

LSMS GUIDEBOOK

January 2020

Disability Measurement in Household Surveys

A Guidebook for Designing Household Survey Questionnaires

Marco Tiberti and Valentina Costa

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Marco Tiberti

World Bank

Valentina Costa

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ABOUT LSMS

The Living Standards Measurement Study (LSMS), a survey program housed within the World Bank's Development Data Group, provides technical assistance to national statistical offices in the design and implementation of multi-topic household surveys. Since its inception in the early 1980s, the LSMS program has worked with dozens of statistical offices around the world, generating high-quality data, developing innovative technologies and improved survey methodologies, and building technical capacity. The LSMS team also provides technical support across the World Bank in the design and implementation of household surveys and in the measurement and monitoring of poverty.

ABOUT THIS SERIES

The LSMS Guidebook series offers information on best practices related to survey design and implementation. While the Guidebooks differ in scope, length, and style, they share a common objective: to provide statistical agencies, researchers, and practitioners with rigorous yet practical guidance on a range of issues related to designing and fielding high-quality household surveys. The series aims to achieve this goal by drawing on the experience accumulated from decades of LSMS survey implementation, the expertise of LSMS staff and other survey experts, and new research using LSMS data and methodological validation studies.

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Living Standards Measurement Study (LSMS)

World Bank Development Data Group (DECDG)

lsms@worldbank.org

www.worldbank.org/lsms

data.worldbank.org

Cover images: M. Sabury, M. Goto, J. Issac

Cover design and layout: Deirdre Launt

TABLE OF CONTENTS

ABBREVIATIONS AND ACRONYMS	V
ACKNOWLEDGEMENTS	VI
GLOSSARY	VII
EXECUTIVE SUMMARY	VIII
I BACKGROUND AND DEFINITIONS	I
1.1. UNDERSTANDING DISABILITY AS HUMAN CONDITION.....	I
1.2. UNDERSTANDING DISABILITY RIGHTS AS A DEVELOPMENT GOAL IN THE SDGS	2
2. METHODS FOR DISABILITY MEASUREMENT IN SURVEYS	4
2.1. CONCEPTUAL FRAMEWORK.....	4
2.2. SHORT SET OF QUESTIONS	5
2.2.1. WASHINGTON GROUP – SHORT SET ON FUNCTIONING (WG-SS).....	5
2.2.2. WHO - WORLD HEALTH SURVEY (WHS-SS) & DISABILITY ASSESSMENT SCHEDULE 2.0 (WHODAS 2.0-SS) ...	7
2.2.3. USAID - DEMOGRAPHIC AND HEALTH SURVEYS PROGRAM ON DISABILITIES (DHS-SS).....	8
2.3. EXTENDED SETS OF QUESTIONS.....	8
2.3.1. WASHINGTON GROUP – EXTENDED SET ON FUNCTIONING (WG-ES).....	8
2.3.2. WASHINGTON GROUP – MODULE ON CHILD FUNCTIONING (WG-ES-C).....	8
2.3.3. WASHINGTON GROUP – MODULE ON SCHOOL PARTICIPATION (WG-ES-P)	9
2.3.4. WHO - MODEL DISABILITY SURVEY (MD-ES), DISABILITY ASSESSMENT SCHEDULE 2.0 (WHODAS 2.0 - ES) & WORLD HEALTH SURVEY (WHS-ES)	9
3. MEASURING DISABILITY IN HOUSEHOLD SURVEYS AT THE WORLD BANK	11
3.1. A DISABILITY MODULE FOR MULTI-TOPIC HOUSEHOLD SURVEYS	11
3.2. CHALLENGES IN IMPLEMENTING THE DISABILITY MODULE IN MULTI-TOPIC HOUSEHOLD SURVEYS.....	12
3.2.1. SAMPLING DISABILITY	12
3.2.2. TOPIC IMPLEMENTATION ON MENTAL HEALTH.....	14
3.2.3. TRAINING TO DISABILITY QUESTIONS.....	14
3.2.4. INCLUDING ENVIRONMENTAL FACTORS IN A DISABILITY MODULE	15
REFERENCES	16
ANNEX.....	18

LIST OF FIGURES

Figure 1: The ICF	4
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LIST OF TABLES

Table 1. Definitions of disability	3
Table 2. ICF qualifiers scales for impairments and environmental factors	5
Table 3. ICF qualifiers for activity and participation	5
Table 4. Employment disaggregated by varying disability definitions: adults 18-64 years (WG-SS)	13
ANNEX Table 1A. SDGs that address disability indirectly	18
ANNEX Table 1B. SDGs that address disability directly	20
ANNEX Table 2. Comparing disability question sets	21
ANNEX Table 3. Disability module/questions: comparison between LSMS surveys, DHS-7, and Washington group recommendations	24

ABBREVIATIONS AND ACRONYMS

ADAPT	Able Disabled All People Together (formerly known: The Spastics Society of India)
CIDH	International classification of impairments, disabilities and handicaps
CRPD	Convention on the Rights of People with disabilities
DFAT	Australian Department of Foreign Affairs and Trade
DFID	Department for International Development (UK)
DHS	Demographic and Health Surveys
DPO	Disabled People's Organization
EHIS	European Health Interview Survey
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for Children & Youth
ICIDH	International Classification of Impairments, Disabilities and Handicaps
LSMS	Living Standards Measurement Study
LSMS-ISA	Living Standards Measurement Study – Integrated Surveys on Agriculture
MDS	Model Disability Survey
MICS	Multiple Indicator Cluster Survey
NCHS	National Center for Health Statistics
NHIS	National Health Interview Survey (U.S.)
SAGE	Study on Global Aging and Adult Health
SDGs	Sustainable Development Goals
UN	United Nations
UNDP	United Nations Development Programme
UNECE	United Nations Economic Commission for Europe
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNICEF	United Nations International Children's Emergency Fund
UNSD	United Nations Statistical Division
USAID	United States Agency for International Development
WG	Washington Group on Disability Statistics
WG-ES	Washington Group Extended Set
WG-ES-C	Washington Group Extended Set on Child Functioning
WG-ES-F	Extended Set Functioning
WG-ES-P	Module on School Participation
WG-SS	Washington Group Short Set
WHO	World Health Organization
WHODAS 2.0	World Health Organization Disability Assessment Schedule
WHO-WHS	World Health Organization World Health Survey

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GLOSSARY^I

Functioning – An umbrella term including 1) body functions and structures (anatomy, physiology, and psychology) and 2) activity and participation (communication, mobility, self-care, etc.). The term denotes aspects of the interaction between an individual with a health condition and that individual's contextual factors (environmental and personal factors).

Participation – A person's involvement in a life situation (i.e. marriage or family formation, employment, education, use of the transportation system, etc.). The term represents the societal perspective of functioning.

Impairment – Problem in body function or structure as a significant deviation or loss.

Environment – The external or extrinsic world that forms the context of an individual's life. Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives. These factors are external to the individual and can have a positive or negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure.

Body functions – The physiological functions of body systems, including psychological functions. "Body" refers to the human organism as a whole, including the brain. Hence, mental (or psychological) functions are subsumed under body functions. The standard for these functions is considered to be the statistical norm for humans.

Body structures – The structural or anatomical parts of the body such as organs, limbs, and their components classified according to body systems. The standard for these structures is considered to be the statistical norm for humans.

Activity – The execution of a task or action by an individual. The term represents the individual perspective of functioning.

^I Definitions taken from International Classification of Functioning, Disability & Health (WHO, 2001)

EXECUTIVE SUMMARY

An estimated one billion people worldwide live with disabilities. Of the world's poorest people, one in five live with disabilities, in conditions where they lack material resources as well as opportunities to exercise power, reach their full potential, and flourish in various aspects of life. These numbers are rising particularly quickly in high-income countries, where national populations are growing older at unprecedented rates, leading to a higher incidence of diabetes, cardiovascular diseases, and mental disorders (WHO and World Bank, 2011).

People with disabilities were not listed as a priority in the Millennium Development Goals. As a result, they were excluded from many development initiatives, representing a lost opportunity to address the economic, educational, social, and health concerns of millions of the world's most marginalized citizens (UN, 2011). In contrast, for the 2030 Agenda for Sustainable Development, United Nations member states pledged to leave no one behind, recognizing that development programming must be inclusive of people with disabilities.

To ensure disability-inclusive development, disability data must capture the degree to which society is inclusive in all aspects of life: work, school, family, transportation, and civic participation, *inter alia*. Disaggregating disability indicators will allow us to understand the quality of life of people with disabilities, towards developing programs and policies to address existing disparities.

At the Global Disability Summit in July 2018, the World Bank announced new commitments on disability inclusion.² Responding to the urgent need for accelerated action at scale to achieve disability-inclusive development, one of these commitments recognized the importance of data disaggregation. Specifically, the Bank pledged resources to strengthen disability data by scaling up disability data collection and use, guided by global standards and best practices.

This commitment is aligned with the World Bank's October 2015 pledge to support the 78 poorest countries in conducting household surveys every three years. Regular household surveys are an excellent option for disability measurement, as they can be stratified to oversample people who are more likely to experience limited participation in society. In multi-topic household surveys, disability data can be collected along with other socioeconomic data, enabling a richer analysis of the experiences of people with disabilities. Finally, regular household survey programs can measure the change over time and space in key indicators such as the frequency of types of disability, severity of disability, quality of life, opportunities and participation of people with disabilities, and rehabilitation needs. For example, the recently launched 50x30 initiative may offer a good opportunity to collect disaggregated farm- and rural-related indicators by disability status.³

To facilitate the World Bank's commitment to disability-inclusive development, this guidebook supports the implementation of the Washington Group Short Set (WG-SS) in multi-topic household surveys, towards improving the collection of disaggregated disability data.

The first section presents an overview of definitions of disability from the sociopsychological literature in order to explore how disability is defined and who is considered disabled. The World Bank Group endorses the World Health Organization (WHO) definition of disability as a human and environmental condition, indicating that surveys should capture data on body functions as well as participation restrictions due to contextual conditions (WHO, 2001). The second section looks at three different methods for disability measurement in multi-topic household surveys: the Washington Group (WG) question sets, the World Health Organization (WHO) survey instruments for disabilities, and the Demographic and Health Surveys (DHS) module on disabilities. The final section presents the Functioning

² For further information on WB commitments on disability-inclusive development, please see: <http://www.worldbank.org/en/topic/socialdevelopment/brief/world-bank-group-commitments-on-disability-inclusion-development>

³ The 50x30 initiative was launched at the Data to End Hunger side event during the United Nations General Assembly in October 2018. The initiative brings together a coalition of several multilateral agencies with public and private donors, with the aim of conducting regular surveys of farming households in 50 low and lower-middle income countries by 2030.

Disability Module that comprises the six core WG-SS functional domains (seeing, hearing, walking, cognition, self-care, and communication), to be administered to household members above five years of age (proxy respondents are allowed). These questions avoid the use of terms such as disabilities, handicaps, and suffering, which have negative connotations and may result in the underreporting of conditions (Mont, 2007). The response options – ‘No, no difficulty’, ‘Yes, some difficulty’, ‘Yes, a lot of difficulty’, or ‘Cannot do it at all’ – are read aloud after each of the six questions.

Including the WG-SS in multi-topic household surveys allows for comparing participation levels in education, employment, family, and civic life for people with and without disabilities, thus assisting in assessing equitable access to opportunities. However, several problems remain with collecting disability data in multi-topic household surveys. For example, the low prevalence rate of disability in a random sample can result in inadequate sample size for estimate precision, especially when a stratified sampling strategy is not applied, leading to large standard errors. A stratum specific to disability ensures sufficient sample size for meaningfully precise estimates. However, targeting individuals with disabilities ex-ante cannot be done in multi-topic household surveys that base the selection of primary sampling units on census enumeration frames that contain little to no information on the attributes of the population therein. For example, only 0.92 percent of the population surveyed in the 2010 Living Standards Measurement Study survey in Malawi indicated having at least one serious disability. Small samples can compromise analytical research, limiting the possibility of disaggregating indicators by disability status.

The WG-SS questions are not without limitations. For one, they do not capture the general population under 5 years of age, nor the environmental factors that hinder the participation of people with disabilities in daily life events. In general, data on children with disabilities are better collected by using the WG Child Functioning Module (Loeb et al, 2018; Cappa et al, 2018). Additionally, the WG-SS questions do not capture mental health problems. Major constraints remain on including mental health questions in multi-topic household surveys. In many places, especially low- and middle-income countries with low literacy rates and low indices of mental health support and advocacy, asking someone how often they experience “depression” or “anxiety” would require qualified personnel and additional methodological work on questionnaire design. Mental health and psychosocial functioning questions on anxiety and depression are in their early stages of development and need further cognitive and field testing.

I. Background and Definitions

I.1 UNDERSTANDING DISABILITY AS HUMAN CONDITION

Disability is part of the human condition. Most people will temporarily or permanently experience difficulties in functioning at various points of life, often increasing with age. Regardless of its diffusion, defining disability is not an easy task for project leaders and data analysts. Disability is an evolving concept and has historically been predicated on various models. The now outdated Medical Model initially defined disability as an “impairment” directly caused by a physical disease or an injury that interacts with structures of the body and requires prevention interventions or medical care in the form of treatment and rehabilitation (see Table I). The International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980) developed disability definitions accordingly.

Aside from functions and structures of the body, however, the Medical Model was not able to capture the environmental factors that may create disability by imposing barriers that discourage the participation and inclusion of people with disabilities. The increasing importance of environmental factors in understanding disabilities led to the development of a new Bio-social Model, which identified disability as a social construct that interacts with social perceptions and norms (see Table I). According to this model, people with disabilities do not suffer from their health condition as long as environmental impediments do not exist (WHO and World Bank, 2011). Social inequalities by disability are also compared to those encountered by other minorities based on race, ethnicity, or sex, such as “extraordinary high rates of unemployment, poverty and welfare dependency, school segregation, inadequate housing and transportation, and exclusion from many public facilities” (Hahn, 2002). Societal oppression and discrimination are at the heart of this model, with the environment being the “focal point of action” for a policy agenda on disability (Oliver, 1990; Oliver, 1996).

The ICIDH was thus replaced by the International Classification of Functioning, Disability and Health (ICF), and disability was not only classified as a negative aspect of body functions and structures, but for the first time also referred to activity limitations and participation restrictions (WHO, 2001). According to the ICF's classification, body functions include mental functions; sensory function and pain; voice and speech functions; functions of the cardiovascular, hematological, immunological, and respiratory systems; functions of the digestive, metabolic, and endocrine systems; genitourinary and reproductive functions; neuromusculoskeletal and movement-related functions; and functions of the skin and related structures. These functions are enabled by a complex set of bones, muscles, organs, limbs, and other anatomical parts that compose the body structure. Functions and structures of the body reveal the quality of the individual's health condition, allow the execution of tasks or actions by an individual and affect their involvement in life situations such as learning and applying knowledge, communication and interpersonal social interactions, mobility, and self-care.

For instance, people who suffer from vitiligo have patchy areas of depigmented skin. These patches are initially small, but often grow and change color over time. Vitiligo becomes a major impairment when the loss of skin pigmentation is noticeable, for instance around the eyes, mouth, and hands. Vitiligo does not cause any activity limitation and is a non-contagious autoimmune disease. However, people who have vitiligo may be stigmatized for their condition and isolated due to the unfounded fear of contagion. Thus, they may experience social participation restrictions and depression (WHO, 2001). In contrast, in the case of spinal cord injuries, people experience limitations in body functioning, including partial or complete paralysis, which may effectively limit working activities if buildings lack physical features such as ramps and elevators. Similarly, the lack of accessible information and communication infrastructure in workplaces, such as clear signage and computers equipped with software, can prevent blind people from being employed.

The ICF suggests that technology development, natural environment, social support and relationships, and services and policies are the prominent environmental factors in the perception of one's disability (Maart et al., 2007). Legislation, policy recommendations, capacity building, and technical developments that improve health conditions and prevent impairments all play a key role in improving the overall quality of life for people with disabilities.

Moreover, the ICF recognizes personal characteristics, such as motivation and self-esteem, sex, age, lifestyle, social background, education, profession, past and current experience, and character as factors that influence how disability is experienced by the individual. For instance, in an environment where women are limited in their freedom outside their homes, equipping a woman with a wheelchair will not improve her mobility. The household environment also matters: some people with disabilities face discrimination within the household, such as not being given an equal share of household resources, while others have very supportive families that can help them overcome barriers.

Finally, the recent Human Development Model (Mitra, 2018) defines disability as a deprivation of “functioning” and/or “capability” and/or “agency” in response to the immediate environment (family, home, and workplace), the meso-environment (the community), and the macro-environment (regional, national, and global) (see Table 1). Forced, oppressed, or passive people, with difficulties in reaching their own “functionings” (or personal achievements) and in realizing their own “capabilities” (or practical opportunities) may have low levels of well-being despite having perfectly functional bodies (Sen, 1999). Health deprivation is a necessary but insufficient ingredient for disability in the Human Development Model.

1.2 UNDERSTANDING DISABILITY RIGHTS AS A DEVELOPMENT GOAL

Disability rights is a socioeconomic and human goal, with a bi-directional link to poverty. On one hand, disability may affect socioeconomic conditions, worsening wellbeing for individuals and households. Not only are children with disabilities less likely to attend school, but adults with disabilities are less likely to be employed. When employed, they are often either forced to work in low-paid, low-level positions with poor prospects for career development compared to their peers without disabilities, or are self-employed, facing instability and lack of social protection (ESCAP, 2015). Moreover, households with members with disabilities may have extra

direct and indirect costs resulting from disability⁴ and are thus more likely to experience poverty and deprivation (Mitra et al., 2017).

On the other hand, poverty may increase disability risk, due to a lack of access to appropriate health and rehabilitation services. According to the World Report on Disability, approximately one billion people worldwide and one in five of the world's poorest people have disabilities (WHO and World Bank, 2011). Some recent research in low- and middle-income countries has consistently found that disability is associated with a higher likelihood of experiencing simultaneous multiple deprivations (Hanass-Hancock and McKensie, 2017; Mitra et al., 2013; Trani and Cuning, 2013; Trani et al., 2015, 2016). Poverty is not exclusively determined by lacking material resources but is also a proxy of people's ability to exercise their agency, reach their full human potential, and flourish in society. It is therefore essential to address disability in all programming rather than as a stand-alone thematic issue; in short, addressing disability issues must be mainstreamed into all operations.

In 2006, the United Nations adopted the Convention on the Rights of People with Disabilities (CRPD), making it the first comprehensive human rights treaty of the 21st century. The CRPD provides a framework with which to understand disability, by noting that people with disabilities are *those who have long-term physical, mental, intellectual, or sensory impairments which in interactions with various barriers may hinder their full and effective participation in society on an equal basis with others* (UNDP, 2006). This definition of disability, besides entailing a broad spectrum of impairments, emphasizes the functional, environmental and participatory aspects of disability discussed above. The CRPD establishes a new approach towards people with disabilities. Rather than considering them to be “objects” of charity, medical treatment, and social protection, the CRPD considers people with disabilities as “subjects” with rights, capable of claiming those rights irrespective of their disability. This enables them to be active members of society, making decisions for their lives based on their free and informed consent (see Table 1 below). Furthermore, the CRPD illustrates how various human rights apply to people with disabilities and identifies areas where adaptations must be made to enable everyone to exercise their rights. Article 3 lists the General Principles while Article 5 (Equality and Non-discrimination) address participation and access to edu-

⁴ Direct costs include health services, medications, help with daily activities, and disability-specific aid that the family needs to provide to the family member with disabilities, while indirect costs include foregone economic activities.

cation, employment, family and civic life – in other words, the equalization of opportunities. Article 31 on statistics and data collection is particularly relevant to the collection of data for the abovementioned policy purposes, and will facilitate the monitoring of participation in cultural life, leisure, and recreation (Article 30), as well as work and employment (Article 27).

After years of intense intergovernmental negotiations, United Nations Member States adopted the 2030 Agenda in 2015, which includes 17 goals and 169 targets for sustainable development. The 2030 Agenda makes 11 explicit references to people with disabilities and includes disaggregation of data by disability as a core principle, particularly with regards

to education, growth and employment, inequality, the accessibility of human settlements, and general data collection and monitoring of the SDGs. Table 1A and Table 1B in Annex shows the indicators that directly and indirectly address disability for each goal.

To leave no one behind, development must be inclusive; if not, the gap in outcomes between people with and without disabilities will increase. Collecting data on people with disabilities and the barriers they face is crucial to monitor this requisite inclusivity. The next section presents key methods for disability measurement in household surveys.

Table 1. Definitions of disability

Model	Definition	Framework
Medical Model	Disability is a “impairment” directly caused by a physical disease or an injury that interacts with structures of the body and requires prevention interventions or medical care in the form of treatment and rehabilitation.	International Classification of Impairments, Disabilities and Handicaps (WHO, 1980)
Bio-social Model	Disability is a human and environmental condition due to negative aspects of body functions and on participation restrictions due to contextual conditions.	International Classification of Functioning, Disability and Health (WHO, 2001)
Human Development Model	Disability is a deprivation of “functioning” and/or “capability” and/or “agency” in response to the immediate environment, the meso-environment and the macro-environment.	Capability Approach (Sen, 1999)
Human Right Approach	Disability is a socioeconomic and human right goal linked to poverty bidirectionally.	Convention on the Rights of People with disabilities (UNDP, 2006)

2. Methods for Disability Measurement in Surveys

2.1. CONCEPTUAL FRAMEWORK

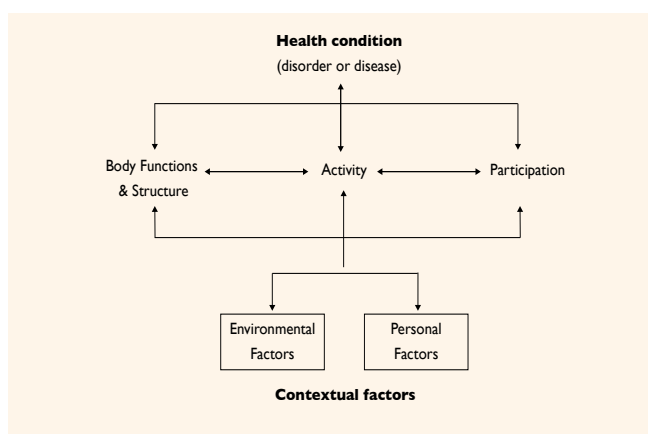
In line with the World Bank endorsement to accelerate global action for disability-inclusive development in key areas such as education, digital development, data collection, gender, post-disaster reconstruction, transport, private sector investments, and social protection,⁵ this section informs project leaders about key advancements made by the international community in measuring disability.

The ICF framework is the first and most commonly used international standard framework that conceptualizes the interconnections between diseases/disability and the environment. The ICF highlights the bi-directional link between health conditions and environmental and personal factors (such as lack of social support, the existence of social barriers, sex, and age), as well as the bi-directional impact of stress and social relationships (see Figure 1).

Disability, thus, is not the same as an impairment (recall our previous example of vitiligo). People have disabilities if their physical, institutional, and cultural environment lacks assistive devices or support networks, and not simply if they, for example, have problems moving their legs.⁶

The ICF framework provides a platform of common language that can be used by different surveys. The first section, on *impairments of body functions*, captures the extent and the nature of mental functions; sensory function and pain; voice and speech functions; functions of the cardiovascular, hematological, immunological, and respiratory systems; functions of the digestive, metabolic, and endocrine systems; genitourinary and reproductive functions; neuromusculoskeletal and move-

Figure 1. The ICF



Source: WHO, 2001

ment-related functions; and functions of the skin and related structures. Body impairments are coded by the appropriate category of impairment and two qualifiers: the severity of the problem on a 0-4 scale, and the nature of the change on a 0-7 scale (see Table 2).

The second section, on *environmental factors*, captures products and technology; natural environment and human changes to environment; support and relationships; attitudes; and services, systems, and policies. As with impairments of body functions, environmental factors are coded by appropriate category and the same two qualifiers: extent and nature of the change. Additionally, environmental factors may have either negative or positive natures (barriers or facilitations, respectively). To quantify the impact of environmental factors on individual functioning, the ICF offers two more options: measuring either the amount of change wrought by the environmental factor on the functioning of the individual, or the difference between performance and capacity observed for the categories on which the specific environmental factor is acting (see Table 2).

⁵ The announcement of the ten commitments took place at the Global Disability Summit in July 2018 in London. The event was co-hosted by the United Kingdom Department for International Development (DfID) in partnership with the Government of Kenya and the International Disability Alliance.

⁶ Further information on ICF are available on <http://www.washingtongroup-disability.com/washington-group-blog/washington-group-questions-consistent-social-model-disability/>

Table 2. ICF qualifiers scales for impairments and environmental factors

ICF codes for **impairments and environmental factors** use the same qualifiers to denote the extent (or severity) of the problem and the nature of the change. Additionally, environmental factors may have either negative (-) or positive (+) natures (barriers or facilitations, respectively).

Code	Extent of the problem	Cut-offs
0	NO problem	0-4%
1	MILD problem	5-24%
2	MODERATE problem	25-49%
3	SEVERE problem	50-95%
4	COMPLETE problem	96-100%
8	not specified	
9	not applicable	

Code	Nature of the change
0	NO change
1	TOTAL absence
2	PARTIAL absence
3	ADDITIONAL part
4	ABERRANT dimensions
5	DISCONTINUITY
6	DEVIATING position
7	QUALITATIVE change
8	not specified
9	not applicable

Source: WHO, 2001

The third section, on *activity limitations & participation restriction*, captures learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas such as education, economic self-sufficient, remunerative employment, and basic economic transactions; and communication and social/civic life. Each category is coded by performance and by capacity, each using a 0-4 scale. The performance qualifier captures the extent of participation restriction by describing an individual's actual performance of an action in their current environment (or "involvement in a life situation"). Meanwhile, the capacity qualifier indicates the extent of activity limitation by describing an individual's ability to execute an action in a standard environment (see Table 3).

Table 3. ICF qualifiers for activity and participation

ICF codes for activity and participation denote the performance and the capacity of the individual in executing certain activities.

Code	Performance/Capacity	Cut-offs
0	NO difficulty	0-4%
1	MILD difficulty	5-24%
2	MODERATE difficulty	25-49%
3	SEVERE difficulty	50-95%
4	COMPLETE difficulty	96-100%
8	not specified	
9	not applicable	

Source: WHO, 2001

Finally, personal factors may convey important information for a complete description of an individual's functioning profile. For instance, despite having the needed capacity, a person may not be employed due to a lack of expertise matching job market requirements. For this reason, the final section of the ICF framework is not coded, but instead contains open boxes for including personal factors.

In line with the ICF's framework, the Washington Group (WG), the World Health Organization (WHO), and the United States Agency for International Development (USAID) have developed short and long question sets, which are examined in the next section.

2.2. THE SHORT SETS OF QUESTIONS

2.2.1. WASHINGTON GROUP - SHORT SET ON FUNCTIONING (WG-SS)

The WG was formed in 2001 to address the urgent need for high quality, comparable disability statistics. It promotes international cooperation in the area of health statistics, based on disability measures suitable for censuses or national surveys and including voices from developing countries. Over several years, the WG developed and tested its Short Set of Questions (WG-SS), which were endorsed by the Inter-Agency Expert Group on the Sustainable Development Goals in 2017. The WG-SS targets individual functioning at the activity level and is intended to provide a fast, low-cost way to collect data that allows for disaggregation by disability status. The WG-SS can be used in censuses, sample-based national surveys (such as multi-topic household surveys), or other data collection formats.

At the Global Disability Summit in July 2018, the World Bank endorsed the WG-SS as the global standard and best practice for scaling up disability data collection and use. These

questions have already been implemented in several surveys supported by the World Bank. For example, they have been included in the following Living Standards Measurement Study – Integrated Surveys on Agriculture (LSMS-ISA) surveys: Ethiopia 2011/12, 2013/14, and 2015/16; Malawi 2011/12; Nigeria 2010/11, 2012/13, and 2015/16 (only seeing question); Tanzania 2010/11 and 2014/15; and Uganda 2009/10 and 2010/11.

The World Bank has already incorporated the full set of WG-SS into the Living Conditions Household Surveys of 23 countries⁷ and some of the WG-SS questions into the 8 Latin American Countries (LAC).⁸

The WG-SS includes questions about an individual's *difficulties* in executing basic activities in six core functional domains. It is intended for a general population of 5 years of age and above (see Table 2 in Annex). The full set of questions should be always administered in the order presented below, with the introductory sentence: "The next questions ask about difficulties you may have doing certain activities because of a health problem".

Q1: Do you have difficulty seeing, even if wearing glasses?

The purpose of this question is to identify people who have vision disability or problems seeing even when wearing glasses (if they wear glasses). Seeing refers to people using their eyes and visual capacity to perceive or observe what is happening around them. *Even if wearing glasses* refers to difficulty of the respondent in seeing with glasses if the respondent has and uses them – NOT how vision would be if glasses, or better glasses, were provided to one who needed them. Any difficulty with vision that is considered a problem by the respondent should be captured.

Each question has four response categories, which are read immediately after each question and capture the full spectrum of functioning from mild to moderate to severe:

1. No, no difficulty
2. Yes, some difficulty (mild)
3. Yes, a lot of difficulty (moderate)
4. Cannot do it at all (severe)

Scaled responses are preferred because they improve the respondents' ability to report their own perception of "difficul-

ty" in doing certain actions, whereas response dichotomies (such as "yes" or "no") tend to force respondents into a category with which they may not want to identify; thus, given only a yes/no option, they may prefer to choose "no" (Mont, 2007).

Q2: Do you have difficulty hearing, even if using a hearing aid?

The purpose of this question is to identify people who have limitations or issues with their hearing even when using a hearing aid (if they wear a hearing aid). Hearing refers to people using their ears and auditory capacity to perceive or observe what is happening around them. *Even if using a hearing aid* refers to difficulty of the respondent in hearing with a hearing aid – NOT how hearing would be if hearing aids, or better hearing aids, were provided to one who needed them. All problems with hearing considered a disability by the respondent should be captured.

Q3: Do you have difficulty walking or climbing steps?

The purpose of this question is to identify people who have limitations or problems of any kind getting around on foot. The capacity to walk (i.e. the use of legs) should be without the assistance of any device (wheelchair, crutches, walker, etc.) or human support. Any difficulty with walking that is considered a problem by the respondent should be captured. Difficulties walking can include those resulting from impairments in balance, endurance, or other non-musculoskeletal systems, for example, blind people having difficulty walking in an unfamiliar place or deaf people having difficulty climbing stairs when there is no lighting.

Q4: Do you have difficulty remembering or concentrating?

The purpose of this question is to identify people who have issues with remembering or focusing attention that may obstruct their daily activities. Remembering should not be equated with memorizing or having a good or bad memory. With younger people, remembering is often associated with recalling facts learned in school. Concentrating refers to the focus needed to complete a particular task. It is the mental ability to accomplish tasks such as reading, calculating numbers, and learning something new. All problems with remembering, concentrating, or understanding the surrounding environment that are considered a problem by the respondent should be captured. Note that difficulties in remembering or concentrating due to high workload, stress, or substance abuse are excluded.

7 Afghanistan, Bangladesh, Bhutan, Eswatini, Gabon, Liberia, Malawi, Namibia, Nigeria, Senegal, South Africa, Tanzania, Uganda, Zimbabwe, Djibouti, Tunisia, West Bank and Gaza, Yemen, Lebanon, Cambodia, Bolivia, Chile, and Mexico

8 Costa Rica, Grenada, Guyana, Peru, St. Kitts and Nevis, St. Lucia, St. Vincent and the Grenadines, and Trinidad and Tobago

Q5: Do you have difficulty with self-care such as washing all over or dressing?

The purpose of this question is to identify people who have problems with taking care of themselves independently. “Washing all over” refers to the ability of a person to clean their own body in a culturally appropriate manner. “Dressing” refers to all aspects of putting on clothing, including the actions of gathering clothing from storage areas (i.e. closet, dressers), securing buttons, tying knots, zipping, and so on. Washing and dressing represent tasks that occur on a daily basis and are considered basic, universal activities.

Q6: Using your usual language, do you have difficulty communicating such as understanding or being understood by others?

The purpose of this question is to identify people who have problems with talking or listening that impede comprehension when using the same language. Communication difficulties can involve mechanical problems such as hearing or speech impairments as well as the inability of the mind to interpret sounds reported by the auditory system, recognize words, or compose/speak a sentence even when the person knows the words. Note that difficulties in understanding or being understood when using a non-native or unfamiliar language are not included.

Finally, the WG-SS questions do not address duration. Based on test results, most of the respondents tend to report difficulties they have in their usual state. For instance, an individual with a broken leg who temporarily has difficulty with walking will answer “no difficulty”, because they usually do not have any difficulty. However, it may be possible that respondents also report temporary difficulties, but the WG does not consider this to be a problem for estimating disability prevalence rate.⁹

2.2.2.WHO - WORLD HEALTH SURVEY (WHS-SS) AND THE DISABILITY ASSESSMENT SCHEDULE 2.0 (WHODAS 2.0-SS)

The first version of the WHO Disability Assessment Schedule (WHODAS) was published in 1999 as an instrument for assessing body functioning, mainly for people with psychiatric disorders. It was implemented between 2002 and 2004 in 70 countries selected to represent all regions of the world. Since

then, it has undergone considerable revisions, leading in 2010 to the WHODAS 2.0, intended to be a single generic instrument for assessing health status and disability. The 12-item version (WHODAS 2.0-SS) is based on the WG-SS domains, with the same categorical response options and taking five minutes on average to be administered. However, there are some key differences with the WG-SS. First of all, the vision and hearing domains are not included, while additional questions are included for other domains: mobility (standing for long periods such as 30 minutes; walking a long distance, such as a kilometer), cognition (concentrating on doing something for 10 minutes; learning a new task, for example, learning how to get to a new place), self-care (washing your whole body; getting dressed), and social interaction (joining in community activities such as festivities, religious or other activities, in the same way as anyone else can; emotionally affected by your health problems; dealing with people you do not know; maintaining a friendship). Secondly, the WHODAS 2.0-SS includes questions on labor impact (taking care of your household responsibilities; impact day-to-day work/school). Another key difference with the WG-SS is related to the reference period. The WHODAS 2.0-SS uses the last 30 days for its reference period, while the WG-SS does not refer to time and the response categories go from 0 (none) to 5 (extreme) (see Table 2 in Annex).

In 2002-2004 the WHO implemented the World Health Survey (WHS) to strengthen national capacity to monitor the responsiveness of health systems and critical health outcomes (such as disability, HIV, and domestic violence) by using comparable household and individual survey instruments. The current version includes household data on health insurance coverage, health expenditures, and indicators of permanent income or wealth, as well as individual-level data on sociodemographic information, health state descriptions, health state valuations, risk factors, chronic conditions, mortality, health care, responsiveness of health systems, and social capital. The WHS addresses disability in its Module on Health State Descriptions, which includes questions on seeing, moving, concentrating, self-caring, and social interaction, but not on communication and hearing domains. Differently from the WG-SS, the module includes additional questions for vision (*‘Do you (does NAME) wear glasses? (Yes/No)’* and *If Yes, ‘in the past 30 days how much difficulty did you have in recognizing a person, you know across the road?’*) and social interaction domains (*‘In the past 30 days how much difficulty did you have in (i) ... personal relationship or participate in the community?; (ii) ... feeling sad or depressed?; (iii) ... dealing with conflicts and tensions? (iv) ... feeling worried or anxious?’*). Moreover, unlike the WG-SS,

⁹ See <http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-2-The-Washington-Group-Short-Set-on-Functioning.pdf> for an explanation of the costs of identifying those with only long-term difficulties.

the module uses the last 30 days for its reference period the response categories go from 0 (none) to 5 (extreme) (see Table 2 in Annex).

2.2.3. DEMOGRAPHIC AND HEALTH SURVEYS PROGRAM ON DISABILITIES (DHS-SS) - USAID

Since 1984, the DHS has provided technical assistance to more than 300 surveys in over 90 countries worldwide on several topics, especially related to health (such as HIV knowledge and prevention, malaria, female genital cutting, and so on). It has also addressed education, domestic violence, nutrition, and tobacco use (Corsi et al. 2012). In 2017, the DHS Program (DHS-7) released a new optional Disability Module, based on the WG-SS, which collects disability data on a 1-4 scale for all people in the household five years of age and older, across six core functional domains. Unlike the WG-SS, vision and hearing sections include an initial Yes/No question on whether the person suffers from the problem (*‘Does (NAME) wear glasses or contact lenses to help them see?’* or *‘Does (NAME) wear a hearing aid?’*), followed by another question on the difficulty of the action (*‘[If YES] I would like to know if (NAME) has difficulty seeing even when wearing glasses or contact lenses’*; *‘[If YES] I would like to know if (NAME) has difficulty hearing even when wearing a hearing aid’*). Moreover, the question on hearing is not administered in countries where hearing aids are not common. The DHS Disability Module is being implemented and tested in several countries and has been endorsed by the United Nations for use in population-based data collection activities (see Table 2 in Annex).

2.3. THE EXTENDED SET OF QUESTIONS

2.3.1. WASHINGTON GROUP - EXTENDED SET FUNCTIONING (WG-ES-F)

The WG developed an *Extended Set of Functioning Questions* (WG-ES-F) to be used in a disability module in a household survey or in a dedicated disability survey (see Table 2 in Annex). The set of questions comprises the six WG-SS core functional domains, with six additional questions on vision (*‘Do you (does NAME) wear glasses?’*), on hearing (*‘Do you use a hearing aid?’*) and mobility (*‘Do you have difficulty moving around inside your home?’*; *‘Do you have difficulty going outside of your home?’*; *‘Do you have difficulty walking a long distance such as a kilometer or equivalent?’*; *‘Do you have difficulty in using your hands and fingers, such as for picking up small objects or opening and closing containers?’*). The extended set questions for cognition, self-care, and communication are as short as the WG-SS questions and have the same response categories.

Unlike the WG-SS, the extended version also includes questions on mental health, such as anxiety (frequency of feeling worried, nervous or anxious; if any medication is taken for these feelings; degree/intensity of these feelings the last time they were experienced), depression (frequency of feeling depressed, if any medication is taken for depression, and degree/intensity of depression), pain (frequency and degree/intensity of the pain), upper-body (difficulty in raising a 2-liter bottle of water or soda from waist to eye level and difficulty in using own hands and fingers for picking up small objects), and fatigue (frequency, degree/intensity and duration of feeling tired and exhausted) (detailed questions are reported in the Annex).¹⁰

Adding these domains increases the number of people with disabilities that can be identified, at the cost and administration time of additional questions. For instance, in the US, the WG-SS yields a 9.5 percent disability prevalence rate, which increases to 11.9 percent when adding Anxiety, Depression, and Upper-Body questions.¹¹

2.3.2. WASHINGTON GROUP – MODULE ON CHILD FUNCTIONING (WG-ES-C)

To complement the WG-ES-F, in 2009 the WG began developing a Module on Child Functioning, coinciding with UNICEF’s plans to revise the data collection module used in its Multiple Indicator Cluster Survey (MICS) program.¹² The *UN Convention on the Rights of People with Disabilities* requires member states to collect appropriate information on children with disabilities, including statistical and research data, to formulate and implement policies that give effect to the UN Convention (Article 31). Disability is different for children and adults: adults face difficulties in mobility, sensory, and personal care, especially with advancing years, while children experience disabilities related to intellectual functioning, affect, and behavior. While the WG-SS can be used for children over five years old, disability prevalence for children under five years of age must be addressed by using a specific module to avoid undercounting.

10 http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/WG_Extended_Question_Set_on_Functioning.pdf

11 <http://www.washingtongroup-disability.com/washington-group-blog/identify-pwd/>

12 The Multiple Indicator Cluster Survey (MICS) program is available online at <https://mics.unicef.org/>

The WG-ES-C module aims to identify the subpopulation of children who are at greater risk of disability relative to other children of the same age, or who are experiencing limited participation in an unaccommodating environment. In particular, the module considers two age groups – 2-4 years and 5-17 years – and captures the level of functioning in the following domains of life: Speech and Language, Hearing, Vision, Learning (cognition and intellectual development), Mobility and Motor skills, and Emotions and Behaviors. Categorical responses are on a 0-4 scale of functional difficulty, as the one used in the WG-SS. To standardize the child's functioning in relation to the child's age, the questions should begin with “*Compared with children of the same age...*”, where appropriate.

After an extensive review by experts and several tests in different countries in order to ensure the quality of questions and the cultural understanding by respondents, a 2017 joint statement issued by multiple UN agencies, member states, organizations of people with disabilities, and other stakeholders recommended this module as the appropriate tool for SDG data disaggregation for children, with the cut-off for disability at level 3 (“*a lot of difficulty*”).

2.3.3. WASHINGTON GROUP – MODULE ON SCHOOL PARTICIPATION (WG-ES-P)

UNICEF and the WG also promote reliable and cross-country comparable data collection to support the right to education for children with disabilities, in line with Article 28 of the Convention on the Rights of the Child (UNICEF, 1989), Article 24 of the Convention on the Rights of People with Disabilities, and Goal 4 of the SDGs. Children with disabilities are usually less likely to ever go to school and more likely to drop out before completing a full course of education. Disability can thus be a significant factor of exclusion from education, putting children at higher risk of negative social and economic outcomes, and preventing their full participation in society.

For this reason, UNICEF and the WG have developed the Module on Inclusive Education (WG ES-P), which addresses three main domains related to potential environmental barriers to education: attitudes, accessibility, and affordability. This set of questions collects information that can inform policy, provides a statistical summary of environmental influences on participation in school, and identifies key areas with bottlenecks to address. The module can be added to other surveys and can be used across a variety of school contexts. The questions focus on education through a formal mechanism (as opposed to home school or tutoring) and are designed to capture the interactions between the participant and the

environment, by obtaining parental or teachers' responses to questions across the three domains.

The first domain is intended for the general adult population, with the purpose of capturing attitudes towards education for all children, and specifically for children with disabilities. The second section is meant to be administered to teachers or caregivers of children who are attending school. It includes questions that evaluate the accessibility of the physical space, the curriculum, and other aspects of the school environment such as teachers' attendance, availability of toilet facilities, and access to social activities. The final component focuses on out-of-school children and attempts to gain a deeper understanding of the environmental barriers to school participation, including safety, transportation, accessibility of the curriculum, and affordability.

The module has already completed several rounds of revision and cognitive testing in India, the US, and Mongolia. UNICEF and WG suggest the use of “*at least a lot of difficulty or not able at all in one domain*” as the cut-off for the disaggregation of outcome indicators (such as school attendance) by disability status. However, for education systems, the WG also suggests the use of the cut-off “*some difficulty*” with accompanying clinical assessment to capture children who require services and learning support.

2.3.4. WHO MODULES: MODEL DISABILITY SURVEY (MD-ES), DISABILITY ASSESSMENT SCHEDULE 2.0 (WHODAS 2.0 - ES) & WORLD HEALTH SURVEY (WHS-ES)

The Model Disability Survey (MDS), developed by the WHO and the World Bank in 2017, is a stand-alone data collection instrument to provide in-depth information for disabled populations at regional or national levels, and to monitor the United Nations Convention on the Rights of People with Disabilities. Designed to be implemented every 5-10 years, the full MDS has 294 questions and takes approximately two hours to administer.

Data on disability are collected in the Health Conditions Module.¹³ The Health Conditions Module collects information on current health conditions or diseases to determine the number of individuals who have health problems and of those, how many receive treatment. An additional fifteen questions

¹³ The full set of questions included in the MDS can be browsed at <http://www.who.int/disabilities/data/model-disability-survey4.pdf?ua=1>. The Environmental Factors Module will be discussed in paragraph 3.4.

cover difficulties with hand and arm use, bodily aches or pains, sleep and energy, breathing, affect, interpersonal relationships, handling stress, household tasks, community and citizenship participation, caring for others, and work and schooling. For instance, the mobility domain includes the following questions: – a. “How much difficulty do you have moving around because of your health?”; b. “Because of your health, how much difficulty do you have doing things that require the use of your hands and fingers, such as picking up small objects or opening a container?”; c. “How much difficulty do you have with shortness of breath because of your health?”; d. “How much difficulty do you have doing household tasks because of your health?”; e. “Because of your health, how much difficulty do you have coping with all the things you have to do?”; f. “How many bodily aches or pains do you have?” (detailed questions of the other domains are reported in the Annex, Table 2). The response categories capture the full spectrum of functioning from mild to severe (1=No, no difficulty; 2=Yes, some difficulty; 3=Yes, a lot of difficulty; 4=Cannot do it at all) (see Table 2 in Annex).

Additionally, the WHO has also developed the ‘Brief Version’ that includes only fundamental MDS modules necessary to describe disability, such as module 3000 (environmental factors), module 4000 (functioning), module 5000 (capacity and health conditions), and a reduced number of questions (38 questions).¹⁴ With ‘only’ 38 questions, the Brief MDS version is intended to be included in health and other specialized surveys, and has already been implemented in national health surveys in Chile (2016-2017)¹⁵ and Brazil (2017).¹⁶

Moreover, the WHO developed an extended 36-item version of the WHODAS that is the most detailed and extended set of questions, capturing the six core domains covered by the WG-SS as well as level of functioning in other domains of life (WHODAS2.0-ES). This includes Cognition (understanding and communicating); Mobility (moving and getting around); Self-care (attending to one’s hygiene, dressing, eating, and staying alone); Getting along (interacting with other people); Life activities (domestic responsibilities, leisure, work, and school); and Participation (joining in community activities,

participating in society, and making friends). The average time to administer this questionnaire is 20 minutes. This extended version has been already administered by the United Nations Economic and Social Commission for Asia and the Pacific in five countries.¹⁷

In addition, the WHO provides a hybrid WHODAS2.0 version that begins with the short-set of 12 questions (WHODAS2.0-SS, explained in section 2.2), which are used to screen for domains of functioning. On the basis of positive responses to these, up to 24 additional questions can be asked. This version can be only administered by interview or computer-adaptive testing (CAT).¹⁸

Finally, the WHO has also developed an extended version of the Module on Health State Descriptions (WHS-ES) that defines ‘The module includes questions on Overall health (mental and physical health); Mobility (moving and getting around); Self-care (attending to one’s hygiene, dressing, eating, and staying alone); Pain and Discomfort (feeling body pains or aches); Cognition (concentrating and remembering things); Interpersonal Activities (joining in community activities, participating in society); Vision (seeing people from far); Sleep and Energy (not feeling rested and refreshed); and Affect (feeling sad or depressed) (see Table 2 in Annex). Questions on Hearing and Communication domains are not included, and the module refers to the last 30 days reference period. Responses are based on difficulty of condition on a 0-4 scale, from none to extreme difficulty.¹⁹

14 The Brief MDS is available on the following websites: <https://www.who.int/disabilities/data/Implementation-guide-Brief-MDS.pdf?ua=1> and <https://unstats.un.org/unsd/demographic-social/meetings/2016/bangkok--disability-measurement-and-statistics/Session-4/WHO.pdf>

15 The national health survey (III Encuesta Nacional de Salud) 2016-2017 of Chile is available on the Ministry of Health website at http://epi.minsal.cl/wp-content/uploads/2018/05/ENS_FI_corr8Mayo.pdf

16 The national health survey (Pesquisa Nacional de Saúde) 2017 of Brazil is available on Brazilian Institute of Geography and Statistics (IBGE) website at <https://www.ibge.gov.br/estatisticas-novoportal/sociais/saude/9160-pesquisa-nacional-de-saude.html?edicao=9177&t=microdados> (click on “Arquivos de Microdados da PNS 2013” updated on March 23rd, 2017)

17 The full questionnaire is accessible at https://www.who.int/classifications/icf/WHODAS2.0_36itemsSELF.pdf

18 The three versions of the WHODAS 2.0 are accessible at https://apps.who.int/iris/bitstream/handle/10665/43974/9789241547598_eng.pdf;jsessionid=3C32F831016AD226EDCA8BD33E71B88F?sequence=1

19 The full questionnaire is accessible at <https://www.who.int/healthinfo/survey/instruments/en/>

3. Measuring Disability in Household Surveys at the World Bank

3.1. A DISABILITY MODULE FOR MULTI-TOPIC HOUSEHOLD SURVEYS

This final section presents a set of key recommendations for implementing a Disability Module in multi-topic household surveys. As the World Bank moves towards a consistent methodology for collecting disability data with National Statistical Offices (NSOs), several factors should be considered in determining the standard set of questions. These include identifying the key indicators and intended purposes for which this data will be used and compared across countries, and deciding whether mental health issues should be included in the disability definition, among others.

Standardization, both in the definition and the harmonization of data collection questions, is required to ensure the international comparability of disability data. Globally, there is increasing consensus that the WG-SS is the most appropriate set of questions to use (unless the focus of the study is on children). This was confirmed by its endorsement from the Disability Data Disaggregation Joint Statement by the Disability Sector, which was signed in 2017 by UN agencies during the fifth meeting of the Inter-Agency Expert Group on the Sustainable Development Goals ‘to ensure international comparability and comparability over time for the purposes of SDG data disaggregation for adults’.²⁰ The WG-SS was also endorsed by several international commissions and institutions, such as the United Nations Statistical Division and the United Nations Economic Commission for Europe. Furthermore, countries in the Asia and Pacific Region, through the United Nations Economic and Social Commission for Asia and the Pacific, have recommended their use, as well as bilateral agencies like DfID and the Australian Department of Foreign Affairs and Trade.

For disaggregation by disability among children, the recommended tool is the UNICEF/Washington Group’s Module on Child Functioning (WG-ES-C).²¹

In line with the global consensus, this guidebook recommends the core set of disability questions of the WG. The WG-SS can be added to any national living standards or multi-topic household survey, typically conducted every three to five years, to capture changes in disability prevalence. It can also be used in specialized surveys; a module for use in Labor Force Surveys (LFS) is currently being field tested, in partnership with the International Labor Organization (ILO).

The purpose of the WG-SS module is to capture comparable data on ‘functional disability’ across time and country, enabling the disaggregation of specific SDG indicators by disability status. To that end, this module focuses on ‘measuring difficulty functioning in six basic, universal actions (capabilities) that, in an unaccommodating environment would place an individual at risk of restricted social participation’.²² The choice of the six domains – seeing, hearing, walking, cognition, self-care, and communication – follows the criteria of simplicity, brevity, universality, and comparability, and refers to the areas that most often limit the participation of individuals living in a variety of countries with different cultures and economic resources. However, as noted in the 3rd revision of the *Principles and Recommendations for Population and Housing Censuses*,²³ seeing, hearing, walking or climbing steps, and remembering or con-

20 The Disability Data Disaggregation Joint Statement by the Disability Sector is available on line at <http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/Joint-statement-on-disaggregation-of-data-by-disability-Final.pdf>

21 The UNICEF/Washington Group module on Child Functioning is available on line at <http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/>

22 <http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-2-The-Washington-Group-Short-Set-on-Functioning.pdf>

23 Document available at https://unstats.un.org/unsd/demographic-social/Standards-and-Methods/files/Principles_and_Recommendations/Population-and-Housing-Censuses/Series_M67rev3-E.pdf

centrating are the four domains considered the most essential in determining disability status from census data in a way that would allow for international comparison. In circumstances where it is not possible to ask all six questions due to time or space constraints (especially in household surveys), these four domains should be included as the essential minimum.

In the process of including this module in household surveys, project leaders should consider the main WG recommendations on reference period, respondents, target population and module position inside the questionnaire. First of all, the WG-SS does not refer to a specific reference period, meaning that it does not address the duration or onset of the disability. Test results suggest that people answering the WG-SS questions report difficulties they have in their usual/ongoing state. Only a small portion of respondents reported having difficulties in one or more of the six domains, if such difficulties were expected to be temporary (for example, limited walking ability because of a leg in a temporary cast).

Secondly, the questions should be self-reported and proxy respondents avoided, except for people who are not capable of responding themselves. Ideally, the data should also include indications of when a proxy respondent is used.

Thirdly, the WG-SS module is intended for the general population five years of age and above. However, due to circumstances of child development and transitions from infancy through adolescence, the WG acknowledges that disability prevalence among those between five and 17 years of age is usually underestimated using the WG-SS. The WG thus developed the Child Functioning Module, which is more appropriate for children from 2 to 17 years of age. However, because the Child Functioning Module may be too long to include in a multi-topic household survey, the WG-SS should also be administered to children between 5 and 17 years of age. Though it may result in an underestimation of the disability prevalence among children and adolescents, it will at least provide an indication of child functioning in the domains covered for this population.

Finally, the Disability Module should be included as a subsection of an individual-level health section, or with the demographic module collecting information on household family members. The WG does not recommend including the module at the end of a questionnaire.

3.2. CHALLENGES IN IMPLEMENTING

THE DISABILITY MODULE IN MULTI-TOPIC HOUSEHOLD SURVEYS

Multi-topic household surveys that intend to capture disability data face two main challenges: setting the best sample size for the information desired and deciding whether to implement mental health questions.

3.2.1. SAMPLING DISABILITY

Multi-topic household surveys can capture information on disability prevalence as well as the characteristics of people with disabilities (i.e. sex, education, occupation, etc.). Sample size is determined by the survey's overall objectives and expands with the degree of disaggregation that the survey intends to capture, such as gender, age, ethnicity, region of residence, or type of disability. Disaggregating data by disability type allows for analyzing the relationship between disability and various demographic or socioeconomic factors like education or employment status. The sample size needed for measuring disability prevalence is smaller than the sample needed for examining the correlation between disability and other characteristics.²⁴

However, in many surveys, the low disability prevalence rate will result in an inadequate sample size for estimate precision, leading to large standard errors in a random sample, especially when a stratified sampling strategy is not applied. According to the WG, a stratum specific to disability ensures sufficient sample for meaningfully precise estimates. However, targeting individuals with disabilities ex-ante cannot easily be done in multi-topic household surveys that base selection of primary sampling units on census enumeration frames that contain little to no health information on the attributes of the population therein. For example, in the LSMS-ISA multi-topic household survey in Malawi (2010), only 0.92 percent of people interviewed had at least a severe disability. Conversely, when the WG-SS are added in census questionnaires, the disability prevalence rate is higher than in multitopic household surveys. For instance, the WG-SS questions were included in the 2009 Vietnam Population and Housing Census (VPHC), and the proportion of households with at least one member who has a severe disability was 5.3 percent (Mont and Nguyen, 2018). In general, small disability samples can compromise analytical research and the possibility of disaggregating indicators by disability status.

Generating a sufficiently large sample of people with disabilities in a general population is the main challenge for

24 Sampling information are available on the WG website at <http://www.washingtongroup-disability.com/washington-group-blog/sampling-blog/>

Table 4. Employment disaggregated by varying disability definitions: adults 18-64 years (WG-SS)

Definition of disabled:	Overall prevalence	% working	
		Without disability	With Disability
1 domain 'some difficulty'	35.4%	76.6%	60.2%
2 domains 'some difficulty'	14.9%	74.6%	48.5%
1 domain 'a lot of difficulty'	6.6%	73.5%	30.8%
1 domain 'unable to do it'	1.2%	71.4 %	14.6%

Source: U.S. National Center for Health Statistics, 2013. Note: Employment disaggregated question is "What was your employment status last week?". Disability status determined by use of the WG-SS (for 6 domains). The disability cut-off is defined in each row according to the first column.

measuring correlations between disability and other factors. Disability prevalence and disaggregation are sensitive to the definition used for disability. For instance, in line with SDG 8.5.2, Table 4 shows employment disaggregated by disability status using data from the 2013 US National Health Interview Survey (NHIS). The NHIS survey includes the WG-SS questions (explained above in Section 2.2). An individual can present different levels of difficulty in one, some, or every domain.

The recommended cut-off for defining a disabled person is *'at least one domain reported as a lot of difficulty'* (highlighted in bold, Table 4). By this definition, the estimates for people 18-64 years of age illustrate that those with a disability are much less likely to be working (30.8 percent) than those without a disability (73.5 percent). Table 4 illustrates how different definitions elicit different results: higher prevalence and less disparity in employment when the cut-off includes those with minor difficulties; and lower prevalence and greater disparity when the cut-off is more restrictive and includes only those with the most severe difficulties.

In developing countries, most of the LSMS-ISA surveys included the WG-SS in different waves to capture the disability prevalence rate and disaggregation in household surveys (see Table 3 in Annex). For instance, the 2011/12 Ethiopian Rural Socioeconomic Survey uses the WG-SS and reports a 2.21 percent prevalence rate of disability (*'a lot of difficulty or not able at all in at least one domain'*) (see Table 3A in Annex). Conversely, the Ethiopia's 2007 Census used a single question asking if the person has *'a problem of seeing, hearing, speaking and/ or standing/ walking/ sitting, body parts movement, functioning of hands/legs or mental retardation or mental problem or mental/ physical damages'* and found a national disability prevalence of 1 percent (CSA, 2007). A single question asking directly about disability tends to capture only very extreme and permanent

disabilities, leading to very low prevalence rates (Mont, 2007).

In the LSMS-ISA surveys, the smallest prevalence of individuals with disability, defined as *'at least a lot of difficulty or not able at all in one domain'*, are reported in Malawi (0.92 percent, or 517 of 56,218 people in IHS3 2010/11), in Uganda (3.05 percent, or 419 of 13,752 people in UNPS 2009/2010, and 2.7 percent, or 343 of 12,693 people in UNPS 2010/2011), and in Nigeria (2.51 percent, or 691 of 27,573 people in NGHS 2010/11, and 2.01 percent, or 555 of 27,573 people in NGHS 2011/12). Larger disability prevalence is reported in Tanzania, where more than 1,500 people have *'at least a lot of difficulty or not able at all in one domain'* (7.86 percent, or 1,616 of 20,562 people in NPS 2010/11).

The low rate of disability prevalence might be due to non-sampling problems, such as question comprehension. For instance, at the beginning of the disability questions, the WG provides a short introductory transition sentence that may not ensure the fully comprehension of the questions by enumerators and respondents. Thus, enumerators need to be well-trained on the WG-SS questions as well as on having an empathic attitude towards the respondent. To better capture disability prevalence, more time and attention should also be dedicated to reviewing how the disability questions are translated, especially the critical words whose meaning might affect the response.²⁵

25 A translated protocol is available at the WG website: <http://www.washingtongroup-disability.com/washington-group-question-sets/translations/>

This guidebook recommends defining people with disabilities as those with at least one domain reported as ‘a lot of difficulty’ or ‘not able to do at all’. We also recommend following the WG instructions on sampling disability in order to ensure international comparability. With regards to disaggregation by disability among children, the recommended tool is the WG-ES-C.

3.2.2. TRAINING ON DISABILITY QUESTIONS

Asking about disability and impairments is not straightforward, particularly in contexts where such impairments are associated with social stigma. Disability is a sensitive topic and to collect high quality data, training on how to interview people with disabilities should receive extra attention.²⁶ Interviewers should be trained on:

- Learning how to interact with people with disabilities, being respectful (as with any other respondent), and asking about difficulties without shame or stigma. This includes finding quiet spaces for the interview, using a sign language interpreter in case of hearing difficulties, or speaking slowly or clearly in case of communication difficulties. In particular, interviewers must refrain from treating respondents like children or using a tone or gestures that imply a certain response option as the “correct” one.
- Understanding and asking the WG-SS questions in terms of difficulties experienced in doing certain activities for whatever reason, and then recording the responses. The WG suggests reading the responses categories only for the first three questions, to avoid straining the respondent’s patience. Words such as ‘disability’ or ‘handicap’ should never be mentioned in the interview process. These terms often conjure a negative impression and tend to result in underreporting of disabilities. Similarly, the word ‘suffering’, which is often associated with disease or illness but not necessarily with the life experiences of a person with disability, should not be used (Mont, 2007). The WG also discourages training the interviewers on the ICF framework and various disability models, as it may create more anxiety about the administration of these questions.

Additionally, the WG-SS questions should be translated using official tested translations. If this is not possible, it is important that the interviewers are trained to interpret the questions in a way that identifies difficulties in doing the six activities and does not refer to disability or impairments; translations that reflect this should be agreed upon prior to fieldwork and used consistently across interviews.

This guidebook recommends giving extra attention to disability data collection during training sessions by encouraging empathic interactions with respondents with disabilities, avoiding the use of the word ‘disability’, and supporting official translations of the WG-SS questions.

3.2.3. MENTAL HEALTH IN DISABILITY MODULES

Sampling and training issues are particularly crucial on mental health and environmental barriers data collection. Questions on mental health disabilities may not be uniformly appropriate across all contexts. In many places, especially low- and middle-income countries with low literacy rates and low indices of mental health support and advocacy, asking about depression or anxiety would require qualified personnel and additional methodological work to define these mental health issues in context and to identify the appropriate questions to use. Questions with these complex concepts should not be added to national multi-topic household surveys, in part because they have not been cognitively tested in low-income countries, and further analysis is needed on cognitive testing in middle-income countries. Regarding an indicator for anxiety or depression, or broader behavior-based questions such as those in the WHODAS2.0 modules or in the WG-ES-F, the same cultural contexts for mental health issues would need to be considered, for example by involving trained professionals in establishing culturally-appropriate questions for common behaviors associated with anxiety and depression.

This guidebook, thus, does not recommend including mental health questions in disability modules for national multi-topic household surveys, as it would increase design and implementation costs and reduce international comparability.

26 <http://www.washingtongroup-disability.com/washington-group-blog/training-ask-disability-questions-censuses-surveys/>

3.2.4. ENVIRONMENTAL FACTORS IN DISABILITY MODULE

The WG-SS does not capture environmental factors. When there is interest in capturing the nature of environmental barriers and the reason for non-participation, additional questions should be included.

Data on environmental barriers and supports are very rarely collected, leading to a limited understanding of the daily life experienced by people with disabilities. Identifying the environmental and attitudinal barriers that hinder the participation of people with disabilities in life events should thus be a priority in the next steps of the disability data agenda. For instance, the Living Conditions Among People with Disability Survey 2013 - Key Findings Report in Zimbabwe (UNICEF, 2013) measured the magnitude of different environmental barriers, including Transport, Other surroundings, Availability of information, Availability of health care, Could not get help at home, Could not get help at work or school, Attitudes at home, Attitudes at school or work, Prejudice or discrimination, Policies and rules of organizations, Government programs and policies, and Natural environment. The response options were daily, weekly, monthly, less than monthly, and never. Natural environment was found to be among the most disabling of the barriers and included situations where people could develop allergies or asthma.

Moreover, since 2013, the WHO collects environmental data by administrating the MDS Environmental Factors Module (module 3000), which identifies environmental factors that may influence health-related daily life problems, such as accessibility, level of social support and/or negative attitudes of others, accessibility of information, and use of medication (module 3000A). The WHO has also developed the 'BriefVer-

sion' for integration in existing and regular household surveys.. However, this version may still be too long for a multi-topic household survey such as an LSMS survey.

For this reason, the WG has partnered with ILO to develop a survey module that addresses barriers to employment for Labor Force Surveys (LFS), and with UNICEF to develop a similar module on education. When publicly released, these modules will provide detailed information on environmental factors affecting employment and education, respectively.

In conclusion, for a complete understanding of persons with disability, a disability module in a multi-topic household survey should capture the immediate environment as well as the factors related to the social and civic activities of individuals. This includes the physical and material features of the environment that an individual comes face to face with, as well as direct contact with others such as family, acquaintances, peers, and strangers. In particular, it should capture information about factors that have a potential impact on health-related daily life problems, such as the accessibility of the broad environment the individual faces (including settings such as home, workplace and school), the level of social support, the attitudes of others, and their social relationships. Moreover, information about the availability and need of personal assistance, assistive technologies, and modifications should be collected at the individual level in a household questionnaire. In addition, questions about environmental and infrastructural barriers should be included in a community level questionnaire. Finally, the integration of geospatial data with multi-topic household surveys should also be explored, to better assess the potential benefit of using geospatial data in understanding the interactions between the environment and people with disabilities at the community level.

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ANNEX

I. Disability by SDGs

Table 1A. SDGs that address disability indirectly

Target	Indicator
Goal 1. End poverty in all its forms everywhere	
1.1. By 2030, eradicate extreme poverty for all people everywhere, currently measured as people living on less than \$1.25 a day	1.1.1. Proportion of population below the international poverty line, by sex, age, employment status and geographical location (urban/rural)
1.2. By 2030, reduce at least by half the proportion of men, women and children of all ages living in poverty in all its dimensions according to national definitions	1.2.1. Proportion of population living below the national poverty line, by sex and age
1.3. Implement nationally appropriate social protection systems and measures for all, including floors, and by 2030 achieve substantial coverage of the poor and the vulnerable	1.3.1. Proportion of population covered by social protection floors/systems, by sex, distinguishing children, unemployed people, older people, people with disabilities, pregnant women, newborns, work-injury victims and the poor and the vulnerable
Goal 3. Ensure healthy lives and promote well-being for all at all ages	
3.3. By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases	3.3.1. Number of new HIV infections per 1,000 uninfected population, by sex, age and key populations
3.8. Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all	3.8.1. Coverage of essential health services (defined as the average coverage of essential services based on tracer interventions that include reproductive, maternal, newborn and child health, infectious diseases, non-communicable diseases and service capacity and access, among the general and the most disadvantaged population)
	3.8.2. Number of people covered by health insurance or a public health system per 1,000 population
Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all	
4.1. By 2030, ensure that all girls and boys complete free, equitable and quality primary and secondary education leading to relevant and effective learning outcomes	4.1.1. Proportion of children and young people: (a) in grades 2/3; (b) at the end of primary; and (c) at the end of lower secondary achieving at least a minimum proficiency level in (i) reading and (ii) mathematics, by sex
4.2. By 2030, ensure that all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education	4.2.1. Proportion of children under 5 years of age who are developmentally on track in health, learning and psychosocial well-being, by sex
4.3. By 2030, ensure equal access for all women and men to affordable and quality technical, vocational and tertiary education, including university	4.3.1. Participation rate of youth and adults in formal and non-formal education and training in the previous 12 months, by sex
4.4. By 2030, substantially increase the number of youth and adults who have relevant skills, including technical and vocational skills, for employment, decent jobs and entrepreneurship	4.4.1. Proportion of youth and adults with information and communications technology (ICT) skills, by type of skill
4.6. By 2030, ensure that all youth and a substantial proportion of adults, both men and women, achieve literacy and numeracy	4.6.1. Percentage of population in a given age group achieving at least a fixed level of proficiency in functional (a) literacy and (b) numeracy skills, by sex

Table 1A. SDGs that address disability indirectly (cont.)

Target	Indicator
Goal 5. Achieve gender equality and empower all women and girls	
5.2. Eliminate all forms of violence against all women and girls in the public and private spheres, including trafficking and sexual and other types of exploitation	5.2.1. Proportion of ever-partnered women and girls aged 15 years and older subjected to physical, sexual or psychological violence by a current or former intimate partner in the previous 12 months, by form of violence and by age
	5.2.2. Proportion of women and girls aged 15 years and older subjected to sexual violence by people other than an intimate partner in the previous 12 months, by age and place of occurrence
5.6. Ensure universal access to sexual and reproductive health and reproductive rights as agreed in accordance with the Programme of Action of the International Conference on Population and Development and the Beijing Platform for Action and the outcome documents of their review conferences	5.6.1. Proportion of women aged 15-49 years who make their own informed decisions regarding sexual relations, contraceptive use and reproductive health care
Goal 10. Reduce inequality within and among countries	
10.3. Ensure equal opportunity and reduce inequalities of outcome, including by eliminating discriminatory laws, policies and practices and promoting appropriate legislation, policies and action in this regard	10.3.1. Proportion of the population reporting having personally felt discriminated against or harassed within the previous 12 months on the basis of a ground of discrimination prohibited under international human rights law
Goal 16. Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels	
16.1. Significantly reduce all forms of violence and related death rates everywhere	16.1.3. Proportion of population subjected to physical, psychological or sexual violence in the previous 12 months
	16.1.4. Proportion of population that feel safe walking alone around the area they live
16.2. End abuse, exploitation, trafficking and all forms of violence against and torture of children	16.2.1. Proportion of children aged 1-17 years who experienced any physical punishment and/or psychological aggression by caregivers in the past month
	16.2.3. Proportion of young women and men aged 18-29 years who experienced sexual violence by age 18
16.9. By 2030, provide legal identity for all, including birth registration	16.9.1. Proportion of children under 5 years of age whose births have been registered with a civil authority, by age
16.b. Promote and enforce non-discriminatory laws and policies for sustainable development	16.b.1. Proportion of population reporting having personally felt discriminated against or harassed in the previous 12 months on the basis of a ground of discrimination prohibited under international human rights law
Goal 17. Strengthen the means of implementation and revitalize the global partnership for sustainable development	
17.8. Fully operationalize the technology bank and science, technology and innovation capacity-building mechanism for least developed countries by 2017 and enhance the use of enabling technology, in particular information and communications technology	17.8.1. Proportion of individuals using the Internet

Source: <https://sustainabledevelopment.un.org/?menu=1300>

Table 1B. SDGs that address disability directly

Target	Indicator
Goal 4. Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all	
4.5. By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including people with disabilities, indigenous peoples and children in vulnerable situations	4.5.1. Parity indices (female/male, rural/urban, bottom/top wealth quintile and others such as disability status, indigenous peoples and conflict-affected, as data become available) for all education indicators on this list that can be disaggregated
4.a. Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, nonviolent, inclusive and effective learning environments for all	4.a.1. Proportion of schools with access to: (a) electricity; (b) the Internet for pedagogical purposes; (c) computers for pedagogical purposes; (d) adapted infrastructure and materials for students with disabilities; (e) basic drinking water; (f) single-sex basic sanitation facilities; and (g) basic handwashing facilities (as per the WASH indicator definitions)
Goal 8. Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all	
8.5. By 2030, achieve full and productive employment and decent work for all women and men, including for young people and people with disabilities, and equal pay for work of equal value	8.5.1. Average hourly earnings of female and male employees, by occupation, age and people with disabilities
	8.5.2. Unemployment rate, by sex, age and people with disabilities
Goal 10. Reduce inequality within and among countries	
10.2. By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status	10.2.1. Proportion of people living below 50 percent of median income, by age, sex and people with disabilities
Goal 11. Make cities and human settlements inclusive, safe, resilient and sustainable	
11.2. By 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, people with disabilities and older people	11.2.1. Proportion of population that has convenient access to public transport, by sex, age and people with disabilities
11.7. By 2030, provide universal access to safe, inclusive and accessible, green and public spaces, in particular for women and children, older people and people with disabilities	11.7.1. Average share of the built-up area of cities that is open space for public use for all, by sex, age and people with disabilities
	11.7.2. Proportion of people victim of physical or sexual harassment, by sex, age, disability status and place of occurrence, in the previous 12 months
Goal 16. Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels	
16.7. Ensure responsive, inclusive, participatory and representative decision-making at all levels	16.7.1 Proportions of positions (by sex, age, people with disabilities and population groups) in public institutions (national and local legislatures, public service, and judiciary) compared to national distributions 16.7.2 Proportion of population who believe decision-making is inclusive and responsive, by sex, age, disability and population group

Source: <https://sustainabledevelopment.un.org/?menu=1300>

2. Short and Extended Sets of Questions by Surveys

Table 2. Comparing disability question sets

	WG-SS	WG-ES	DHS-7	WHODAS 2.0-ES	WHODAS 2.0-SS	WHS-ES	WHS-SS	MDS
INTRO	If ages 5 or older The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.	If ages 5 or older Same as WG-SS	If ages 5 or older Would you say that (NAME) has...?	[no age filter] In the past 30 days, how much difficulty did you have in...	[no age filter] In the past 30 days, how much difficulty did you have in...	[no age filter] In the past 30 days, how much difficulty did you have in...	[no age filter] In the past 30 days, how much difficulty did you have in...	[no age filter] In the past 30 days, how much difficulty did you have in...
ANSWER OPTIONS	1. No - no difficulty 2. Yes - some difficulty 3. Yes - a lot of difficulty 4. Cannot do at all	Same as WG-SS Plus: Read answer options again with each question.	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot [DO IT] at all 8. Don't know	0. None 1. Mild 2. Moderate 3. Severe 4. Extreme	0. None 1. Mild 2. Moderate 3. Severe 4. Extreme	0. None 1. Mild 2. Moderate 3. Severe 4. Extreme	Same as WHS-ES	Same as WG-SS
VISION	1. Do you have difficulty seeing even if wearing glasses?	Do you (does NAME) wear glasses? (Yes/No) Do you have difficulty seeing (even if wearing glasses)?	Does (NAME) wear glasses or contact lenses to help them see? [Yes/No] [If YES] I would like to know if (NAME) has difficulty seeing even when wearing glasses or contact lenses. [If NO] I would like to know if (NAME) has difficulty seeing.	(none)	(none)	Do you (does NAME) wear glasses? (Yes/No) [If YES] ... recognizing a person, you know across the road? ... recognizing an object at arm's length?	Do you (does NAME) wear glasses? (Yes/No) [If YES] ... recognizing a person, you know across the road?	Same as WG-SS
HEARING	2. Do you have difficulty hearing (even if using a hearing aid)?	Do you (does NAME) use a hearing aid? Do you have difficulty hearing (even if using a hearing aid)?	Does (NAME) wear a hearing aid? [Yes/No] ** Exclude in countries where hearing aid is not common. [If YES] I would like to know if (NAME) has difficulty hearing. [If NO] I would like to know if (NAME) has difficulty hearing even when using a hearing aid?	(none)	(none)	(none)	(none)	Same as WG-SS

Table 2. Comparing disability question sets (cont.)

	WG-SS	WG-ES	DHS-7	WHODAS 2.0-ES	WHODAS 2.0-SS	WHS-ES	WHS-SS	MDS
MOBILITY	3. Do you have difficulty walking or climbing steps?	Same as WG-SS PLUS, Additional recommendations*: Do you have difficulty moving around inside your home? Do you have difficulty going outside of your home? Do you have difficulty walking a long distance such as a kilometer (or equivalent)? Do you have difficulty in using your hands and fingers, such as for picking up small objects or opening and closing containers?	Same as WG-SS Note: in all cases where DHS-7 is "Same as WG-SS", the sentence is a bit different ("I would like to know if (NAME) has difficulty..." but the content/task is identical.	... standing for long periods such as 30 minutes? ... standing up from sitting down? ... moving around inside your home? ... getting out of your home? ... walking a long distance, such as a kilometer?	... standing for long periods such as 30 minutes? ... walking a long distance, such as a kilometer?	... moving around? ... doing vigorous activities (such as running 3km or cycling?)	... moving around?	Same as WG-SS PLUS: How much difficulty do you have moving around because of your health? Because of your health, how much difficulty do you have doing things that require the use of your hands and fingers, such as picking up small objects or opening a container? How much difficulty do you have with shortness of breath because of your health? How much difficulty do you have doing household tasks because of your health? Because of your health, how much difficulty do you have coping with all the things you have to do? How many bodily aches or pains do you have?
	4. Do you have difficulty remembering or concentrating?	Same as WG-SS	Same as WG-SS	... concentrating on doing something for 10 minutes? ... remembering to do important things? ... analyzing and finding solutions to problems in day-to-day life? ... learning a new task, for example, learning how to get to a new place? ... generally understanding what people say? ... starting and maintaining a conversation?	... concentrating on doing something for 10 minutes? ... learning a new task, for example, learning how to get to a new place?	... concentrating and remembering things? ... learning a new task?	... concentrating and remembering things?	Same as WG-SS PLUS: How much difficulty do you have learning a new task because of your health?
SELF-CARE	5. Do you have difficulty (with self-care such as) washing all over or dressing?	Same as WG-SS	Almost the same as WG-SS I would like to know if (NAME) has difficulty washing all over or dressing.	... washing your whole body? ... getting dressed? ... eating? ... staying by yourself for a few days?	... washing your whole body? ... getting dressed?	... washing or getting dressed by yourself? ... maintaining your general appearance?	... washing or getting dressed by yourself?	Same as WG-SS PLUS: Because of your health, how much difficulty do you have toileting?

Table 2. Comparing disability question sets (cont.)

	WG-SS	WG-ES	DHS-7	WHODAS 2.0-ES	WHODAS 2.0-SS	WHS-ES	WHS-SS	MDS
COMMUNICATION	6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	Same as WG-SS	I would like to know if (NAME) has difficulty communicating when using his/her usual language.	(as in cognition) ... generally understanding what people say? ... starting and maintaining a conversation? (see below)	(see below)	(none)	(none)	Same as WG-SS PLUS: Because of your health, how much difficulty do you have on starting, sustaining and ending a conversation?
SOCIAL INTERACTION & EMOTIONAL HEALTH	(none)	(none)	(none)	... how much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can? ... how much of a problem did you have because of barriers or hindrances in the world around you? ... how much of a problem did you have living with dignity because of the attitudes and actions of others? ... how much time did you spend on your health condition or its consequences? ... how much have you been emotionally affected by your health problems? ... how much of a problem did your family have because of your health problems? ... how much of a problem did you have in doing things by yourself for relaxation or pleasure? ... dealing with people you do not know? ... maintaining a friendship? ... getting along with people who are close to you? ... making new friends? ... sexual activities?	... how much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can? ... how much have you been emotionally affected by your health problems? ... dealing with people you do not know? ... maintaining a friendship? ... getting along with people who are close to you? ... making new friends? ... sexual activities?	... how much of a problem did you have in joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can? ... how much have you been emotionally affected by your health problems? ... dealing with people you do not know? ... maintaining a friendship?	... personal relationship or participate in the community? ... feeling sad or depressed? ... dealing with conflicts and tensions? ... feeling worried or anxious?	... personal relationship or participate in the community? ... feeling sad or depressed? To what extent do you feel sad, low or depressed because of your health? To what extent do you feel worried, nervous or anxious because of your health? Because of your health, how much difficulty do you have getting along with people who are close to you, including your family and friends?
LABOR IMPACT	(none)	(none)	(none)	... taking care of your household responsibilities? ... doing your most important household tasks well? ... getting all the household work done that you needed to do? ... getting your household work done as quickly as needed? ... your day-to-day work/school? ... doing your most important work/school tasks well? ... getting all the work done that you need to do? ... getting your work done as quickly as needed? ... have you had to work at a lower level because of a health condition? ... did you earn less money as the result of a health condition?	... taking care of your household responsibilities?	(none)	(none)	Same as WG-SS PLUS: • How much difficulty do you have with your day-to-day work or school because of your health?

Source: Own compilation

3. WG-SS across LSMS-ISA surveys

Table 3. Disability module/questions: comparison between lsms surveys, dhs-7, and washington group recommendations

	Washington Group 6 core questions (and some recommended*) <i>Proposed additions for the 2016 Extended Set are indicated in italics.</i>	DHS-7	Malawi IHS3 2010/11	Uganda - UNPS 2009/10 and 2010/11	Ethiopia – E(R) SS 2011/12, 2013/14 and	Tanzania – NPS 2010/11	Nigeria – GHS 2010/11 and 2012/13
INTRO	If ages 5 or older The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.	If ages 5 or older	If ages 5 or older	If ages 5 or older: Because of a physical, mental or emotional health condition...	Asked of all ages in 2011, asked only for ages 5+ in following years	If ages 5 or older: Because of a physical, mental or emotional health condition...	No age filter
ANSWER OPTIONS (UNLESS OTHERWISE INDICATED)	a. No - no difficulty b. Yes - some difficulty c. Yes - a lot of difficulty d. Cannot do at all <i>Read answer options again with each question.</i>	Would you say that (NAME) has...? 1. No difficulty (seeing) 2. Some difficulty 3. A lot of difficulty 4. Cannot (see) at all 5. Don't know	1. No difficulty 2. Yes - some difficulty 3. Yes - a lot of difficulty 4. Cannot perform activity at all	1. No - no difficulty 2. Yes - some difficulty 3. Yes - a lot of difficulty 4. Cannot (see) at all	1. No difficulty 2. Yes - some difficulty 3. Yes - a lot of difficulty 4. Cannot perform activity at all	1. No, not at all 2. No, no difficulty with assistive device 3. Yes, some difficulty 4. Yes, a lot of difficulty 4. Cannot perform	1. No. no difficulty 2. Yes. some 3. Yes. a lot 4. Cannot (see)
VISION	<i>Do you (does NAME) wear glasses?</i>	26. Does (NAME) wear glasses or contact lenses to help them see? 1= Yes 2=No	(none)	(none)	(none)	(none)	(none)
	1. Do you have difficulty seeing (even if wearing glasses)?	27. [If 26=1] I would like to know if (NAME) has difficulty seeing even when wearing glasses or contact lenses. 28. [If 26=2] I would like to know if (NAME) has difficulty seeing.	Same as WG	Does [NAME] have difficulty seeing, even if he/she is wearing glasses?	Same as WG	Same as Uganda	Same as WG
HEARING	<i>Do you (does NAME) use a hearing aid?</i>	29. Does (NAME) wear a hearing aid? **This question may be excluded in countries where wearing a hearing aid is not common.	(none)	(none)	(none)	(none)	(none)
	2. Do you have difficulty hearing (even if using a hearing aid)?	30. [If 29=1] I would like to know if (NAME) has difficulty hearing. 31. [If 29=1] I would like to know if (NAME) has difficulty hearing even when using a hearing aid? **This question may be excluded in countries where wearing a hearing aid is not common.	Same as WG	Does [NAME] have difficulty hearing, even if he/she is wearing a hearing aid?	Same as WG	Same as Uganda	Same as WG

Table 3. Disability module/questions: comparison between lsms surveys, dhs-7, and washington group recommendations (cont.)

	Washington Group 6 core questions (and some recommended*) Proposed additions for the 2016 Extended Set are indicated in italics.	DHS-7	Malawi IHS3 2010/11	Uganda - UNPS 2009/10 and 2010/11	Ethiopia – E(R)SS 2011/12, 2013/14 and	Tanzania – NPS 2010/11	Nigeria – GHS 2010/11 and 2012/13
HEARING (CONT.)	2. Do you have difficulty hearing (even if using a hearing aid)?	30. [If 29=1] I would like to know if (NAME) has difficulty hearing. 31. [If 29=1] I would like to know if (NAME) has difficulty hearing even when using a hearing aid? ** This question may be excluded in countries where wearing a hearing aid is not common.	Same as WG	Does [NAME] have difficulty hearing, even if he/she is wearing a hearing aid?	Same as WG	Same as Uganda	Same as WG
MOBILITY	3. Do you have difficulty walking or climbing steps?	34. I would like to know if (NAME) has difficulty walking or climbing steps.	Same as WG	Does [NAME] have difficulty walking or climbing steps?	Same as WG	Same as Uganda	Same as WG
	(none)	(none)	(none)	(none)	(none)	(none)	Additional (all Y/N): Can you do vigorous activities like running, lifting heavy objects, participating in sports or doing hard labor? Can you walk uphill? Can you do activities such as bending over or stooping? Can you walk over 100 meters? Can you walk more than one kilometer?
COGNITION	4. Do you have difficulty remembering or concentrating?	33. I would like to know if (NAME) has difficulty remembering or concentrating.	Same as WG	Does [NAME] have difficulty remembering or concentrating?	Same as WG	Same as Uganda	Same as WG
SELF-CARE	5. Do you have difficulty (with self-care such as) washing all over or dressing?	35. I would like to know if (NAME) has difficulty washing all over or dressing.	Do you have difficulty (with self-care such as) washing all over or dressing, feeding, toileting, etc.?	Does [NAME] have difficulty (with self-care such as) washing all over or dressing, feeding, toileting, etc.?	Same as Malawi	Same as Uganda	Same as Malawi
COMMUNICATION	6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?	32. I would like to know if (NAME) has difficulty communicating when using his/her usual language.	6. Using your usual language, do you have difficulty communicating, for example understanding or being understood?	Using your usual [NAME OF LANGUAGE] language, does [NAME] have difficulty communicating, for example, understanding or being understood?	Same as Malawi	Same as Uganda	Same as Malawi

Table 3. Disability module/questions: comparison between lsms surveys, dhs-7, and washington group recommendations(cont.)

	Washington Group 6 core questions (and some recommended*) Proposed additions for the 2016 Extended Set are indicated in <i>italics</i> .	DHS-7	Malawi IHS3 2010/11	Uganda - UNPS 2009/10 and 2010/11	Ethiopia – E(R)SS 2011/12, 2013/14 and 2014/15	Tanzania – NPS 2010/11	Nigeria – GHS 2010/11 and 2012/13
ONSET	(none)	(none)	(none)	(none)	For each question: year of onset any of the above answer codes 2-4:	For each question: How old was [NAME] when the difficulty seeing began?	For each question: How old were you when the difficulty (seeing) began?
LABOR IMPACT	(none)	(none)	Asked once per HH member if any of the above answer codes 2-4: Does this difficulty reduce the amount of work [NAME] can do at home, at work or at school? 1= Yes, all the time 2= Yes, sometimes 3= No 4= NA (If not working or not attend- ing school) Separate answers for (a) at home, (b) at school, and (c) at work.	Same as Malawi	Asked once per HH member if any of the above answer codes 2-4: Does this difficulty reduce the amount of work you can do at home, at work or at school? 1= Yes, all the time 2= Yes, sometimes 3= No 4= NA (If not working or not attending school)	Same as Malawi	Same as Malawi
REHABILITATION	(none)	(none)	During the past 12 months, what measures are taken to improve [NAME]'s performance of activities? 1= None 2= Surgical operation 3= Medication 4= Assistive devices (glasses, wheel- chair, braces, hearing aid, artificial limbs) 5= Special education 6= Skills training (vocational) 7= Activity of Daily Living (ADL) training 8= Counseling 9= Spiritual/traditional healer 96= Other (specify)	Same as Malawi	(none)	Same as Malawi	Same as Malawi

