcloth or water.

‘Self-care’ also refers to ‘dressing’ and represents all aspects of putting clothing or garments on the upper and lower body, including the feet if culturally appropriate. Gathering clothing from storage areas (i.e. closet, dressers), securing buttons, tying knots, and zipping, among others, should be considered part of the dressing activity.

Furthermore, ‘self-care’ differentiates from that of other functional domains in the WG-SS, since it is considered the most rudimentary form of participation. Members of the WG felt it was important to include it for two reasons: First, because it could identify a person with a severe functional limitation in any domain; second, because the population of people incapable of self-care is considered as an important group for policy considerations.

Box 8. Cognition

This includes many functions such as remembering, concentrating, decision-making, understanding spoken and written language, finding one’s way or following a map, doing mathematical calculations, reading and thinking.

Deciding on a cross-culturally similar function that would represent even one aspect of cognition is difficult. However, remembering and concentrating or making decisions would probably serve the cultural compatibility aspects the best.

Principles and Recommendations for Population and Housing Censuses, Revision 3, (ST/ESA/STAT/SER.M/67/Rev.3), 2015, para 4.203.

‘Communication’ refers to a person exchanging information or ideas with other people through language. People may communicate using their voices or making signs or writing information down. Communication can be interrupted at numerous places within the exchange process. It may, for example, involve mechanical problems like hearing or speaking impairment. It may also be related to the ability of the mind to interpret the sounds that the auditory system is gathering and to recognize the words that are being used. The intention is not to include communication problems due to issues relating to non-native or unfamiliar language.

D. Use of assistive devices

The aim of the WG-SS is to identify persons who have functioning difficulties when they are not using assistive devices or assistance, namely, those at risk of restricted participation. Moreover, as assistive devices become more readily available, the gaps in participation between those with and those without functional difficulties will lessen.

However, in order to measure the impact of the growing availability of assistive devices among the population – expressly, a narrower participation gap – it is important to measure the population of persons with disabilities, as defined by the CRPD, and therefore persons for whom assistive devices are relevant.

However, easily obtainable assistive devices can almost completely accommodate a large proportion of people with impaired vision and hearing functioning. Therefore, asking the WG-SS ‘seeing’ question to those without the use of assistive devices like eyeglasses would greatly increase the number of persons identified as having disabilities. Moreover, that group would have a high degree of heterogeneity, in that it would include persons at none or very little risk of facing problems participating in society, along with those at greater risk. Consequently, questions on ‘seeing’ difficulties should be asked in conjunction with eyeglasses use.

Box 9. Use of assistive devices

There is a need for countries to assess and decide, within a national context, whether to include “assistive devices” or not in the question on ‘seeing’ or ‘hearing’, depending on their availability, accessibility and affordability to the public. Countries that do not include “assistive devices” would be able to reflect on the prevalence of disability more accurately if such devices were able to be identified as being unaffordable, subsidized or available for most people.

However, for countries that include “assistive devices”, the prevalence of disability would be more accurately estimated if such devices were affordable and accessible to most people.

Box 10. Accessibility to assistive devices in Arab countries

Since many people in the Arab region may not necessarily have access to healthcare or insurance coverage, concern exists regarding public accessibility to assistive devices. Such devices are imported and expensive, the cost of which may not be subsidized by respective governments. In addition, inexpensive over-the-counter replacement eyeglasses do not exist in most Arab countries. The general population, including those in rural areas, consider assistive devices as luxury items. Therefore, if eyeglasses are scarce, countries may consider excluding the “even if using glasses” clause, and similarly for the hearing aids.

While prosthetic correction for hearing impairment is generally not as successful as vision correction, difficulty in hearing is usually measured by whether hearing aids, are used, in order to be consistent with the vision question. In some countries, the availability – or even knowledge – of hearing aids may be extremely limited. In such cases, it is permissible to exclude the clause “even if using a hearing aid” from the hearing question, since including it would cause confusion among the vast majority of respondents. Excluding it, however, would pick up very few people, if any, whose hearing difficulties are fully accommodated.

E. Time reference of a difficulty

The WG-SS do not address the duration of difficulties. Through testing, the WG determined that when people answer the Short Set questions, they usually think of the difficulties they have in their typical state. For example, if someone usually has no difficulty in walking but currently has a broken leg – and thus has temporary difficulty in walking – they tend to answer no difficulty because in their usual state, they do not have any difficulty walking: once the cast is removed, they will return to their normal state of functioning.

However, some respondents may answer that they do have difficulty walking, even if that difficulty is expected to be temporary. The WG considers this to be less of a problem than the confusion caused in the minds of respondents when given a question that includes a clause referring to duration.

Furthermore, modifying the questions to direct the respondent to answer only in terms of their usual functioning involves adding a long, complex introductory section, or complicating qualifying clauses. Testing has shown that the errors from misinterpreting references to duration were larger than the occasional reporting of a temporary disability. Moreover, even people with temporary disabilities face barriers to participation at the time they are interviewed. Individuals who answer in this way are also temporarily at risk

Box 11. Duration of difficulty

Avoid specifying the duration when asking about difficulties.

COUNTRY EXAMPLE	
Difficulties you may have for at least 6 months because of a health problem	
Do you have difficulty	Degree of difficulty
1. Seeing even if wearing glasses	1. Some difficulty
2. Hearing even if using a hearing aid	2. A Lot of difficulty
3. Talking	3. Cannot do at all
4. Walking or climbing steps	
5. Remembering or concentrating	
6. Self-care	
7. Communication	
8. Other	
9. No difficulty	

of participation restrictions and in need of accommodations.

F. Advantages and limitations of the Washington Group Short Set

The WG-SS has several key advantages.

- Functional approach: asking about difficulties with basic activities avoids the stigma and preconceptions inherent in asking about “disability”.
- Tested: the WG-SS has undergone extensive cognitive and field testing in a variety of countries, with persons of low-to-high income, and in every region of the world.

- Internationally comparable: the questions address core, basic activities that are easy to compare across different countries and cultures, as borne out by test results.
- Comprehensive: the questions identify the majority of persons who have disabilities. To identify more people, more questions, such as those in the WG-ES, are needed.
- Feasible: these questions are succinct and simple enough to be easily added to existing censuses and surveys or to project-based data. They take approximately 1.25 minutes per person to administer.

That there are only six questions means there are also limitations. The WG-SS will, as mentioned, identify most, but not all, people with disabilities. In addition, the WG-SS is:

- Inappropriate for children under the age of 5: the questions cannot accurately identify small children with disabilities.
- Less effective for children aged between 5 and 18: while the questions are able to identify most children with seeing, hearing, and mobility disabilities, they probably miss many children with developmental disabilities.
- Less effective for psychosocial disabilities: while data show that many people with psychosocial disabilities are identified by the WG-SS via the cognition (remembering or concentrating) and communication questions, others are missed. Furthermore, those identified as having a disability cannot be identified as having a psychosocial issue.
- Omitting aspects of disability: the questions fail to capture important concepts such as the age of onset, the cause of the disability, the use and impact of assistive devices, or the nature of environmental barriers.

To address these limitations, more questions beyond the six in the WG-SS are required. Many of them are

addressed in the WG-ES, and the Module on Child Functioning.

G. The Washington Group Extended Set on Functioning

The WG-ES¹ was designed to add additional functional domains to identify people with disabilities who are not captured by the WG-SS. These additional domains include upper-body mobility, psychosocial functioning, pain and fatigue. In addition, questions were added to capture more information on existing domains (e.g., walking a short distance and walking a longer distance) to better capture the continuum of functioning.

The approach taken in the WG-ES is the same as that of the WG-SS, regarding the concept of disability and how to identify it in a quantitative survey. In fact, the WG-SS is embedded within the WG-ES in order to allow cross-over between the two sets of question.

Since the WG-ES includes multiple questions within each functional domain, a rubric is needed for combining those responses to devise the disability status for that domain. For example, what is the level of difficulty someone has in upper-body mobility if they have a lot of difficulty lifting things, but little difficulty grabbing things?

The WG has undertaken analyses to address this question and, via various rounds of testing, has devised recommendations that are available on its website. In addition, Statistical Package for the Social Sciences, known as SPSS code for converting questions responses into disability identification is also available on the website.

H. The Module on Child Functioning

The WG-SS is successful in identifying children with functional difficulties. However, as previously

mentioned, the questions are unsuitable for children who are under 5 years of age, and it fails to identify many children with developmental disabilities. The WG determined, therefore, that a special set of questions that is devoted to measuring child functioning was needed to address the aspects of child development that were not being addressed by the WG-SS.

The WG, in partnership with UNICEF, developed the Module on Child Functioning, a set of survey questions for identifying children with disabilities, of which the rationale and principles can be found on the WG website (<http://www.washingtongroup-disability.com>).

Furthermore, the Module on Child Functioning can be a component of national population surveys or used as survey supplements on specific topics of interest. As with other WG question sets, disability is defined as “difficulty undertaking basic activities,” and therefore, the work draws upon the previously developed WG question sets for adults.

As stated on the WG website, the Module on Child Functioning has been designed to tackle the following:

- Expand the functional domains for children: the distribution of disability types is different for children than that of adults, whose major problems (especially in advancing years) are mobility, sensory and cognition (remembering or concentrating). However, the main disabilities found in children are related to intellectual functioning, affect and behavior.
- Incorporate a fuller age range: the reference age for the Module on Child Functioning is between 2 and 17 years. The workgroup decided it was unfeasible to capture disabilities among children under 2 years of age through population

surveys. Furthermore, there are different sets of questions for children between the ages of 2 and 4 and those between the ages of 5 and 17.

- Recognize the range of disability: answer categories were designed to reflect the continuum of functional difficulties with the ability to determine appropriate cut-offs based on the requirements for the disability data collection.
- Identify age-appropriate difficulties: for reference and to focus the respondent on the functioning of their own child regarding that child’s cohort, where appropriate, questions are prefaced with the clause: “Compared with children of the same age...”.
- Rely on proxy respondents: due to the standard methodology of survey administration, the ethical considerations of interviewing children, and the inability of young children to answer these types of questions reliably, the questions were designed to be administered to the child’s parent or primary caregiver.
- Preserve international comparability: the aim of the questions is to provide comparable data cross-nationally.
- Follow rigorous standards of development: questions were designed in consultation with a wide range of experts. This included survey statisticians, pediatricians, developmental psychologists, speech therapists etc. Questions were then validated through cognitive and field testing, following established WG procedures.

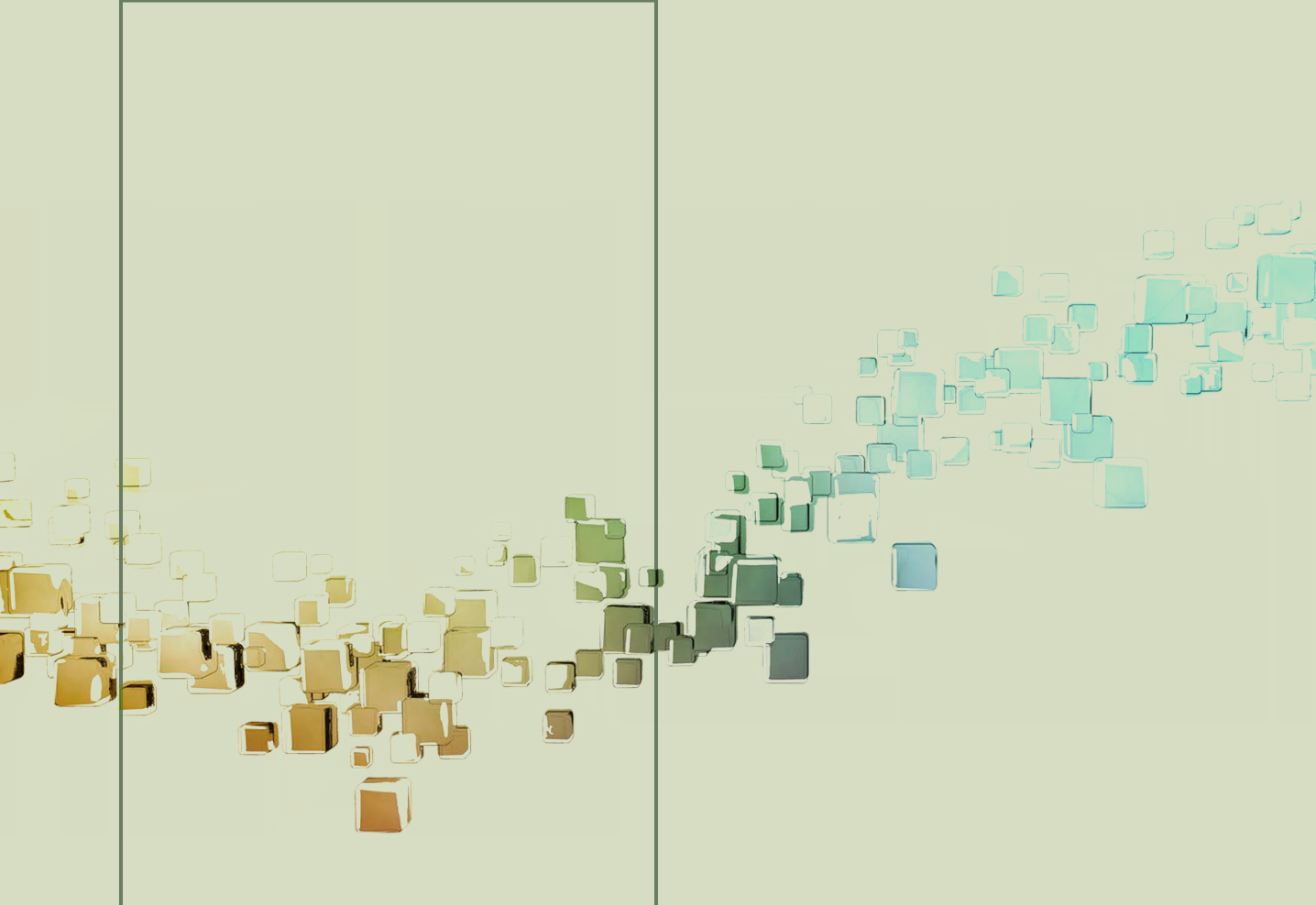
The full Module on Child Functioning for children between 2 and 4 years of age and between 5 and 17 years of age can be found in the Module on Child Functioning, Ages 2-4² and the Module on Child Functioning, Ages 5-17.³



4

Best Practices for Data Collection

A. Implementing the Washington Group Short Set	P. 37
B. Translation	P. 37
C. Placement of the module in the questionnaire	P. 39
D. The screening question	P. 40
E. The introductory statement	P. 42
F. The term "difficulty" instead of "disability"	P. 42
G. Response categories	P. 42
H. Asking the questions	P. 43
I. Proxy respondents	P. 44
J. Adding or omitting domains	P. 44
K. "Other," "multi-difficulties" and "main"	P. 45
L. Causes	P. 46
M. Age suitability	P. 46
N. Interviewer training and instructions	P. 47
O. Mainstreaming disability statistics	P. 47



"There is no silver bullet, but the central, fundamental requirement is to include disabled people and their organizations in planning for and implementing responses to humanitarian crises," which will "make for a better, more effective and humane response".

Mark Lowcock, United Nations Emergency Relief Coordinator at the first-ever United Nations-backed Global Disability Summit, London, 24 July 2018

4. Best Practices for Data Collection

A. Implementing the Washington Group Short Set

The WG-SS can only be an effective tool in identifying people with disabilities if it is properly implemented. In some countries, errors have generated unreliable results.

Therefore, the several key elements that are essential to avoid such unreliability and to ensure proper implementation of the WG-SS, are as follows:

- Questions must be appropriately translated into the local language.
- Any lead-in or introductory statement prior to asking the questions must make no mention of the term “disability”.
- No screening questions should be used.
- The questions must be asked in exactly the way that they are written, including the four response categories for each question.

B. Translation

The purpose of translating the questionnaire is to produce instruments that maintain an equivalence measurement across languages and/or dialects, and to achieve a functional and culturally appropriate version of the original instrument. Only then is it possible to achieve results that are comparable cross-nationally.

An accurate translation that conveys the context or conceptual meaning – rather than a literal translation – of the WG-SS is crucial. Literal translation – even

with back translation as a validation mechanism – is insufficient, since it can leave many inconsistencies or misinterpretations in place.

For example, in one disability survey undertaken in Mumbai, India, a question put forward for consideration was “Does your child have difficulty walking around the house?” In native-English-speaking countries, “around the house” generally means within the house, for example walking from room to room. However, when this is interpreted into Marathi (an Indian language spoken predominantly by the Marathi people of Maharashtra), the phrase actually means “walking around the circumference of the house,” and would thus yield a high degree of confusion and prompt respondents to ask why their child would circle the outside of their house.

Evidently, back translation failed to catch this error, since translating back from Marathi to English yielded the exact same English words but failed to catch the fact that in the two languages they were two different questions. After testing the translation, it was determined that the words for “across the room” in Marathi captured the intended concept without causing confusion among respondents.

Consequently, the WG applies an alternative protocol for the translation of its tools, which recommends that two individuals or two teams first review the WG-SS concepts before working separately to translate the questions and response options into the target language. The teams, and at least one reviewer, subsequently meet to review the translations and, comment on issues found or, by consensus, recommend changes. An adjudicator (who may or may not be at the review meeting) ultimately decides whether to adopt the changes or recommendations, or to make alternative changes based on the findings.

Table 1. Selected national translations of domains in the Arabic language

Country	Seeing	Hearing	Mobility (walking or climbing steps)	Cognition (remembering or concentrating)	Self-care	Communication	Other
Egypt	Vision (even when wearing glasses)	Hearing (even when using a hearing device)	Walking or climbing stairs	Remembering and concentrating	Self-care (washing all over/ dressing...)	Communicating with others (understanding or being understood by others)	
Iraq	Seeing	Hearing	Mobility	Cognition		Communicating	
Morocco	Seeing	Hearing	Walking and climbing stairs	Remembering or concentrating	Self-care such as washing all over or dressing	Communicating using your usual language	
Oman	Seeing, even if wearing glasses	Hearing, even if wearing earphone	Walking or climbing steps	Remembering and concentrating	Taking care of him/ herself	Communicating in normal language	Movement of the upper part of the body
Qatar	Seeing, even if wearing glasses	Hearing, even if using a hearing aid	Walking or climbing stairs	Remembering or concentrating	Self-care	Communication/ Talking	Other
Saudi Arabia	Seeing	Hearing	Mobility	Remembering	Self-care	Talking using usual language	Other (Specify)
United Arab Emirates (Abu Dhabi)	Seeing, even if wearing glasses/ contact lenses	Hearing, even if using hearing aids	Walking or climbing 10 steps	Remembering and concentrating	Self-care such as washing all over the body or dressing	Communicating (understanding or being understood by others)	Using their arms, hands or fingers
Yemen	Seeing, even if wearing glasses	Hearing, even if using a hearing aid	Walking or climbing steps	Remembering or concentrating	Self-care such as washing all over or dressing	Communicating (understanding or being understood)	

Table 2. National translations of the four levels of difficulty

Country	No difficulty	Some difficulty	A lot of difficulty	Cannot do at all
Iraq, Jordan, Tunisia, Egypt, Oman, State of Palestine	No facing difficulty	Yes, some difficulty	Yes, a lot of difficulty	Cannot at all
Morocco	Without difficulty	Little difficulty	A lot of difficulty	Not able to do it
Saudi Arabia	None	Light difficulty	Intense difficulty	Extreme difficulty (Cannot)
Qatar, Yemen, United Arab Emirates (Abu Dhabi)	No, has no difficulty	Yes, has some difficulty	Yes, has a lot of difficulty	Yes, cannot do it at all

The reviewed translated document is then cognitively pretested.

Therefore, translators should:

- Have excellent knowledge of the source and target languages
- Be familiar with the concepts upon which the questions are based
- Be aware of when literal translation is insufficient
- Be bicultural rather than just bilingual.

Furthermore, it is equally important that the translation procedure is applied in both the questions and the response categories. Throughout the translation process, decisions made at every step are documented to inform designers and analysts on how the final translation was reached.

Since this process is vital, questions and response options should be of the highest quality. Furthermore, a great deal of effort and expense goes into administering a survey, the data from which can be used for many years by diverse stakeholders to help design and evaluate public policies.

The translation of the disability domains differed among the countries in the Arab region implementing the WG-SS (Table 1), with some

terms also translated differently from the exact English terms. For example:

- “Seeing” – vision, looking and eyesight
- “Walking” – motion, mobility and movement
- “Memory” – remembering, understanding and perception
- “Communication” – understanding and pronunciation

Similarly, translation of the levels of difficulty showed a variety in the use of Arabic terms in some countries. Table 2 provides examples of some national translations of the four levels of difficulty.

C. Placement of the module in the questionnaire

The six questions of the WG-SS are best situated either at the beginning of a survey or census questionnaire (together with the demographic information collected on household family members) or towards the beginning of a section that deals with health information. The module should not be added at the end of the questionnaire. Under no circumstances should the questions immediately follow any questions on disability, since this affects how respondents will react to the questions.

Table 3. Selected national practices of the placement of the disability questions

Country	Name of Survey/ Census + Year	Demographic characteristics	Educational characteristics	Economic characteristics
Bahrain	Census 2010	X		
Egypt	Labour Force Survey 2016			X
Iraq	Poverty Map and Maternal Mortality Survey 2013	X		
Jordan	Census 2015		X	
Lebanon	Household Budget Survey 2011			X
Libya	PAPFAM 2014			X
Mauritania	Census 2013	X		
Morocco	Census 2014	X		
Oman	Census 2010			X
State of Palestine	Census 2007	X		
Qatar	Census 2010	X		
Saudi Arabia	Demographic Survey 2016			X
Sudan	Census 2008	X		
Syrian Arab Republic	Budget Survey 2007			X
Tunisia	Census 2014			X
United Arab Emirates (Sharjah)	Census 2015			X
United Arab Emirates (Abu Dhabi)	Labour Force Survey 2014			X
Yemen	Household Budget Survey 2014		X	

Table 3 shows selected national practices in the placement of the questions within questionnaires related to disability (marked by “x”) that were part of recent Household Surveys or Population Censuses implemented by some Arab countries. Bahrain, Iraq, Mauritania, Morocco, the State of Palestine, Qatar and the Sudan have placed the questions related to disability with the demographic characteristics, while the rest of

the countries located them towards the end of the questionnaire.

D. The screening question

A screening question (Box 13) should not be used before asking the WG-SS. If a screener is used, then,

Box 12. The use of census to screen for disability and follow up with other surveys

Countries that are planning specialized surveys on disability may use the census to develop a sampling frame for such surveys by including a screening instrument to identify persons who will be subsequently interviewed. The main purpose of a screening instrument is to be as inclusive as possible in order to identify the largest group of people who could be studied further (para 4.211).

However, before embarking on using the census to develop a frame for a follow-up survey, it is important that the legal implications of using the census data for this purpose are fully considered. Respondents should be informed that the data may be used for follow-up studies and that national authorities responsible for ensuring the privacy rights of the population may need to be consulted in order to obtain their approval (para 4.213).

Principles and Recommendations for Population and Housing Censuses, Revision 3, (ST/ESA/STAT/SER.M/67/Rev.3), 2015

can describe their difficulty through the activities they can perform, often they cannot report on their conditions. For example, respondents may be unaware of their conditions due to a lack of medical care and therefore knowledge. Furthermore, no list of conditions can ever be complete. The search for a one or two question screener that would identify the population of interest and result in no false negatives has been universally unsuccessful.

The Principles and Recommendations for Population and Housing Censuses, Revision 3, recommends to countries the use of the six Washington Group Short Set questions to identify persons with disability. Countries that are planning additional specialized surveys on disability may want to use the census to develop a sampling frame for these surveys. In such cases, the disability data collected as part of the census may be used as a screening instrument to identify persons with disabilities who will be interviewed in a follow-up survey. Before embarking on using the census to develop a frame for a follow-up survey, it is important that the legal implications of using the census data for this purpose are fully considered. When required by country-specific policies, respondents should be informed that the data may be used for follow-up surveys or studies, and national authorities responsible for ensuring the privacy rights of the population may need to be consulted in order to obtain their approval on this matter (Box 12).

in effect, it is the screener that is being used to identify people with disabilities and not the WG-SS. Thus, a screener completely undermines the WG approach.

Evidence shows that single screener questions do not adequately identify the population of interest. Most screeners are of the form “do you have a disability?” with yes/no answer categories. A question with a yes/no response option forces the person answering to self-identify as having the difficulty or not, and, as previously mentioned, the term “disability” is problematic.

Some screeners do not use the term “disability” but ask about medical conditions. While respondents

Box 13. Avoid using the screening question

COUNTRY EXAMPLE		
Do you have any difficulty in normal functioning?	Type of difficulty	Cause of difficulty
1. Yes		
2. No		

E. The introductory statement

When the WG-SS is included in a survey, especially when it is not a health survey or a census, it is useful to have a lead-in statement to make the transition from the previous survey topic. Lead-in questions should be short, simple and refer only to having difficulty in performing certain activities related to a health issue, such as in the example that follows:

“The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.”

F. The term “difficulty” instead of “disability”

“Disability” is a word whose meaning can vary not only across cultures, but among people within the same culture. Moreover, in some cultures the term is associated with shame and/or stigma. It also predisposes people to consider only the most severe functional limitations.

Box 14. Avoid using the word “disability”

COUNTRY EXAMPLE

What is the main type of disability the person is suffering from?

Classification answers:

1. Seeing, even if wearing glasses
2. Hearing, even if wearing earphone
3. Mobility (Walking or climbing steps)
4. Cognition (Remembering or concentrating)
5. Self-care
6. Communicating in normal language
7. Movement of the upper part of the body

Therefore, no reference should be made to the impact on the life of people resulting from such difficulties. In addition, the word “disability” should not appear in the introductory statement, or even the title of the survey.

The purpose of the introductory statement is to inform respondents that the context of the next set of questions is health. For example, if the questions were to follow a series of questions on another subject, such as sanitation, for example, the introductory statement would provide a transition to a more health-related subject matter. In a larger survey, whereby this module might follow other health-related questions, and where the context is already established, the introductory statement can be dropped if the flow of the questionnaire is not adversely affected.

G. Response categories

The four WG-SS response categories – “cannot do at all,” “a lot of difficulty,” “some difficulty,” “no difficulty” – must be used. Substituting yes/no response categories undermines the validity of the questions. First, human functioning is not a dichotomous variable. A range of difficulties (or disabilities) exists. Collecting data using yes/no response categories fails to allow for analysis of the continuum of functioning. Second, some respondents who answer “yes” may only have minor difficulties that do not rise to the level generally considered to be disabling and thus may generate false positives. Third, where people draw a line between “yes” and “no” may vary based on their cultural and socio-economic backgrounds. This is less true for the four category responses because the gradations between response categories are smaller.

However, a number of countries have opted for the “yes/no” approach rather than the four response categories. This is because they believe this approach takes less time to administer. Cognitive testing of the WG questions, however, suggests this is not the case, because respondents take longer to figure out if they should answer yes or no if they have more mild difficulties.

Box 15. Question wording

It is recommended that special attention be given when designing census or survey questions to measure disability. The wording and the construct of questions greatly affect the precision in identifying persons with disabilities. Each domain should be asked through a separate question. The language used should be clear, unambiguous and simple. Negative terms should always be avoided. The questions on disability should be addressed to each single household member and general questions on the presence of persons with disabilities in the household should be avoided. If necessary, a proxy respondent can be used to report for the family member who is incapacitated. What is important is to account for each family member individually rather than ask a blanket question. Scaled response categories can also improve the reporting of disability.

Principles and Recommendations for Population and Housing Censuses, Revision 3, (ST/ESA/STAT/SER.M/67/Rev.3), 2015, para 4.207.

H. Asking the questions

It is recommended that the six questions from the WG-SS are read separately and in the exact way they are written, including the response options after each question. For example:

*Do you have difficulty walking or climbing steps?
Would you say:*

1. *No difficulty*
2. *Some difficulty*
3. *A lot of difficulty*
4. *Cannot do at all*

Respondents may become familiar with the answer

categories after the first few questions, therefore, the recommendation to repeat the categories can be relaxed. This is most likely to occur when the questions are asked of multiple people in the same household. If respondents provide responses using the correct answer categories, the categories do not need to be repeated after every question. However, they should be repeated as soon as the respondent fails to use the required category (e.g. responds “yes”) or after the third or fourth question. It is important that enumerators are trained in when it is appropriate not to read the answer categories.

If time and space permit, it may be preferable to split the two sensory questions, as in the WG-ES. For example:

First, ask:

Do you wear glasses?

1. *Yes*
2. *No*

Depending on the answer, ask:

If Yes: Do you have difficulty seeing even when wearing your glasses?

If No: Do you have difficulty seeing?

Followed by the four response options.

The WG questions should not be combined into a single question but read in the exact way they are written, including the response options after each question as shown in Box 16. For example, it is not good practice to ask: “do you have difficulty seeing or hearing, or walking or climbing steps?” Often, respondents will either forget the list of activities or believe they must have difficulties in all those areas to answer positively. Furthermore, if a person has some difficulty seeing but is unable to walk, it will be difficult for them to determine what response category is relevant to them.

Box 16. An example of a good format of a disability module in applying the WG-SS

The next questions ask about difficulties you/(NAME) may have doing certain activities because of a HEALTH PROBLEM

Do you/(NAME) have difficulty seeing, even if wearing glasses?	Do you/(NAME) have difficulty hearing, even if using a hearing aid?	Do you/(NAME) have difficulty walking or climbing steps?	Do you/(NAME) have difficulty remembering or concentrating?	Do you/(NAME) have difficulty with self-care such as washing all over or dressing?	Using your usual language, do you/(NAME) have difficulty communicating, for example understanding or being understood?
1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all

I. Proxy respondents

Ideally, the questions should be answered by the individual in question (self-report), except in cases for those who themselves are incapable of responding. However, in a census setting, it is common to have a primary respondent report for all other household members, which is acceptable.

In self-report situations, no one should be excluded because they cannot respond on their own, due to, for example, difficulty in hearing, communication or an intellectual disability. A proxy respondent should be sought, however, the choice of such a person should be carefully considered. Furthermore, it is recommended that every effort should be made to collect data from all household individuals targeted in the survey or census.

One exception to this is when implementing the Module on Child Functioning. As explained further on in this guidebook, such questions were designed to be answered by the parent or primary caretaker of the child.

J. Adding or omitting domains

A number of countries may consider identifying certain conditions such as albinism or autism. While the WG-SS will identify such conditions as they contribute to a person having a disability (e.g. people with albinism usually have seeing difficulties), some countries may want to specifically identify people who have these conditions for purposes of policymaking. In this case, questions to identify such conditions should follow the WG-SS

Box 17. Sequence of domains

It is recommended that the sequence of WG-SS domains is preserved when being applied in the questionnaire.

Additional domains from WG-ES set such as “upper body” or a national specific domain such as “albinism” should come after the WG-SS question.

questions, in order not to affect the mindset with which respondents answer the WG-SS.

If countries want to ask about domains that go beyond the WG-SS, it is recommended to use the WG-ES, which was designed to include additional domains that are pertinent, such as upper-body movement particularly the use of arms and hands, in addition to other domains.

Furthermore, Arab policymakers have expressed concern about not including the upper-body functions in national estimates. The upper-body functioning domain is important in developing countries where work, car accidents and conflict, among others, are prevalent and insurance is scarce. Turkey, for example, included upper-body functioning within the short questions. The International Labour Organization (ILO) is also considering adopting the WG-SS with the upper body and depression or anxiety domains. Upper-body functions include some of the characteristics of self-care but are also more inclusive of other characteristics that are considered more prevalent in the Arab region.

Therefore, it would be wise to maintain all six domains including “self-care” and add extend the questions to include “arms” and “hand” functioning in order to better reflect the prevalence of persons with disabilities and explain “self-care” in an acceptable context.

K. “Other,” “multi-difficulties” and “main”

It is highly recommended that countries refrain from using the terms “other,” “multi-difficulties” or “main” when referencing alternative unnamed domains. The name of a specific domain is important for answering a policy question. Moreover, multi-difficulties fail at adding useful information. Since the WG-SS asks each domain separately, it is easy to identify people with difficulties in more than one domain during data analysis and identify which specific difficulties are reported including level of severity. Adding “other,” “multi-difficulties” and “main” may negatively affect the accuracy of prevalence rates.

The countries covered by ESCWA failed to uniformly apply the same WG-SS standards, thus, differences in the implementation of the WG-SS were observed in relation to the coverage of age groups, and the selection of domains. Table 4 shows that not all countries included all six domains of the short set questions. For cultural reasons, some excluded ‘self-care’, another country excluded the essential domain of ‘cognition’ (remembering or concentrating), while others added ‘upper body’ from the WG extended domains.

Table 4. Country practices in selecting the domain of disabilities

Country	Seeing	Hearing	Mobility (walking or climbing steps)	Cognition (remembering or concentrating)	Self-care	Communication	Upper body
Egypt	x	x	x	x	x	x	
Iraq	x	x	x	x		x	
Jordan	x	x	x	x	x	x	
Morocco	x	x	x	x	x	x	
Oman	x	x	x	x	x	x	x
State of Palestine	x	x	x	x		x	
Qatar	x	x	x	x	x	x	
Saudi Arabia	x	x	x	x	x	x	
Tunis	x	x	x	x	x	x	
United Arab Emirates (Abu Dhabi)	x	x	x	x	x	x	x
Yemen	x	x	x	x	x	x	

Box 20. Multiple needs for disability data

It should be noted that there is not one set of measures to satisfy the multiple needs for disability data or cover all population segments, such as very young children, the homeless, the floating population, and those in institutions.

Furthermore, the WG has acknowledged that disability among children – due to the circumstances of child development and transition from infancy through adolescence – is not adequately covered by these questions. However, in the absence of alternative measures and alternative data collection exercises, the questions do provide an indication of child functioning for the population between 5 and 17 years of age on the domains covered.

Nonetheless, the WG has developed the Module on Child Functioning, a separate set of child-centered questions that can be used in surveys to more accurately identify children with disabilities between 2 and 17 years of age.

At the regional level, almost all countries have applied the disability questions to the entire population. The one exception is Jordan, which limited the age group to those aged 5 years and above. In this type of case, it is recommended that in the absence of implementing the Module on Child Functioning, the WG-SS or WG-ES questions be asked of all respondents of 5 years of age and above.

N. Interviewer training and instructions

Interviewer training for all surveys (including those that ask the WG questions) should deal with making the administration of the survey more inclusive, in terms of the importance of consistency when administering survey content, and the following best practices:

- All questions should be asked as they have been written.
- Checks should be in place to ensure all respondents answer each question. Assumptions should not be made by observation only. Interviewers who are unsure of someone's response must ask the respondent to repeat it.
- Assumptions regarding the ability of a person to respond must be avoided, since some people who may appear to have communication or cognition difficulties that prevent them from answering are, in fact, very capable.
- A proxy should only be used when necessary. Interviewers should be prepared for dealing with people who, for example, communicate by sign language.
- Interviewers should remain calm and respectful with respondents who have significant disabilities. Interviewers may find it useful to conduct practice interviews with people with disabilities beforehand.

It is not difficult to administer the WG-SS and, therefore, no specialist training on disability is required beyond sensitivity awareness training that should be provided for all data collection, and the admonition not to talk negatively about "disability".

O. Mainstreaming disability statistics

Arguably, the easiest and most effective way to monitor people with disabilities is to include the WG-SS in all on-going data instruments, for example household income and expenditure surveys, demographic and health surveys, and labour force surveys, among others.

By leveraging the power of existing surveys and censuses, all indicators currently used by a government can be disaggregated by disability status. The inclusion of the WG-SS is expected to increase the survey time by approximately 1.25

Box 21. Registered and census/household data

Countries whose registration system provides regular data on persons with the most severe types of impairments may use the census or household surveys to complement such data with information related to selected aspects of the broader concept of disability and functioning based on the 'International Classification of Functioning, Disability and Health' (ICF).

Census or household survey data can be utilized for general planning programmes and services (prevention and rehabilitation), monitoring selected aspects of disability trends in a country, evaluation of national programmes and services concerning the equalization of opportunities, and international comparison of selected aspects of disability prevalence in countries.

Principles and Recommendations for Population and Housing Censuses, Revision 3, (ST/ESA/STAT/SER.M/67/Rev.3), 2015, para 4.193.

minutes per survey, and even less if it replaces alternative yet less effective disability questions.

Furthermore, questions that become integrated into core statistical systems result in the availability of core information on disability for use by all governmental agencies and civil society.

Mainstreaming disability data collection has several important advantages:

- It allows for the disaggregation of existing indicators that are well understood, including for those of the SDGs

- It reduces, effectively, disability data collection costs by only adding a disability module into existing tools
- It provides a signal that the considerations of persons with disabilities are a core policy issue, rather than being tangential and suitable only for special surveys (ESCAP, 2014).

The collection tools used for data on disability in Arab countries have varied between adding the module through a variety of household surveys or in population censuses. To avoid wasted resources, therefore, selecting an appropriate and official source for measuring disability statistics, the allocation of an appropriate budget, and the design of the questionnaire is important for monitoring purposes.

Furthermore, when the official source of data is being selected, countries need to consider survey or census periodicity (three years maximum) and the age group targeted (five years or more). Another important factor to be considered is population coverage, to which the following questions should be directed: does the sample cover nationals and non-nationals; nomads, migrants or refugees; or any institutionalized population?

It should be noted that in some instances the WG-SS does not have to be added to every survey administration. For example, if a labour force survey is conducted monthly (or quarterly), it may only be necessary to include the WG-SS on one round of the survey per year.


Countries should also consider alternating two different sources, one for using the set of short questions every year in a household survey or every ten years in a census, and the WG-ES or the WG-ES 'light' version every three years in a household survey.



5

Measuring the Prevalence of Disability

A. Importance of measuring disability	P. 51
B. Prevalence and cut-off thresholds	P. 51
C. Disaggregating disability	P. 52
D. Cross-tabulations	P. 53
E. Disability indicators for policy analysis	P. 54



Cementing and protecting the rights of around 1.5 billion people around the world in accordance with the Convention on the Rights of Persons with Disabilities is a "moral imperative".

"But, signing and ratifying the Convention is not enough. Implementation is essential".

"Societies must be organized so that all people, including those with disabilities, can exercise their rights freely".

*United Nations Secretary-General
António Guterres on 12 June 2018,
Conference of signatories to the
Convention on the Rights of Persons
with Disabilities at United Nations
Headquarters in New York*

5. Measuring the Prevalence of Disability

A. Importance of measuring disability

Persons with disabilities are a highly heterogeneous group with different needs, capacities and barriers. Although the impact of disability can manifest itself in many ways across every sector of society, not one simple statistic exists that captures these effects. However, the undertaking of standard approaches can allow for the measuring of these impacts and greatly inform public policy and measure.

Measuring disability in any given society can provide critical information on the status of the population in order to monitor progress on disability policies and on the implementation of the CRPD nationally and internationally. In addition, data on disability provides evidence for mainstreaming service provisions at the population level, such as addressing needs for housing, transportation, assistive technology, vocational or educational rehabilitation and long-term care.

Therefore, it is important to compare outcomes for people with and without disabilities disaggregated by characteristics such as sex, age, geographic location, and marital status, among others and in development fields such as housing, health, transportation, education, employment, income or wealth, water and sanitation, in addition to disability specific areas such as access to, and utilization of, assistive devices, rehabilitation services and benefits.

B. Prevalence and cut-off thresholds

It is important to note that there is no single standard measure of the general prevalence of disability. Furthermore, prevalence is a function

Box 22. Cut-off thresholds of persons with disabilities

For making international comparisons, the WG recommends that those with disability are defined as those who answer, “a lot of difficulty” or “cannot do at all”.

A few countries, such as Oman (2010), Qatar (2010) and Tunis (2014), had set their cut-off measure for the population with difficulty in at least one domain in order to include the three levels of those with “a lot of difficulty”, “cannot do at all” or “some difficulty”.

of the inclusion criteria selected, and different criteria are appropriate for different objectives. The choice of inclusion criteria (the selection of a cut-off point on the continuum) determines not only the percentage of the population with disabilities (and therefore prevalence) but, consequently, also the characteristics of that group. A cut-off 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 estimations of prevalence would be valid and useful for the associated intended purpose.

Devising special indicators for persons with disabilities is unnecessary since standard indicators can be used. Although they must be reported separately by their disability status.

Box 23. WG classification of disability

The threshold for those with a disability are defined as those who answer the WG questions with “a lot of difficulty” or “cannot do at all.”

With disability	Without disability
A lot of difficulty Cannot do at all	No difficulty Some difficulty

However, the threshold for identifying persons with disabilities is important. For example, if different thresholds are used by different countries in reporting disability status, their disaggregation results would be clearly incomparable.

Therefore, the WG recommends that for international comparisons, the threshold for those with a disability are defined as those who answer the WG questions with “a lot of difficulty” or “cannot do at all.”

Box 24 Heterogeneity in national disability estimates

A single estimate of disability — like the 15.3 per cent prevalence from the World Report on Disability — masks a great deal of heterogeneity. The World Report points this out and notes that the rate of severe disability is closer to 3 per cent. However, at the country level the cut-off between a person being disabled or not disabled depends on the reason for identification. For the purpose of providing permanent cash benefits, the cut-off might be quite high. A government might only want to provide such benefits to people for whom there is no possibility of work.

However, countries that also apply the “some difficulty” threshold will include in their results people who have minor difficulties and, thus, most likely will have a higher outcome of disability prevalence. Conclusively, the more severe the threshold for defining disability, the bigger the disability gap.

Validity is given to viewing disability as a spectrum, which is also advantageous for analysing the prevalence of persons with varying degrees of disability. Although people who identified as only “some difficulty” are not categorized by the WG as having a disability, some researchers analyse the sub-population of people with “some difficulty” in the six domains related to activity functioning. While these people may not be identified as having a disability, they would most probably benefit from policies that make environments more inclusive.

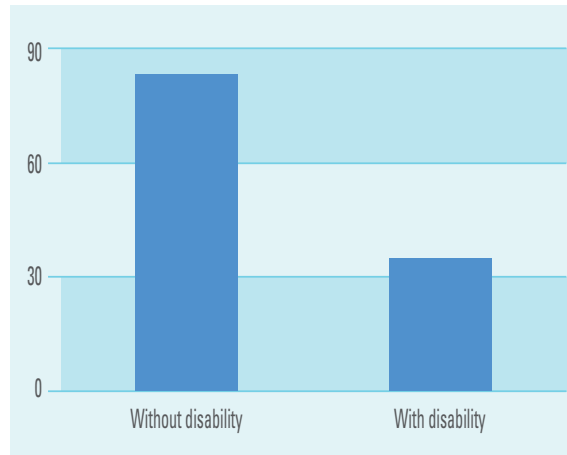
C. Disaggregating disability

The principal topics in the assessment of equalization of opportunities include disaggregation by sex, age, place of residence, type of household, marital status, educational attainment and school attendance, labour-force status, employment, industry, and occupation, among others.

Identifying the prevalence of disability is a first step. The next step is to determine if outcomes for persons with disabilities are different from that of their non-disabled counterparts by asking questions such as: are persons with disabilities less likely to get married? To get educated? To find employment? More likely to be victims of violence? In order to answer such questions, we need to disaggregate outcome indicators by disability status: without disability and with disability.

Only when persons with disabilities have been identified using the WG-SS is it possible to compare the employment rate of people with and without disabilities. A society that is entirely inclusive would reveal no gaps in employment. However, if persons with disabilities faced barriers to employment, their employment rates would

Figure. Proportion of employed people with and without disabilities



be lower than those with no disabilities as in the hypothetical example in the Figure.

Since the disability gap probably differs by sex, age and region of residence, it is important to look not only at the overall gap, but at the gap for various sub-populations. For example, the possibility of having a disability increases greatly from approximately the age of 50.

Disability rates can also vary a great deal by geographic region, maybe because of differences in the exposure to diseases, traffic, conflict, or a variety of causes that can be region specific. In addition, disability varies by sex because sex and disability can interact in ways that magnify the barriers that both disabled people and women, in general, face.

The results may show that the gap for school attendance between children with and without disabilities is bigger for girls than it is for boys. It also may show the gap in marriage rates for persons with disabilities is bigger in rural areas than it is in urban areas.

D. Cross-tabulations

For the purpose of developing statistics on the situation of persons with disabilities, the principal topics that would be necessary for the assessment

of equalization of opportunities include, inter alia sex, age, place of residence, type of household, marital status, educational attainment and school attendance, labour-force status, employment status, industry, occupation and wealth, including other institutional benefits and services made available to the persons with disabilities.

Countries, therefore, need to follow international standards and classification in the definition of variables. For example, most countries collect the well-known global development indicators such as population using safely managed drinking water (SDG 6.1.1) or sanitation services (SDG 6.2.1). However, in most countries such indicators are not collected in accordance to international definitions. Hence, those two indicators are not comparable at the regional nor at the international levels. Box 25 shows a country example inaccurately merging the selections of ‘covered or uncovered well’ into one item. In doing so, the adherence to international definition of safely managed drinking water is negated.

In terms of the labour market, for example, countries should follow the latest International Classification by Status in Employment (ICSE), to define the employed, unemployed and inactive

Box 25. Access to safely managed drinking water

Follow international standards, "uncovered" is not a standard classification

COUNTRY EXAMPLE
What is the main source of water used by the family?
1. Piped water into dwelling, yard or plot
2. Public taps
3. Boreholes or tubewells
4. Covered or uncovered well
5. Protected rainwater
6. Protected springs
7. Other

in the population. When asking about the main occupations or largest sector of economic activity, some countries correctly ask about employed persons, while other countries incorrectly ask about both employed persons and those who were unemployed but have previously worked.

It is a similar situation for education whereby countries should follow the latest International Standard Classification of Education. For further guidance please refer to the second revision of the Principles and Recommendations for Population and Housing Censuses, which provides standardized and detailed tables in many fields according to international definitions and standards.

E. Disability indicators for policy analysis

Experience shows that although an increasing number of countries ask questions about disability in their censuses and surveys, the presentation of data on disability has often been limited. Unfortunately, cross-tabulations with other characteristics are not usually made, which weakens the analysis and development of disability statistics.

To enrich the analysis and provide a valuable source of information for planners and policymakers, the section below provides related policy questions and a list of proposed disability indicators in the areas of demography, education, literacy, employment, industry, occupation, poverty, violence, access and benefits. The proposed indicators are guided by the recommended tabulations of the Principles and Recommendations for Population and Housing Censuses, the SDGs' disability-related indicators, the international standardized indicators of the United Nations Educational, Scientific and Cultural Organization (UNESCO), and the ILO.

Demography

One basic question that can be asked in order to identify the total number of persons with difficulties is: How many persons with disabilities are there in the population?

Rehabilitation programme planners would then need to ask further questions to identify the kinds of specific difficulties, and their frequency, that such persons have. Furthermore, in order to target services appropriately, the variations in frequency or prevalence of disability by age group, sex, marital status, and geographical area also need to be identified.

The results from computing the prevalence of disability in different geographical areas of a country might show that some areas have higher prevalence rates than others. Moreover, information on the marital status of persons with disabilities is important in understanding their social integration. In addition, information on living arrangements for persons with disabilities – living alone, with family or in institutions – is useful in determining the economic and social provisions that may be needed.

- Prevalence of disability in the population by sex and geographical area
- Proportion of population by type of disability, sex and geographical area
- Share of female population by type of disability, age and geographical area
- Distribution of population with a multi-dimensional disability by number of functional disability domains (at least one domain, two domains, three or more domains), sex and geographical area
- Proportion of age-sex distribution of population by disability status/type of disability and geographical area¹
- Proportion of age-specific population by disability status/type of disability, sex and geographical area²
- Sex ratio of population by disability status/ type of disability, age and geographical area
- Proportion of population living in household and in institution³ by disability status, sex, age and geographical area

- Proportion of population (18+ years) by disability status/type of disability, living arrangements, sex and geographical area
 - Proportion of population (18+ years) living alone by disability status, house ownership, sex and geographical area
 - Proportion of households with one or more persons with disabilities, by type and size of household (all sizes)⁴ and geographical area
 - Proportion of population by cause of disability, sex and geographical area
 - Prevalence of disability in the population (15+ years) by marital status, sex, age and geographical area⁵
 - Proportion of age-sex distribution of population by disability status, marital status, and geographical area⁶
 - Proportion of age-specific population by disability status, marital status, sex and geographical area.⁷
- opportunity that persons with disabilities have to participate in the economic, social and cultural development of the country.**
- Proportion of population (5+, 15+ and 25+ years) by disability status/type of disability, educational attainment, sex and geographical area⁸
 - Proportion of population (5-29 years) by disability status/type of disability, school attendance, sex and geographical area⁹
 - Proportion of age-specific population by disability status/type of disability, school attendance¹⁰, sex and geographical area
 - Proportion of population (5+, 15+ and 25+ years) out of school¹¹ by disability status/ type of disability, sex and geographical area
 - Literacy rate of population (15+, 15-24 and 15-64 years) by disability status, sex and geographical area¹².

Education and literacy

In education, planners might ask: What percentage of school-age children with disabilities are in school?

For this question, information is needed on the total number of children with and without disabilities, both in and out of school. The information will allow estimates to be created to compare the attendance rates of children with and without disabilities.

Additional questions could include: How many children are illiterate and did not attend school? Do children face discrimination and restricted access to early-childhood education? Have the educated children been able to improve their living standard?

In addition, the percentage of persons with disabilities who have no schooling can be compared with that of persons without disabilities. This provides information on the status of integration of persons with disabilities and on the

Employment and work

Labour policymakers might ask: What percentage of adults with disabilities are economically active? How does this compare with the percentage for adults without disabilities? How many adults with disabilities are employed and unemployed? Who are they and where do they live?

Data on the population not currently economically active and classified by reason for inactivity may be used for the analysis of potential sources of human resources that are not readily available but that may become so under different circumstances.

What are the types of occupation in which disabled persons work? What sector type are they engaged in? How much do they earn? The answers are critical to understanding the full economic impact of disability. In addition, access to paid work is crucial to achieving self-reliance and ensuring the well-being of adult population, both for persons with and without disabilities. Tabulations by status of economic activity provide a basic measure

of the social and economic integration of the population that may be most disadvantaged.

- Proportion of employed population (5-17¹³, 15-24 and 15-64 years) by disability status/type of disability, educational attainment, sex and geographical area
- Labour force participation rate¹⁴ of population by disability status/type of disability, educational attainment,¹⁵ sex, age and geographical area
- Employment-to-population ratio (employment rate)¹⁶ of population by disability status/type of disability, educational attainment, sex, age and geographical area¹⁷
- Proportion of active population by disability status/type of disability, employment¹⁸ and unemployment status, sex, age and geographical area
- Proportion of employed population by disability status, sector¹⁹ (e.g. manufacturing,²⁰ agriculture, construction and services), sex, age and geographical area
- Proportion of employed population in the major occupational groups²¹ by disability status, sex, age and geographical area
- Unemployment rate²² of population by disability status/type of disability, educational attainment,²³ sex, age and geographical area
- Youth unemployment rate²⁴ of population by disability status/type of disability, sex and geographical area
- Inactivity rate²⁵ of population by disability status/type of disability, educational attainment, sex, age and geographical area
- Proportion of unemployed population by disability status/type of disability, educational attainment, sex, age and geographical area²⁶
- Proportion of youth not in education, employment or training²⁷ (potential youth in

labour market) by disability status, sex and geographical area

- Average hourly earnings of female and male employees, by disability status, occupation, age and geographical area.²⁸

Poverty

Wealth and status can help provide resources for reducing activity limitations and participation restrictions.²⁹ Vulnerable groups such as women, those in the poorest wealth quintile, and older people would have higher prevalence of disability, especially in developing countries. Research shows that persons with disability have lower employment rates, lower educational attainment and higher rates of poverty than persons without disability.

- Proportion of people living below 50 per cent of median income by disability status, employment, education attainment, sex, age and geographical area³⁰
- Ratio of persons with disabilities in employment to the general population in employment by sex and geographical area
- Proportion of population living below the national poverty line by disability status, sex and geographical area.³¹

Violence

Persons with disabilities are at greater risk of violence than those without disabilities. Students with disabilities often become the targets of violent acts including physical threats and abuse, verbal abuse and social isolation.

- Proportion of ever-partnered women and girls (15+ years) subjected to physical, sexual or psychological violence by a current or former intimate partner, in the previous 12 months, by disability status, form of violence, age and geographical area³²
- Proportion of women and girls (15+ years) subjected to sexual violence by persons

other than an intimate partner, in the previous 12 months, by disability status, place of occurrence, age and geographical area³³

- Proportion of persons subjected to physical or sexual harassment, in the previous 12 months, by disability status, place of occurrence, sex, age and geographical area.³⁴

Access

Persons with disabilities often face discrimination and restricted access to services, including those related to information, communication and technology, transport and family planning.

- Proportion of individuals who own a mobile telephone³⁵ by disability status, sex, age and geographical area
- Proportion of individuals using the internet³⁶ by disability status, sex, age and geographical area
- Proportion of population using safely managed drinking water services³⁷ by disability status, sex and geographical area
- Proportion of population using safely managed sanitation services, including a hand-washing

facility with soap and water³⁸ by disability status, sex and geographical area

- Proportion of the population that has convenient access to public transport³⁹, by disability status, sex, age and geographical area
- Proportion of women of reproductive age (between 15 and 49 years) who have their need for family planning satisfied with modern methods⁴⁰ by disability status, age and geographical area.

Benefits

It is also important to monitor the situation of person with disabilities and whether they have access to social services and benefits.

- Proportion of the population covered by social protection floors or systems by disability status, children, the unemployed, old-age persons, pregnant women, newborns, work injury victims, the poor and the vulnerable, sectors, sex, age and geographical area.⁴¹



6

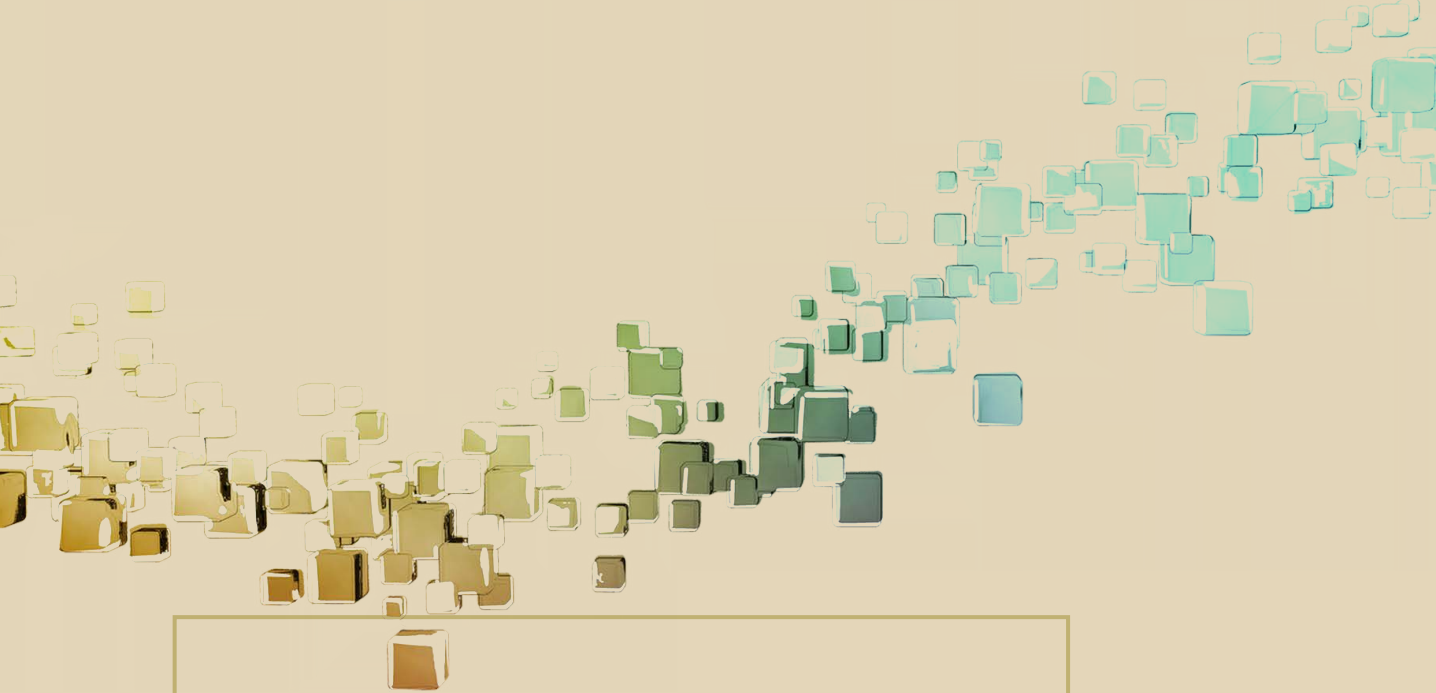
Conclusion and Recommendations

A. Strengths and weaknesses

P. 61

B. Recommendations for moving forward

P. 62



"There is a great demand for public interventions of better and higher quality... only by working together will we fulfil our common goal of leaving no one behind."

"Together, we can remove barriers and raise awareness, so that people with disabilities can play a full part in every sphere of society, around the world."

*Catalina Devandas Aguilar, United Nations
Special Rapporteur on the Rights of Persons with
Disabilities on 12 June 2018, Conference
of signatories to the Convention on the Rights
of Persons with Disabilities at the United Nations
Headquarters in New York*

6. Conclusion and Recommendations

A. Strengths and weaknesses

Arguably, improvements in the collection, analysis and availability of disability statistics are crucial to promote sound evidence-based policymaking and programming decisions. When national household survey and population census data are collected in accordance with WG guidelines, data on disability prevalence is internationally comparable.

The fifth meeting of the ESCWA Task Force for Population and Housing Censuses (2009) recommended the use of the WG-SS on disability in the 2010 Round of Population Censuses (2005-2014), in line with the Principles and Recommendations for Population and Housing Censuses, Revision 2. Accordingly, the number of Arab countries implementing the WG-SS has increased over the years and there are more harmonized data on disability than the previous decade.

The region has accumulated experience in implementing the WG-SS, not only in population censuses, but also in household surveys on such subjects as poverty, labour force, health and household budgets (Table 5). This guidebook

summarizes this experience, reminding readers of the key principles and concepts of the WG-SS approach, and provides statisticians with tips on what to avoid, along with best practices and good national examples to follow.

Nevertheless, some data are not readily available for the purposes of comparable or meaningful analysis. The reasons for this include the lack of comparison with people without disabilities, and that data are not disaggregated nor cross-tabulated into the main socio-economic areas. Moreover, in defining persons with disabilities, some countries disseminated data with a cut-off threshold of “some difficulty” instead of “a lot of difficulty”. However, policymakers have expressed reservation towards the low prevalence rates and requested ESCWA to improve collection methods by including additional domains in order to capture data on the majority of persons with disabilities.

This report has explored the simple to complex approaches of disability data collection and analysis in the Arab countries. Consequently, the current state of disability data collection

Table 5. Selected countries using the WG Short Set on Functioning in census and household surveys

Censuses		Household Surveys	
Jordan	Census 2015	Egypt	LFS 2016
Morocco	Census 2014	Saudi Arabia	DHS 2016
Oman	Census 2010	United Arab Emirates (Abu Dhabi)	LFS 2014
State of Palestine	Census 2007	Yemen	HBS 2014
Qatar	Census 2010	Lebanon	HBS 2011
Tunis	Census 2014	Iraq	I-PMM 2013

and analysis strongly suggest the need for improvement in order to capture data on the majority of persons with disabilities. Therefore, the objectives of the recommendations herein, are to produce and disseminate the harmonization and comparability of disability data at the regional and international levels in the next round of country data collection.

B. Recommendations for moving forward

The complexity of disability has resulted in the proliferation of statistics on disability that are neither comparable nor easy to interpret. Therefore, it is an accomplishment to have most of the Arab countries agreeing and following one standard approach by applying the unified collection method of the WG-SS. However, improvements are required to further extend this collective achievement to obtain comparable analysis at the regional and international levels, and to provide realistic data on the situation of people with disabilities through improving current methods applied by the countries and extending the domains beyond the WG-SS in order to measure other domains of relevance to the region.

Accordingly, ESCWA, in consultation with the mentioned countries and the WG, has developed two sets of recommendations: the first on the Arab Washington Group Extended Short Set on Functioning (AWG-SS+); the second on better implementation of the WG approach.

1. Modified WG-SS for the Arab region

Statistics need to respond to policy needs and countries and, therefore, must compile data on specific domains of difficulty in order to design appropriate programs. A number of countries included in their national questionnaires unspecified domains such as “other” or “multi-difficulty” or “main” as answer options, the information from which is of no value to policymakers. Instead, it is recommended

that countries make better use of the available space within the questionnaire in which specific domains relevant to a specific country could be added. At the regional level, policymakers maintain that upper-body disability like movement of hands and arms are important to measure and would yield higher rates of prevalence at the national and regional levels.

In fact, both Oman and the United Arab Emirates have already considered the upper-body movement domain in their household surveys and censuses. In contrast, Iraq and the State of Palestine have failed to consider the optional WG-SS on “self-care” in their household surveys or censuses for cultural reasons.

Since the domain “self-care” lacks sufficient comprehensiveness and is a sensitive subject to be asked about in some cultures, countries should consider adding two questions under the “self-care” domain relating to the hand and arm functions according to the WG-ES as follows: “Do you have difficulty raising a two-liter bottle of water or soda from waist to eye level?” “Do you have difficulty using your hands and fingers, such as when picking up small objects like a button or pencil, or opening or closing containers or bottles?”. The addition of further questions under “self-care” on “upper-body” movement will be acceptable and more comprehensible by the respondents, and thus yield further information on “self-care” functioning domains and produce accurate and higher prevalence rates.

These two questions, under the “upper body” domain, can be added to the WG-SS six basic activity functioning to constitute the Arab Washington Group Extended Short Set on Functioning (AWG-SS+) to include seven main domains in activity functioning.

Box 26 presents the recommended Arab Washington Group Extended Short Set on Functioning (AWG-SS+) six domains: seeing, hearing, mobility (walking or climbing steps), cognition (remembering or concentrating), self-care, and communication, added to which the upper body domain functioning related to arms and hands functioning.

Box 26. Arab Washington Group Extended Short Set on Functioning (AWG-SS+)

The next questions ask about difficulties you may have doing certain activities because of a **HEALTH PROBLEM**

SEEING

(a) Do you have difficulty seeing, even when wearing glasses?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

If "Cannot do at all" to (a), skip to the next section (Hearing).

(a)_1 Do you wear glasses to see far away?

- 1) Yes
- 2) No

If Yes, include glasses clause in (a)_2.

(a)_2 Do you have difficulty clearly seeing someone's face across a room [even when wearing these glasses]?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

(a)_3 Do you wear glasses for reading or to see up close?

- 1) Yes
- 2) No

If Yes, include glasses clause in (a)_4.

(a)_4 Do you have difficulty clearly seeing the picture on a coin [even when wearing these glasses]?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

HEARING

(b) Do you have difficulty hearing, even when using a hearing aid?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

If "Cannot do at all" to (b), skip to the next section (Mobility).

(b)_1 Do you use a hearing aid?

- 1) Yes
- 2) No

If "No" to (b)_1, skip to (b)_3 and omit [hearing aid clause] in (b)_3 and (b)_4.

If "Yes" to (b)_1, continue with (b)_2 and include [hearing aid clause] in (b)_3 and (b)_4.

(b)_2 How often do you use your hearing aid(s)?

- 1) All of the time
- 2) Some of the time
- 3) Rarely
- 4) Never

(b)_3 Do you have difficulty hearing what is said in a conversation with one other person in a quiet room [even when using your hearing aid(s)]?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

If "Cannot do at all" to (b)_3, skip to the next section (Mobility).

(b)_4 Do you have difficulty hearing what is said in a conversation with one other person in a noisier room [even when using your hearing aid(s)]?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

MOBILITY

(c) Do you have difficulty walking or climbing steps?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

(c)_1 Do you use any equipment or receive help for getting around?

- 1) Yes
- 2) No

If "Yes" to (c)_1, continue with (c)_2.

If "No" to (c)_1, skip to (c)_3.

(c)_2 Do you use any of the following?

- 1) Cane or walking stick?
- 2) Walker or zimmer frame?
- 3) Crutches?
- 4) Wheelchair?
- 5) Artificial limb (leg/foot)?
- 6) Someone's assistance?
- 7) Other (please specify):

If respondent only answers "Wheelchair" to (c)_2, skip to next section (Communication).

Other aid equipment skip to (c)_6.

(c)_3 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block [without the use of aid]?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

If "Cannot do at all" at (c)_3, skip to (c)_5.

(c)_4 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks [without the use of aid]?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

(c)_5 Do you have difficulty walking up or down 12 steps [without the use of aid]?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

If "Cannot do at all", skip to next section (Communication).

(c)_6 Do you have difficulty walking 100 meters on level ground, that would be about the length of one football field or one city block, when using your aid?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

If "Cannot do at all" to (c)_6, skip to next section (Communication).

(c)_7 Do you have difficulty walking half a km on level ground, that would be the length of five football fields or five city blocks, when using your aid?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

COMMUNICATION

(d) Using your usual language, do you have difficulty communicating, for example understanding or being understood?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

(d)_1 Do people have difficulty understanding you when you speak?

- 1) Yes
- 2) No

If "No difficulty" to (d) and "No" to (d)_1, skip to next section (Cognition).

(d)_2 Do you use sign language?

- 1) Yes
- 2) No

COGNITION (remembering or concentrating)

(e) Do you have difficulty remembering or concentrating?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

(e)_1 Do you have difficulty remembering, concentrating, or both?

- 1) Difficulty remembering only
- 2) Difficulty concentrating only
- 3) Difficulty with both remembering and concentrating

If "Difficulty concentrating only", skip to (e)_4.

(e)_2 How often do you have difficulty remembering?

- 1) Sometimes
- 2) Often
- 3) All of the time

(e)_3 Do you have difficulty remembering a few things, a lot of things, or almost everything?

- 1) A few things
- 2) A lot of things
- 3) Almost everything

(e)_4 How much difficulty do you have concentrating for ten minutes?

- 1) A little
- 2) A lot
- 3) Somewhere in between a little and a lot

If difficulty concentrating for ten minutes "somewhere in between a little and a lot of difficulty", continue with (e)_5. Else, skip to next section (Self-care).

(e)_5 Is difficulty ...

- 1) Closer to a little?
- 2) Closer to a lot?
- 3) Exactly in the middle?

SELF-CARE

(f) Do you have difficulty with self care, such as washing all over or dressing?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

UPPER BODY

(g)_1 Do you have difficulty raising a two-litre jug of water or soda from waist to eye level?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

(g)_2 Do you have difficulty using your hands and fingers, such as picking up small objects, for example, buttons or a pencil, or opening or closing containers or bottles?

- 1) No difficulty
- 2) Some difficulty
- 3) A lot of difficulty
- 4) Cannot do at all

Overall disability prevalence is determined according to a response that includes “a lot of difficulty” or “cannot do at all” in at least one of the six domains of functioning. Those with multiple domains at this level of difficulty are counted once. Anyone who has no domain coded “a lot of difficulty” or “cannot do at all” is considered without disability – even if individual domains were coded as “some difficulty”. Only domains with “a lot of difficulty” or “cannot do at all” are counted, thus anyone who has at least one domain coded “a lot of difficulty” or “cannot do at all” is considered with disability – even if individual has other functioning domains coded as “some difficulty”. The same cut-off will apply to individual domains of function: seeing difficulty, walking difficulty etc.

It is important to note that in some countries accessibility to assistive devices by the public may be restricted, especially in rural areas, for low-income families, for those who may not necessarily have access to health insurance, or where the availability – or even knowledge of – hearing aids might be extremely limited, or the devices are imported and thus expensive and may not be subsidized. In such cases, countries may exclude the clause “even when wearing glasses” or “even when using a hearing aid,” from the seeing and hearing questions, respectively. Countries that decide to omit the “assistive devices” clause(s) should provide justification on the extent of availability and use of devices by the public and whether subsidies and/or insurance coverage are applied.

2. Improving the implementation of the WG approach

The WG approach provides standardized tools which, when implemented appropriately, lead to harmonized data. However, implementation practices may differ and, therefore, yield incomparable data. A list of ‘do’s and don’ts’ have been compiled by ESCWA and is based on the actual implementation practices made by the countries in the region to provide tips for better data in the future, as follows:

- i. The recommended approach is to focus on people’s level of difficulty undertaking various activities, to enable comparisons in outcomes between people with and without disabilities, rather than enquiring directly whether or not they have a particular disability; translate questions into the local language; ask questions exactly as written; place the questions before any other questions on disability (if other questions are included); include and read the four response categories; place the WG module at the beginning of a survey or census questionnaire; use the recommended short and simple lead-in statement to make a smooth transition from the previous survey topic; refer only to having difficulty in performing certain activities related to a health issue and not to disability; each domain should be asked through a separate question; questions should be addressed to each single household member; if necessary, a proxy respondent can be used to report for the family member who is incapacitated. Make sure to account for each family member individually rather than ask a blanket question; in the absence of implementing the child functioning module the questions should be asked for five years and above, alternating two different sources one for using the short set of questions every year in a household survey or every ten years in a census, and the extended version every three years in a household survey.
- ii. Key principles to avoid: omitting any of the basic activity functioning; using a screening question or a list of diagnoses; specifying a duration when asking about difficulties; lead-in or introductory statement prior to asking the questions mentioning the term “disability”; making reference to the impact on one’s life resulting from those difficulties; using the word “disability” in the introductory statement, or even the title of the survey; using negative terms; inquiring in general questions on the presence of persons with disabilities in the household; adding the module at the end of the questionnaire; using “other” or “multi-difficulty” or “main” to refer to other unnamed domains; adding causes or any other variable that would affect the recommended sequence of administering the questions.

Endnotes

Introduction

1. The guidebook does not include, however, guidelines on survey sampling, data collection, tabulate, dissemination, etc. Countries may refer to the Guideline and Principals for the Development of Disability Statistics (ST/ESA/STAT/SER.Y/10).

Chapter 1

1. Article 31 can be accessed on the following link: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html>.
2. <https://sustainabledevelopment.un.org/post2015/transformingourworld>.

Chapter 2

1. Old approaches, such as the medical model or charity model approaches, tend to focus policy solely on the individual, “fixing” their condition or supplying them with a safety net.
2. World Health Organization (WHO), 2001.
3. Mont, 2007.
4. Principles and Recommendations for Population and Housing Censuses, Revision 3, (ST/ESA/STAT/SER.M/67/Rev.3), 2015.

Chapter 3

1. http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/WG_Extended_Question_Set_on_Functioning.pdf.
2. http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/Child_Functioning_for_Children_Under_Age_5_Oct-2016_FINAL.pdf.
3. http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/Child_Functioning_for_Children_Age_5_to-17_-Oct-2016_FINAL.pdf.

Chapter 4

1. United Nations Children's Fund (UNICEF), 2008.

Chapter 5

1. P8.1-R Population with and without disabilities by age and sex, UNSD 2nd revision of the Principles and Recommendations for Population and Housing Censuses.
2. Ibid.
3. P8.1-A Total population by disability status, whether living in household or institution, age and sex, UNSD 2nd revision of the Principles and Recommendations for Population and Housing Censuses.
4. P8.2-A Households with one or more persons with disabilities, by type and size of household and sex, UNSD 2nd revision of the Principles and Recommendations for Population and Housing Censuses.
5. P8.3-A Total population 15 of age years and over, by disability status, marital status, age and sex, UNSD 2nd revision of the Principles and Recommendations for Population and Housing Censuses.
6. Ibid.
7. Ibid.
8. P 8.2-R Population 5 years of age and over, by disability status, educational attainment, age and sex, UNSD 2nd revision of the Principles and Recommendations for Population and Housing Censuses.
9. P8.4-A Population 5 to 29 years of age, by disability status, school attendance, age and sex, UNSD 2nd revision of the Principles and Recommendations for Population and Housing Censuses.
10. SDG 4.3.1.
11. P 8.2-R Population 5 years of age and over, by disability status, educational attainment, age and sex, UNSD 2nd revision of the Principles and Recommendations for Population and Housing Censuses.
12. KILM 14d, ILO indicator.
13. SDG 8.7.1.
14. KILM 1, ILO indicator.
15. KILM 14a, ILO indicator.
16. KILM 2, ILO indicator.
17. P 8.3-R Population ... years of age and over, by disability status, current (or usual) activity status, age and sex, UNSD 2nd (employment rate, unemployment rate) revision of the Principles and Recommendations for Population and Housing Censuses.
18. KILM 3, ILO indicator.
19. KILM 4, ILO indicator.
20. SDG 9.2.2.
21. KILM 5, ILO indicator.
22. KLIM 9, ILO indicator and SDG 8.5.2.
23. KLIM 14c, ILO indicator.
24. KLIM 10, ILO indicator.
25. KLIM 13, ILO indicator.
26. KLIM 14b, ILO indicator.
27. SDG 8.6.1.
28. SDG 8.5.1.
29. Grammenos, 2003.
30. SDG 10.2.1.
31. SDG 1.2.1
32. SDG 5.2.1.
33. SDG 5.2.2.
34. SDG 11.7.2.
35. SDG 5.b.1.
36. SDG 17.8.1.
37. SDG 6.1.1.
38. SDG 6.2.1.
39. SDG 11.2.1.
40. SDG 3.7.1.
41. SDG 1.3.1.

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