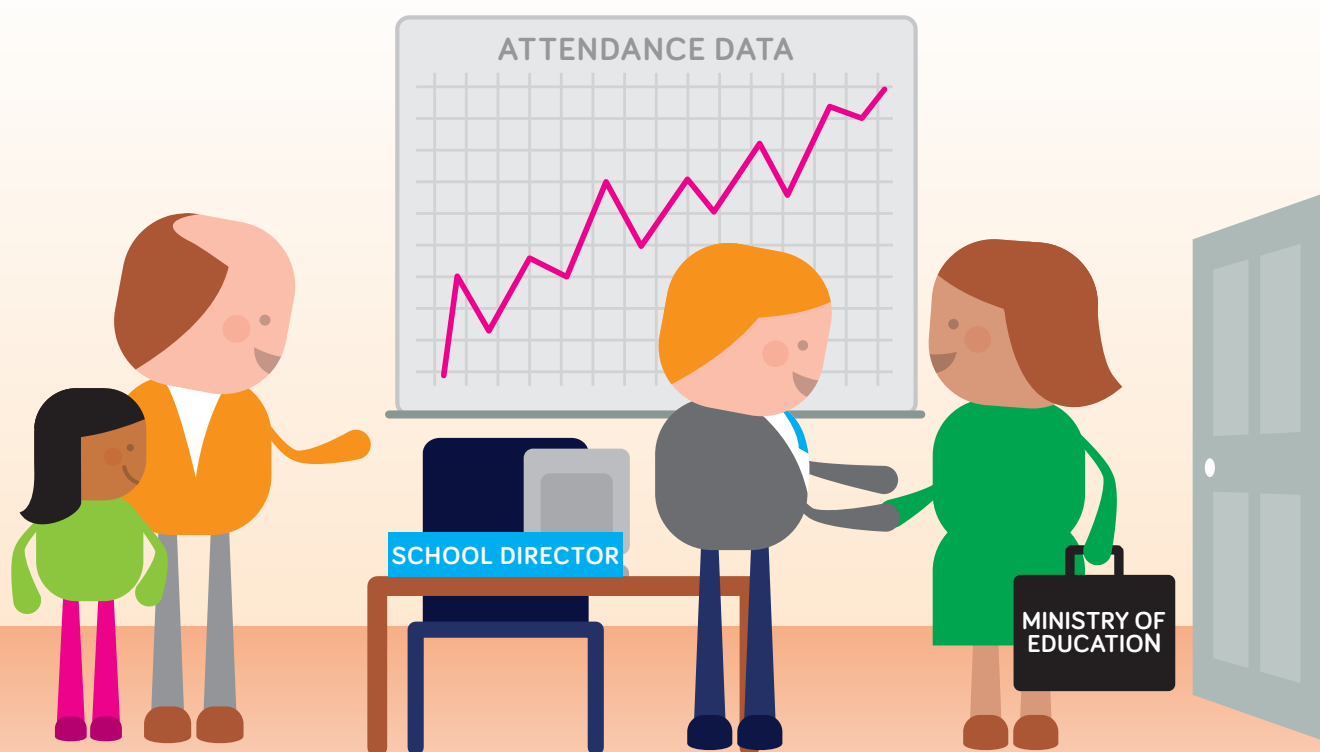


Collecting Data on Child Disability

Webinar 4 - Companion Technical Booklet



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With major thanks to Australian Aid for its strong support to UNICEF and its counterparts and partners, who are committed to realizing the rights of children and persons with disabilities. The Rights, Education and Protection partnership (REAP) is contributing to putting into action UNICEF's mandate to advocate for the protection of all children's rights and expand opportunities to reach their full potential.

Collecting Data on Child Disability

Webinar Booklet

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What this booklet can do for you

The purpose of this booklet and the accompanying webinar is to assist UNICEF staff and our partners to understand why data on disabled children are currently inadequate, the difficulties that surround the gathering of high-quality data on disabled children, and why there is a real need to improve the collection, analysis, dissemination and use of **disability** data.

In this booklet you will be introduced to:

- *How a lack of high-quality data is adversely affecting evidence on child disability.*
- *How this compromises the ability of countries to ensure disabled children achieve their true potentials.*
- *What the key considerations are for data collection, analysis and dissemination.*
- *What the main challenges are to gathering child-disability data.*
- *How reliable data are central to advocating for anti-discriminatory policy, and to foster the inclusion of disability on political agendas.*

For information on the following related topics, refer to the other modules in this series:

1. Conceptualizing Inclusive Education and Contextualizing it within the UNICEF Mission
2. Definition and Classification of Disability
3. Legislation and Policies for Inclusive Education
4. Collecting Data on Child Disability (*this booklet*)
5. Mapping Children with Disabilities Out of School
6. EMIS and Children with Disabilities
7. Partnerships, Advocacy and Communication for Social Change
8. Financing of Inclusive Education
9. Inclusive Pre-School Programmes
10. Access to School and the Learning Environment I – Physical, Information and Communication
11. Access to School and the Learning Environment II – Universal Design for Learning
12. Teachers, Inclusive, Child-Centred Teaching and Pedagogy
13. Parents, Family and Community Participation in Inclusive Education
14. Planning, Monitoring and Evaluation

How to use this booklet

Throughout this booklet you will find keywords highlighted in bold. They are included in a glossary at the end of the document.

If, at any time, you would like to go back to the beginning of this booklet, simply click on the sentence "Webinar 4 - Companion Technical Booklet" at the top of each page, and you will be directed to the Table of Contents.

To access the companion webinar, just scan the QR code



Acronyms and Abbreviations

CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled People's Organization
ICF	International Classification of Functioning, Disability and Health
NGO	Non-Governmental Organization
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

I. Introduction

Children with disabilities have the same right to an education as any other child, as set out in the Convention on the Rights of the Child (CRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). However, reliable statistics on children with disabilities remain limited in quantity, quality and scope, especially in low- and middle-income countries. This makes it difficult to gauge how many are in or out of school, why they are out of school, and what the environmental barriers are that can affect their full participation in school settings.

The current evidence on child disability is affected by the lack of data, but also – when data have been collected – by the use of different definitions, questionnaires and methodologies, which has made comparisons between countries and over time problematic. Limited availability and poor quality of data on children with disabilities have stemmed, in some cases, from a limited understanding of what child disability is and, in other cases, from stigma or insufficient investment in improving measurement. While there is now general agreement that definitions of disability should incorporate social determinants, the measurement of disability is still predominantly medical, with a focus on specific physical or mental impairments. Data on participation restrictions and environmental factors are rarely collected and yet are essential for constructing a complete understanding of disability and identifying areas for programme and policy intervention. This includes, for example, the identification of discriminatory attitudes, physical and communication barriers, as well as gaps in legislation and the delivery of inclusive services. There is currently no established best practice for producing comprehensive and reliable statistics on children with disabilities and this has long compromised the ability of countries and the international community to monitor the well-being of these children and make sure that they are included in policies and programmes that support the achieving of their full potential.

When studies have been implemented, evidence has concurred that children with disabilities are among the most disadvantaged in terms of school participation.¹ Too often, children with disabilities experience participation restrictions because education systems are not adapted or equipped to meet their needs, lacking everything from accessible school buildings to teachers who have been trained to teach in **inclusive settings**. Household survey data from 13 low- and middle-income countries show that children with disabilities aged six to 17 years are significantly less likely to be enrolled or be attending school than their peers without disabilities.² In particular, a 2004 study in Malawi found that children with disabilities were twice as likely to have never attended school as children without disabilities.³ In India, a country that has achieved close to universal enrolment in primary education, out of 2.9 million children with disabilities, 990,000 of them aged six to 14 years (34 per cent) are out of school. The percentages are even higher among children with intellectual disabilities (48 per cent), speech impairments (36 per cent) and multiple disabilities (59 per cent) (SRI-IMRB Survey, 2009). Children living with blindness and participating in integrated classes in selected public schools in Cambodia stated that their teachers did not like them and were not as attentive as they were with other children.⁴

The lack of reliable and comparable data on children with disabilities – their number, the nature of their disabilities, and their educational needs – only adds to the serious challenges they face to their education, making it difficult to develop effective policies and interventions designed to improve their well-being. Reliable data are essential to understanding the contributions of environmental factors that act as barriers to, or facilitators of, full participation of children with disabilities. As such, reliable data are central to gaining the confidence of decision makers and the greater community when advocating for anti-discriminatory policy and programming, and to foster the inclusion of disability on national and international political agendas. Having comparable statistics can also highlight international and intra-national inequities between

different populations of children with disabilities, for example by ethnicity, sex, age, region or type of impairment.

The UN Convention on the Rights of Persons with Disabilities encourages states to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention (Article 31).

The importance of improving statistics on children with disabilities has also been stressed by the UN General Assembly 2011 – special session on ‘Status of the Convention on Rights of the Child’.

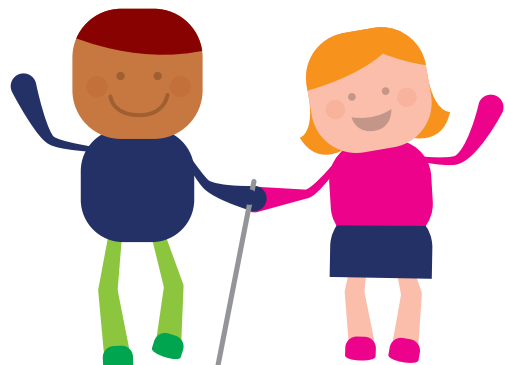


II. Frameworks for the Measurement of Child Disability

When estimating the prevalence of disability in a given population, the conceptual framework used to collect data has a significant impact on the results. The definition of ‘disability’ has evolved over time. The **medical model of disability**, which identifies children based on a diagnosis and focuses on impairments or diseases (e.g., cerebral palsy, blindness, deafness, spina bifida, etc.) has been replaced by a bio-psycho-social definition that incorporates a child’s functional ability in multiple domains. Medical diagnoses and prevalence estimates that focus on impairments and diseases may be useful for planning medical and some rehabilitation interventions, but may under-identify/estimate children with disabilities, which – according to the bio-psycho-social model of disability – includes children with functional difficulties undertaking basic life activities (regardless of cause). In line with the UNCRPD, “people with disabilities include those who have long-term physical, mental and intellectual or sensory impairments which in interaction with various attitudinal and environmental barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1). The adoption of the UNCRPD and the bio-**social model of disability** have produced a shift in the conceptualization of disability, which has in turn generated new and challenging demands in terms of data. This includes the need to collect information both on personal and environmental factors and their interaction, in addition to information about impairments. Most efforts related to the collection of data on disability have so far focused on the identification of impairments and conditions at the individual level, while much less attention has been given to the understanding of the barriers created by society that may prevent children with impairments from enjoying their fundamental rights.

As discussed in Booklet 2 in this series, *Definition and Classification of Disability*, the International Classification of Functioning, Disability and Health (ICF) provides a broad theoretical framework for classifying health-related human functioning and takes into account the multidimensional and interactive nature of disability.⁵ While the ICF does not provide specific directions, questions or specific technical details about measurement of disability, it does offer useful categorizations that can be used to guide the development of comprehensive measures of disability because they capture the complex, interactional nature of the life experiences of children with disabilities and their families. From a statistical point of view, collecting data on impairments alone provides a low prevalence of disability in a population and does not provide a complete picture of the living experience of disability, neither in an individual nor in a population. For example, blindness and deafness will identify a small sub-population of children with severe impairments, but will not offer comprehensive accounts of how such conditions affect their lives. In other words, knowing that a child is blind, deaf, or has cognitive or mobility impairments does not tell us anything about how these impairments affect the child’s participation in their community.

Rather than asking solely about impairments, assessments of disability that are consistent with the ICF would ask about activity limitations and differences in functioning at different levels. Adding some measurement of environmental factors, both facilitators and barriers, makes the data collection both more complex and more complete. The ICF also offers a common language with which to classify functioning, allowing for comparability of disability data within and between countries.⁶ Furthermore, using the ICF as a framework for measurement allows the extent



III. Overview of Data Sources

A wide range of data collection methods are available to gather information on disability, including:

- Censuses.
- Surveys.
- Administrative records.
- Clinical assessments.
- Qualitative studies.

The method of data collection chosen is dictated to some extent by the context of the country in which the study will be conducted. With regards to children specifically, high-income countries are often capable of identifying children with disabilities through infrastructure such as educational and medical settings or national registries. However, in many low- and middle-income countries, children with disabilities might not be adequately identified when schooling or other formal services are lacking. In this instance, other methods of enumeration such as censuses and targeted household surveys have commonly been used to estimate disability prevalence.

Each method described provides different information to answer questions about child disability. For example, household surveys querying children's school participation are different from administrative records containing school enrollment data, because participating in school is not necessarily the same as enrollment. Therefore, each of these methods can be used to measure different aspects of child disability, each having its own merit and limitations. If more than one method is used, in a coordinated fashion, then the strengths of each method will be preserved and the limitations of each avoided.

Censuses

A population census represents a complete enumeration of the entire population because it is a nationwide activity with every person enumerated separately and their characteristics recorded separately. In most national statistical systems, population censuses are the principal sources of statistics on population and its characteristics. Characteristics may include age, sex, household structure, migration, wealth, language, religion, education, employment, occupation and disability. Although this broad range of topics can be included in a census, most topics can be covered only briefly because of budgetary, personnel and time constraints. Population censuses are, therefore, large-scale statistical operations requiring considerable resources, organization and preparation, and are typically carried out every 10 years over the entire nation.

Surveys

Surveys are designed to be administered to a sample selected by some other instrument (often a census) and focus on answering specific questions about a population. Population-based surveys are not intended to enumerate every household or individual in the country; rather, they are designed to be representative of the total population under study. Population-based surveys cover many different and often specialized topics such as health, welfare, labour force, agriculture and other socio-economic issues. During a population-based survey, assessors investigate and record facts, observations and experiences from the sample. When compared to other methods of identifying children with disabilities, population-based surveys

that specifically address the issue of child disability, or that incorporate measures designed specifically to evaluate disability in children, have produced more reliable data that can be compared internationally.

Administrative Records

Governments regularly collect statistics to monitor and manage policy and programmes. Schools, health facilities and other institutions regularly report data on child disability. These data are then used to gauge **outcomes** in relation to national goals and plans, and to determine future development policies, plans and management arrangements. Administrative data collections can take several forms, depending on the nature of the service, the format used, the type of information collected and the method and frequency of collection.⁸ Some examples are population registers, social-security systems, early childhood centres, rehabilitation programmes, assistive device services and other services specifically designed to serve the needs of children with disabilities.

The information is usually collected for reasons concerning the administration of the programme, but can be useful for collecting data on children with disabilities as they often provide unique information that is not captured in a census or survey. For example, access to rehabilitation services over time can be tracked, or records of school attendance can be used as a comparison of the attendance rates of children with disabilities and non-disabled children. Furthermore, these data are often collected annually, which provides a source for data over time on numbers and characteristics of service users, and the type, quantity and cost of services provided.

Clinical Assessments

Clinical assessments provide detailed, comprehensive information on children's functioning within domains and as a summary across domains. Any clinical assessment can be used to provide group-level or population-level data, similar to that in a census⁹, by aggregating across groups.¹⁰

Clinical assessments typically include the taking of a child's history and a physical examination. Questions are asked about prenatal, perinatal and postnatal events and the child's acquisition of developmental milestones. Health records are often consulted, if available, as they can be a valuable source of information, because they contains details of pregnancy, mode of delivery, condition at birth, Apgar scores and birth weight, etc. Observation of the child also provides invaluable information for the assessment, as can reports from parents and other adults, such as school teachers. The information-gathering process is relatively lengthy and detailed, often including developmental testing by a variety of professionals, and team meetings with professionals and parents. The results of the diagnostic assessment are then used to identify and secure appropriate intervention services for children whose development is delayed.

In settings where resources are available to conduct clinical assessments of children found to have activity limitations, the assessment can be enhanced to include and provide documentation of the results of diagnostic tests. Such documentation can be extremely useful for epidemiologic studies of the causes of disability, for planning and monitoring the effects of prevention strategies, for guiding treatment, and for counselling parents and affected children. For treatable causes of impairments associated with disability, such as cataracts, accurate and timely diagnoses are essential because they provide a basis for treatments that can eliminate the activity limitations and associated participation restrictions. Therefore, although diagnostic assessments to determine underlying causes or medical classifications of disability are not essential for the purpose of estimating the frequency of disability in the population, these assessments may be useful or even essential for other purposes.

Qualitative Studies

Sometimes, issues or needs of children with disabilities cannot be assessed by using information that is expressed entirely in numbers, such as percentages, amounts, frequency or size – herein referred to as quantitative data. Quantitative methods, such as censuses and surveys, have their strengths in identifying universalities and making statistical or probabilistic generalizations, and in determining the correlation between two measurable phenomena. But they may not answer questions like ‘Why?’ or ‘How?’ There can also be limitations to using quantitative methods for child disability data collection. For example, the low prevalence rates of different impairment groups can make it difficult to draw statistical conclusions about group differences, and the heterogeneity of impairments, activity limitations and participation restrictions make controlling for variance difficult.^{11,12} To mitigate some of these limitations, qualitative methods may need to be added to the data-collection effort. Qualitative methods are ways of gathering reliable information that cannot be expressed in numbers, such as people’s motives, opinions and feelings, and may include questions such as:

- Why don’t families of children with disabilities take advantage of educational programmes for which they are eligible?
- What are the perceptions of non-disabled children of children with disabilities attending school?
- What are children who use mobility devices’ experiences of using these devices in their schools?

Qualitative methods are better for investigating subjective meanings within a culture, understanding attitudes and beliefs, and unravelling the dynamic constructs of culture and social traditions.¹³ This makes qualitative methods particularly useful for understanding child disability in context¹⁴ and for including the perspectives of children.¹⁵ A secondary-school student with visual impairment quoted in Yamaoka’s study in Ghana provides an example: “When the teachers write on the board, they ask me if I can see it. I can see the board, but sometimes teachers’ handwriting is weak and sometimes they write small. But when I complain to teachers, they start writing big”.¹⁶ Furthermore, as many countries have a dearth of data on child disability, qualitative methods can be appropriate and effective when little or nothing is known about the situation, as questions can be tailored to the local context.¹⁷

Notes

IV. Key Considerations for Data Collection, Data Analysis and Dissemination

Careful planning, design and implementation is required in order to collect high-quality data, whether the goal is to collect data to estimate the prevalence of disability in a group of children or to identify barriers and facilitators to school participation for children with activity limitations. While each data collection effort will face its own particular challenges, there are many common issues to consider, as summarized here:

Planning	Design	Implementation
<ul style="list-style-type: none"> Define scope and objectives. Select indicators. Identify relevant content. Explore ethical implications. 	<ul style="list-style-type: none"> Determine methods. Select tools. Design sample. 	<ul style="list-style-type: none"> Carry out public awareness-raising campaign. Carry out data collection. Assemble and train data-collection team. Establish a referral plan.

In all stages, engaging local collaborators, field workers, local authorities, government agencies and DPOs/NGOs, local-community members, participants and their families will enhance the success of the data-collection effort. Early involvement of the disability community is also imperative because they are often best informed about the needs, priorities and goals of persons with disabilities. Sound information enables governments, DPOs/NGOs and communities to provide services for children and their families – including education programmes.

Data on child disability can be most effectively used to assess the participation and equalization of opportunities for children with disabilities when they are properly analyzed, interpreted and presented to all stakeholders. To maximize the data’s usefulness, it will be important to identify the target audiences and their needs and to take that into account when presenting the results.

To convey more meaningful information to policy-makers and programme planners, tabulations should show the characteristics of children with disabilities in terms of their disability experience as well as their socio-economic and environmental attributes. A comprehensive analysis plan for the child disability data should include cross-tabulations comparing children with and without disabilities on key social and economic characteristics. Including non-disabled children provides a reference population against which the participation and equalization of opportunities of children with disabilities can be assessed. Data analysis can be as simple as converting the number of children with disabilities into a percentage of the overall population, or as complex as employing sophisticated mathematical modeling techniques to interpret the data.

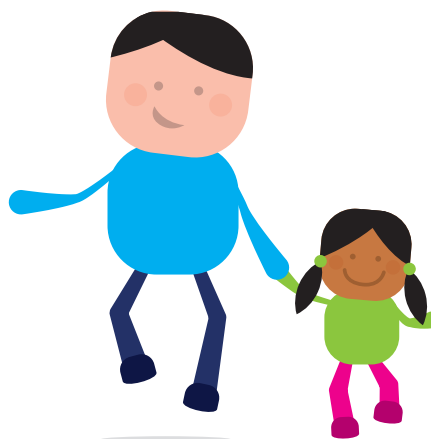
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V. Challenges Affecting Child Disability Data

While many countries have collected data on disability as part of general surveys on their adult populations, children have been less visible in the data-collection agenda. The literature clearly indicates that household surveys and censuses that include general questions about people with disabilities of all ages inadequately identify children with disabilities.¹⁸ Research suggests that children might be overlooked in surveys that do not ask specifically about them.¹⁹ Children of low socio-economic status and girls in general might be particularly under-enumerated by this type of general-data collection instrument. Censuses are particularly prone to underestimation. The UN Statistics Division explicitly highlights in its *Principles and Recommendations for Population and Housing Censuses, Revision 1*, regarding the inclusion of disability as a topic, that: “The limited number of questions included in a census cannot provide a precise measure of the number of people with disability, especially among children...”²⁰

Targeted household surveys designed specifically to address the issue of child disability or those that incorporate measures designed specifically for children have produced better results.²¹ However, even these types of studies can misreport disability if one set of questions is applied to children of all ages. It is generally agreed that capturing disability among children below two years of age may not be feasible through population surveys, given the complex developmental processes that take place at such a young age. Additionally, children are constantly developing and in transition – from infancy to middle childhood, and from middle childhood to adolescence – and their ability to perform certain basic activities changes from one stage of life to another. In measurement terms, this implies the need for specific questions that can reflect the developmental stages and evolving capacities of children of different age groups, which further complicates data-collection efforts.

An additional measurement challenge is due to the fact that the collection of data on children with disabilities relies on the information provided by a proxy respondent. Household surveys and censuses are self-report with questions that are typically posed to parents or other caregivers. Although parents/caregivers often do very well at identifying whether their children are having difficulties performing specific tasks, their responses alone are not sufficient to establish a prevalence of disability. For example, the Micronutrient Status Survey in Tajikistan conducted in 2008 asked respondents the following question: “Are there children under the age of five in this household with the following disabilities: blindness, deafness, motor disability, mental disability?” In this example, parents/caregivers are assumed to be in a position to adequately judge what disability is, and whether their child has a disability or not. In many developing countries, most children have not been previously screened for impairments and parents may not be able to detect, by themselves, manifestations of certain conditions. Even when questions are designed to capture functional difficulties rather than health conditions, parental knowledge of norms and standards, expectations about children’s performances, attitudes towards children’s rights and opinions about their role in families and communities can impact estimates of disability. Properly designed and tested questions are therefore needed to reduce the influence of parental perception in the assessment of children’s abilities, and to get a reliable account of the environmental factors that may affect children’s participation.



VI. Overview of Data Availability

The disparities in the methodologies used to gather child-disability data have contributed to major challenges in producing reliable and comparable international disability statistics. Prevalence rates of disability are extremely sensitive to, and affected by, the way in which disability is defined. The definition of disability has not been consistent over time, across locations, and between data-collection efforts. The way disability is defined impacts what data are gathered, including who is identified as having a disability.²² Practically all countries in the world have collected some information on disability. The majority of countries having completed more than one survey on disability have been collecting data for a very long time (dating back to the early 1800s in some cases), and over the past 50 years the inclusion of disability questions on censuses and surveys has grown dramatically. However, inconsistency in defining and measuring disability has resulted in information that varies in character and quality, hampering our understanding of the scope and nature of disability in children.

As mentioned earlier, questions posed to adults are often inappropriate or not applicable for children (for example, questions about falling over, memory loss, etc.), yet many surveys have applied a single set of questions to both adults and children to assess disability status. The following question was used to determine the prevalence of disability for the entire population (including children) in the 2011 Montenegro Census of Population, Households and Dwellings: “Does the person have any disability that prevents him/her from performing everyday activities due to long lasting illness, invalidity or old age?” Making explicit reference to the elderly/invalid population is clearly not relevant for assessing functioning difficulties among children and introduces a bias in the respondent’s mind in terms of what should be considered as disability.

Asking a generic or filter question on whether there is anyone in the household who is disabled also poses challenges in producing reliable disability statistics for children. For example, in the Sierra Leone 2004 Population and Housing Census, the household head was asked the following question of each member of the household: “Is (name) disabled?” The broad nature of this question means that the interpretation of what constitutes a disability is left entirely to respondents. Not surprisingly, the reported disability prevalence rates were unusually low: below one per cent for those under the age of 25 and about two per cent for those aged 25 years and above. The question used in the 2004 Census in Jordan was: “Does any member of the household suffer from any handicap?”, and the corresponding prevalence data on disability was about one per cent for both children aged 0-14 and persons aged 15 and older. In recent years, more countries have used data-collection Instruments based on a more detailed listing of conditions and a broader focus on functioning. Examples include the set of questions used to determine the prevalence of disability for the entire population (including children) in the 2009 Disability Survey conducted in the United Republic of Tanzania.

As a result of such variation in the design of questions, reported disability prevalence rates for child disability range from below one per cent to close to 50 per cent across countries. Countries with low reported child disability prevalence rates include, for example, Afghanistan, Angola, Argentina, Burkina Faso, Canada, Cambodia, Chad, China, Colombia, Egypt, El Salvador, Greece, Jordan, Lesotho, State of Palestine, Oman, Rwanda, South Africa, Uzbekistan and Viet Nam. At the other end of the scale, countries with high reported child disability prevalence rates include Armenia, Australia, Belize, Bhutan, Central African Republic, Ethiopia, Macedonia, Madagascar, Maldives, New Zealand, Suriname and Yemen. The economic and social development of these countries represent a wide continuum ranging from low to high income with pronounced differences also in cultures, disease patterns, mortality levels and experiences of conflict or disasters caused by natural hazards.

VII. Conclusions

While data on disability are inadequate and much needed for the overall population, children represent a special group that deserves particular consideration – but one that poses special measurement challenges. Large information gaps remain in what is known about disability among children. These include how many children experience limitations and how the environment (including physical, social and attitudinal factors) affects children's participation in their communities. There is a clear need to improve the collection, analysis, dissemination and use of data on disability and to harmonize measurement tools in order to produce estimates that are reliable, valid, comprehensive and internationally comparable. Furthermore, there is a need to collect such information over time to support monitoring of disability-related policies and programmes. This would facilitate appropriate policy and programmatic responses by governments and their international partners, and thus fulfill the requirements of the Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child.

UNICEF Child Disability Measurement Initiatives

Many initiatives are currently being undertaken by UNICEF and its partners to address the need for cross-nationally comparable and reliable data on children with disabilities. These include the design and testing of new questionnaires as well as the development of guidelines for the collection, analysis and dissemination of data.

UNICEF/WG Module on Child Functioning and Disability

UNICEF and the United Nation's Washington Group on Disability Statistics (WG)²³, has developed and tested a new data-collection module on child functioning and disability for use in household surveys and censuses.

In line with the bio-psycho-social model of disability, the module focuses on the presence and extent of functional difficulties rather than on body function and structure or conditions, i.e. causes of those difficulties. These functional difficulties may place children at risk of experiencing limited participation in an unaccommodating environment.

The module covers core domains of functioning for two age groups: two to four years of age and five to 17 years of age. Common domains to both age groups are: seeing, hearing, walking, communication, cognition/learning and behaviour. Included specifically for the younger age group are fine motor functioning and play, while domains for the older cohort include self-care, emotions, attention and coping with change and relationships.

The module has been presented, discussed and revised at several expert consultations since 2011, involving representatives of Disabled People's Organizations, academic institutions, international organizations and national statistical offices. The module has undergone extensive cognitive testing to determine the quality of the questions being asked and ascertain the cultural understanding by the respondents. The module has been tested in India, the USA, Belize, Oman and Montenegro. Field testing has taken place in Cameroon, India, Italy, Haiti and Samoa, and is planned to take place in one more country in early 2015. UNICEF and the WG are also working on the development of a manual to support implementation of the module. The module and manual are expected to be ready for actual data collection and use by countries at the end of 2015.

UNICEF/WG Module on Inclusive Education

UNICEF and the WG are developing a new survey module to measure the school environment and children's participation in education. The module measures the barriers and facilitators to education by children with or without disabilities. This module will complement the module on child functioning and disability. Together, they will provide a comprehensive measurement of disability – assessing functional difficulties as well as children's interactions within their environment. The module will cover: attitudes, accessibility, getting to school and affordability.

The purpose of this set of questions is to provide information that can inform policy, to provide a statistical summary of environmental influences on participation in school, and to identify areas with key bottlenecks that can be followed-up on. The set of questions can be added to another survey. The questions focus on education through a formal mechanism and environmental factors that influence participation in that education. The questions have been designed to capture the interaction between the participant and the environment because to understand problems encountered in school by students with disabilities, it is necessary to explore the interaction of the student and environmental factors involved in participation. Once finalized, the module will undergo cognitive testing and field testing. It is expected to be ready for actual data collection and use by countries in late 2016.

Guidelines on the Measurement of Child Disability

This document will provide guidance for those considering collecting data on children with disabilities. The guidelines discuss conceptual and theoretical issues related to measuring disability in children and review methods and tools that have previously been used to collect data in this area. Considerations for designing, planning and implementing a child disability data collection effort are presented. The guidelines are currently being drafted with inputs from several international experts. They are expected to be finalized in early 2016.

Notes

Glossary of Terms

Disability. Article 1 of the CRPD describes people with a disability as “those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

Inclusive Education is ‘a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the state to educate all children’ (See Booklet 1).

Inclusive Setting is a place (school, college, community learning centre, etc.) where all students can learn and participate meaningfully together.

Medical Model of Disability explains disability as a health problem or medical condition of an individual that can be treated with medical assistance. Therefore, disability is the result of the medical condition. The individual with a disability is seen as being in need of a cure, and it is the health professional's responsibility to alleviate his/her pain and suffering. (*UNICEF challenges this model wherever it is encountered in order to support the systemic introduction of a social model of disability – see Booklet 1*).

Outcomes are intentional, expected effects of an educational system.

Pedagogy is commonly used within education to refer to the act of teaching together with its attendant discourse. It is what one needs to know, and the skills one needs to command.

Social Model of Disability explains disability results from interactions between an individual with a specific physical, intellectual, sensory or mental health impairment and the surrounding social and cultural environment. Disability is therefore understood as a socio-political construct, whereby the attitudinal, environmental and institutional barriers that inherently exist within society systematically exclude and discriminate against people with disabilities. It is only with removal of the barriers that disability can be reduced. (*This is the model UNICEF advocates – see Booklet 1*).

Washington Group is a group established by the UN Statistical Commission to come up with recommendations for improved internationally comparable measures of disability for monitoring and evaluation. Its membership is open to the national statistical offices of all UN member countries. The UN Statistical Commission names its groups after the first city they meet in, hence the name Washington Group. Their website is http://www.cdc.gov/nchs/washington_group.htm.

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23. The WG is a voluntary working group made up of representatives of over 100 National Statistical Offices and international, non-governmental and disability organizations. It was organized under the aegis of the United Nations Statistical Division and has been in existence since 2001. The main purpose of the WG is the promotion and coordination of international cooperation in the area of health statistics focusing on disability measures suitable for censuses and national surveys. Its major objective is to provide basic necessary information on disability that is comparable throughout the world. A major accomplishment of the Washington Group has been the development, testing and endorsement of a short set of questions that can be used in censuses, sample-based national surveys or other statistical formats for the

