PRODUCING DISABILITY-INCLUSIVE DATA

WHY IT MATTERS AND WHAT IT TAKES

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Suggested citation: United Nations Children's Fund, 'Producing Disability-Inclusive Data: Why it matters and what it takes', UNICEF, New York, 2020.

ACKNOWLEDGEMENTS

The preparation of this publication was led by Claudia Cappa and Filipa de Castro (Data and Analytics Section, UNICEF Headquarters).

The publication was edited by Lois Jensen and designed by Era Porth.

PHOTO CREDITS

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PROMOTING THE **RIGHTS OF PERSONS WITH DISABILITIES** THROUGH INCLUSIVE STATISTICS

To ensure no child is left behind, even in the most difficult circumstances, it is important to have high-quality data that account for all children. For example, various global commitments ensure the rights of children with disabilities. However, the scarcity of reliable data, particularly in low- and middle-income countries, can prevent the fulfilment of this obligation. Little is known about the number and characteristics of children with disabilities. Even less is known about their living conditions and quality of life, or the barriers they face in attending school, accessing services and participating in cultural and recreational activities.

When not represented in official statistics, children and adults with disabilities remain politically and socially 'invisible'. Their marginalization is heightened and they become more vulnerable to possible human rights violations. Moreover, their invisibility in mainstream monitoring efforts means that they are likely to be overlooked in strategic policy planning and in emergency preparedness, mitigation and response.

Closing this gap, and generating information that reflects the experience of everyone, requires appropriate inclusion strategies. Inclusivity affects all stages of the data generation process and involves important considerations – from the design of studies to the dissemination of results.

The production of inclusive data demands the involvement of persons with disabilities in all data collection processes. This will help ensure that their experiences and needs are adequately reflected in the evidence being generated. This involves:

- Using data collection **instruments and protocols** that allow the disaggregation of key indicators according to disability status
- Developing and implementing **accommodation strategies** to ensure that persons with disabilities can participate in surveys, censuses and programme evaluation data collection.

Different data collection efforts face different challenges, yet there are common issues to consider when planning, designing and implementing inclusive data collection. The goal of this publication is to provide general recommendations that can be applied through a combination of judgement and careful decision-making during the various stages of the evidence-generation process.

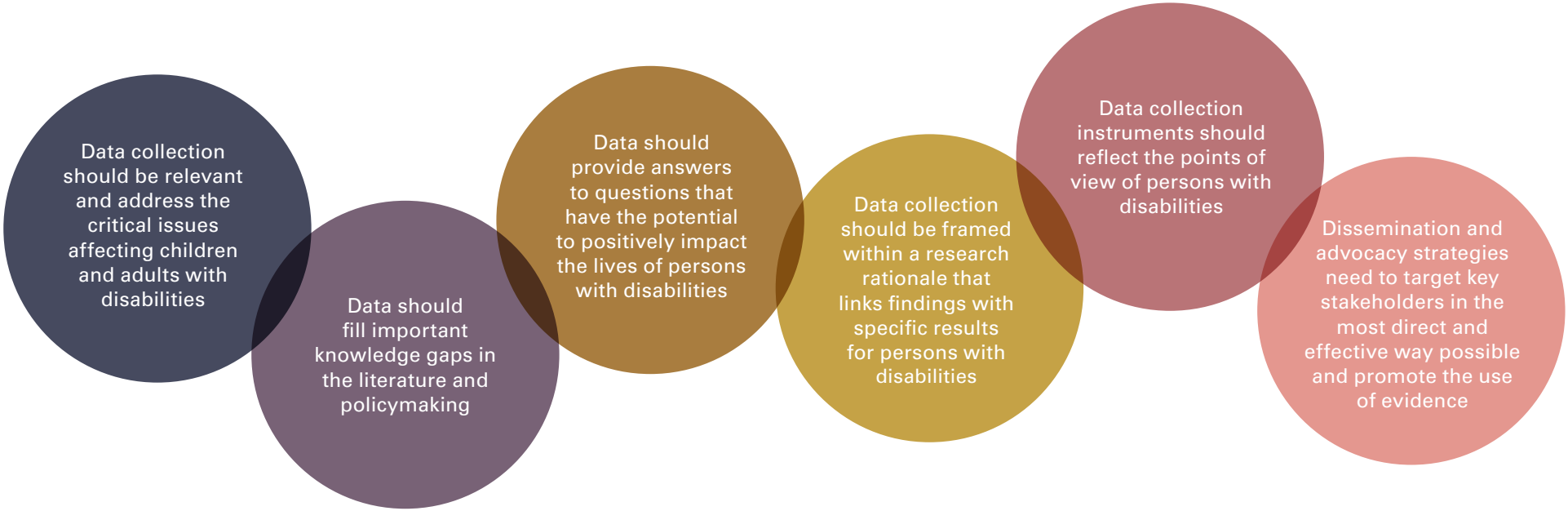
Inclusive data are key to eliminating discrimination on the basis of disability and accelerating global efforts towards inclusive programming.

Governments and organizations need to commit resources and effort to addressing the barriers that prevent equitable access and participation of persons with disabilities in all aspects of human society. Increasingly, they must seek to implement effective approaches to make their data collection and monitoring efforts disability-inclusive.

The 2030 Agenda for Sustainable Development calls for equal opportunity for all and holds deep promise for persons with disabilities.

Goal 17, which focuses on the means of implementing the 2030 Agenda, includes an explicit target on supporting countries to increase the availability of high-quality, timely and disaggregated data. This includes disaggregating data by disability status to ensure that the monitoring of advances towards the 2030 Agenda does not disregard persons with disabilities.

ISSUES TO CONSIDER WHEN PLANNING, DESIGNING AND IMPLEMENTING INCLUSIVE DATA COLLECTION

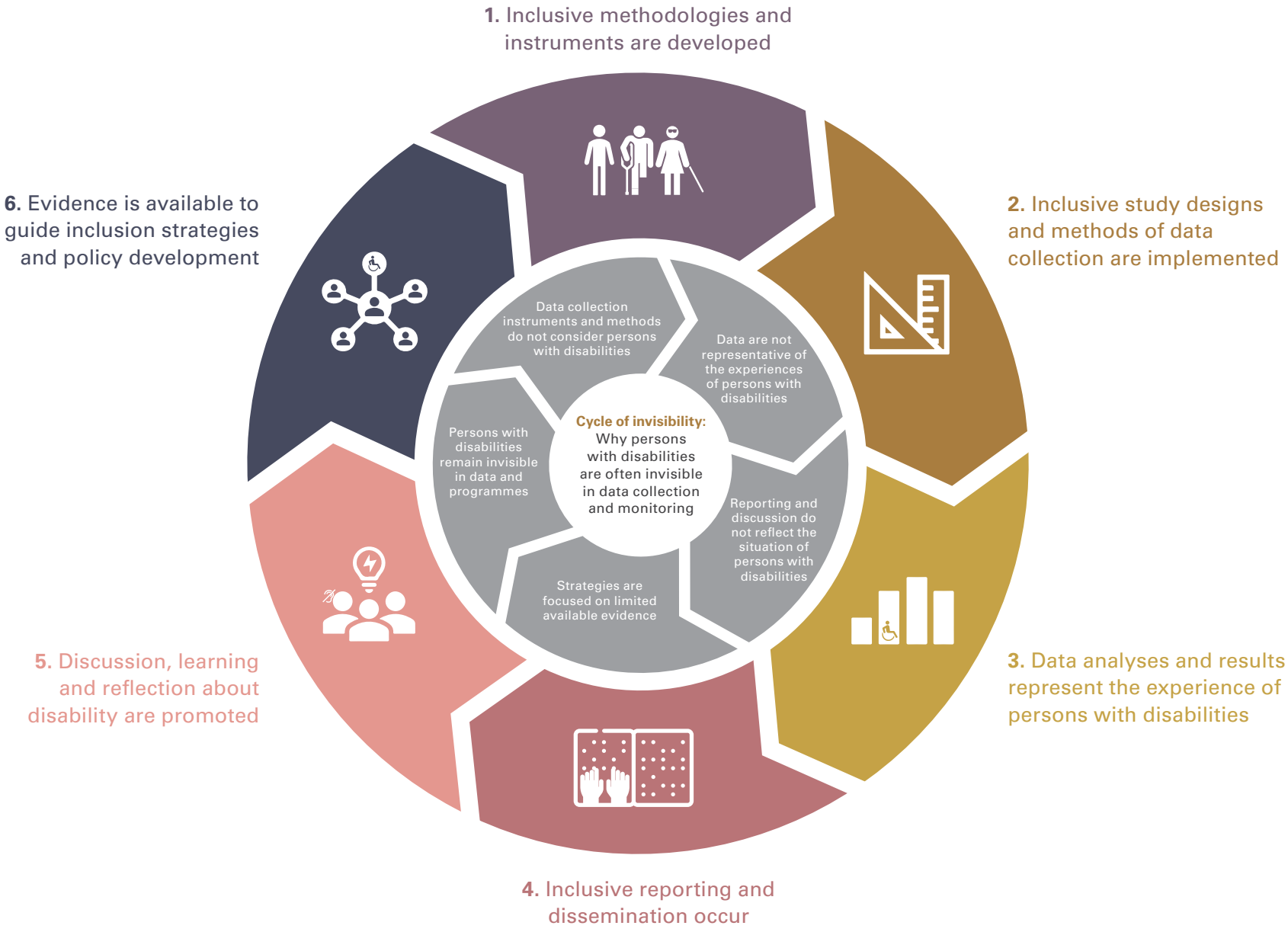


Concepts and definitions used in this publication are aligned with the Convention on the Rights of Persons with Disabilities:

'Discrimination on the basis of disability' means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

'Reasonable accommodation' means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

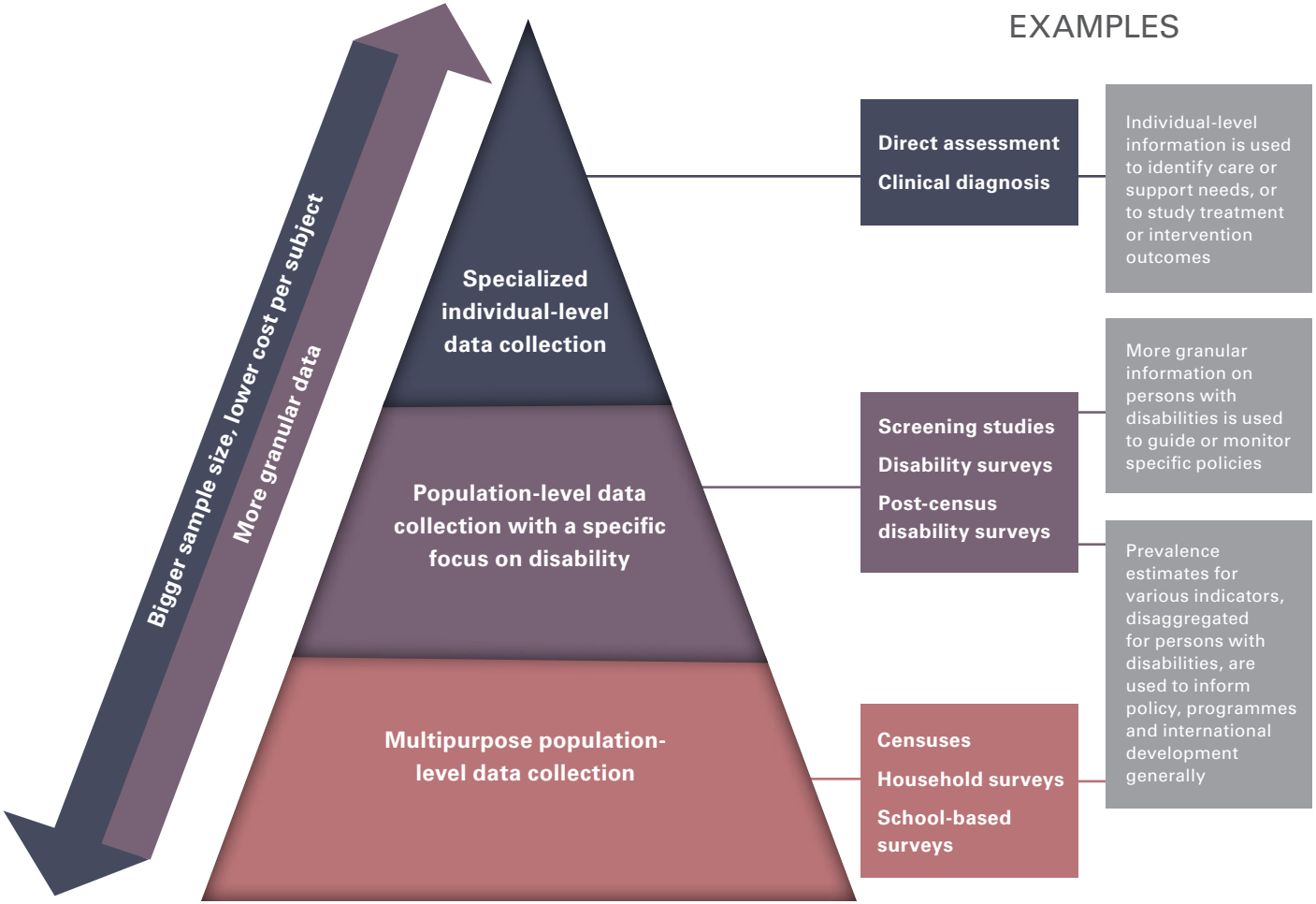
BREAKING THE **CYCLE OF INVISIBILITY** RELATED TO PERSONS WITH DISABILITIES



INCLUSIVENESS SHOULD BE PART OF ANY DATA COLLECTION EFFORTS

The principle of inclusion must be considered at all stages and in various aspects of data collection. This necessitates the identification of barriers that can undermine inclusive data collection and the proactive adoption of strategies to overcome them.

Failure to be inclusive can lead to the collection of inaccurate, incomplete, irrelevant or misleading data.



WHY PERSONS WITH DISABILITIES ARE **OFTEN INVISIBLE** IN DATA COLLECTION AND MONITORING

Persons with disabilities tend to be underidentified, underrepresented or even excluded altogether from official statistics. This can be explained by multiple factors, including low political priority, insufficient capacity and technical constraints.

Practically all countries have generated data about persons with disabilities, some for a very long time. However, currently available information has well-known limitations due to differences in definitions and the lack of standardized approaches to measurement.[1]

From a statistical point of view, the absence of persons with disabilities from official statistics is due to:

- Underrepresentation in the **numerator**
- Underrepresentation in the **denominator**
- Non-disaggregation of key **indicators** according to disability status.

Underrepresentation in the numerator refers to problems in correctly identifying and counting all persons with disabilities. Underidentification may occur when using narrow concepts of disability – such as those that consider disability on the basis of a certain medical definition – as opposed to a broader notion that focuses on limitations or barriers in performing daily activities and restrictions on social participation. Medical concepts of disability lead to underidentification because they are based on diagnostic categories of impairments and fail to account for the varying levels of functional limitations, degree of service utilization, or access to assistive devices.[2] Thus, the use of data collection methods based on such models can lead to the identification of persons with certain conditions only, or those with severe impairments, and can fail to correctly identify a broader spectrum of persons with functional difficulties.

Persons with disabilities can also be underenumerated either as part of formal exclusion criteria or because data collection methods do not allow for their full participation as respondents. Data collection tools may include skips that preclude the administration of questions to respondents with certain types of disabilities. For instance, certain surveys may not be implemented if the interviewer or the household head determines that the person who is eligible for the interview is 'incapacitated'. Even in cases where explicit skips are not in place, persons with disabilities may not be able to be interviewed due to the lack of necessary accommodations, such as the presence of a sign language interpreter. Data collection instruments and protocols need to be designed in a way that ensures participation. This includes the use of specific protocols and tools to gather information from respondents who may have difficulty hearing or seeing or have cognitive or psychosocial disabilities.

Underrepresentation in the denominator derives from the fact that many official statistical efforts are based on population definitions that exclude groups to which persons with disabilities are more likely to belong and where they are often overrepresented.

Non-disaggregation of key indicators according to disability status refers to the absence of estimates for both persons with and without disabilities. Planning, designing and allocating resources for inclusion strategies require collecting information from and about persons with disabilities, and presenting separate results for persons with and without disabilities.

An **indicator** is the observed and measured value of a variable or concept of interest. In population-level measurement, an indicator normally refers to the proportion of the population in which a variable or specific attribute, such as disability, is observed and measured.

The **numerator** of an indicator is the variable or concept that is being measured. In population-level measurement, the numerator is the number of units, for example, of persons presenting the variable or specific attribute being measured.

The **denominator** of an indicator is the population from which the numerator is taken. In population-level measurement, the denominator represents the complete population of persons where the variable of interest is being measured, and thus includes the persons presenting the variable plus the remaining persons not presenting the variable of interest.

UNDERREPRESENTATION IN THE **NUMERATOR**

Consider a sample of 60 subjects, where gold icons represent persons with disabilities.

A survey was conducted and estimated a 5% disability prevalence among the sample. This means that only three subjects were identified as having a disability.

The adjacent text explores reasons for the underrepresentation of persons with disabilities in the estimated indicator and other exclusion issues.

> **If inclusive data collection instruments and procedures had been used, the prevalence of disability for this sample would have been 10% instead of 5%.**

UNDERREPRESENTATION IN THE **DENOMINATOR**

Consider a population of 60 subjects, where gold icons represent persons with disabilities.

In this population, 45 persons live in households (purple buildings) and 15 live in residential care facilities (pink building).

A survey was conducted using a sampling listing of households, but not residential care facilities. It surveyed 45 persons living in households and identified 5 persons with disabilities, which represents an 11% prevalence of disability among the population living in households.

> **If residential care facilities were also included in the sample frame, prevalence of disability for this population would have been 16%.**

BREAKING THE CYCLE OF INVISIBILITY: WHAT NEEDS TO BE DONE

USE INCLUSIVE METHODOLOGIES AND INSTRUMENTS

The definition of disability that is embedded in any given data collection tool has a direct impact on the type and quality of data gathered. It determines who is identified as having a disability and included in the appraisal of evidence and, therefore, who will be considered in terms of designing policies and programmes.[3] The use of stigmatizing labels and offensive terms to gather data on and from persons with disabilities also has a significant impact on the quality and coverage of resulting statistics.

The medical model of disability, which puts emphasis on conditions, diseases and presence of specific impairments, has long dominated the field of disability statistics. Measures developed from this perspective have treated disability as a dichotomous outcome (that is, an individual either has or does not have a disability) and have categorized persons with disabilities as those with certain specific impairments. This approach has contributed to perpetuating stereotypical views of persons with disabilities as 'wheelchair users' or as being blind or deaf. Furthermore, given the emphasis on a subpopulation with more severe conditions and impairments in 'visible' domains of functioning, this narrow approach has resulted in severe underestimations.

Children are at increased risk of being absent from disability estimates. Research suggests that children might be overlooked in surveys that do not specifically ask about them. Data collection efforts that rely on the same set of questions to identify disability in both adults and children, or use questions developed for adults to survey children, have been found to inadequately identify children with disabilities.[4]

On the other hand, the use of age-specific data collection tools that focus on functioning and allow reporting on a continuum of difficulties and across all relevant domains are able capture a fuller spectrum of persons with disabilities. As a result, they yield more inclusive estimates. The UNICEF/Washington Group Child Functioning Module, developed through the extensive participation of experts and stakeholders, is one such tool. The module avoids labels and stigmatizing terminology and is not intended as a diagnostic tool. It relies on a functional approach to measuring disability and assesses difficulties in different functional domains, including hearing, vision, mobility, communication/comprehension, learning and emotions. To better reflect the degree of functional difficulty, each area is assessed according to a rating scale. The purpose is to identify the subpopulation of children who have functional difficulties and are at risk of experiencing limited participation in an unaccommodating environment.

IMPLEMENT INCLUSIVE STUDY DESIGNS AND DATA COLLECTION METHODS

Creating inclusive study designs involves making sure that data are collected across all residential settings and that adequate procedures are in place to address the risk of underenumerating certain population groups. In the case of persons with disabilities, the engagement of organizations of persons with disabilities in data collection efforts can reduce the risk of missing eligible survey respondents who are left out due to segregation or stigma.

STUDY DESIGN

One of the core aspects of study design in population-level studies is the definition of the population of interest and the selection of a sample that accurately represents that population. Defining the population of interest determines who will be represented in the statistics; it also has important implications for all aspects of data collection planning and fieldwork activities.

Household surveys represent a common – and for many countries the sole – source of data on many indicators of child and family well-being. However, these surveys do not provide information on children and adults living outside households, such as those living on the street and in institutions. Household surveys are therefore likely to exclude a significant portion of the population of adults and children with disabilities in countries with high levels of institutionalization or homelessness.

Persons with disabilities tend to be overrepresented among the population living in residential care facilities. Families may feel pressured to place relatives with disabilities in institutions due to stigma or because they do not have adequate resources to care for them at home. That said, numerous studies have revealed that children who remain in institutions often face severe developmental impairments.[5] Many of these children end up spending their lives in institutions, partly due to the difficulty in finding alternative placement options. Because the institutionalized population is typically stationary, a sampling frame can usually be constructed.

Children and adults living on the street are likely to have a higher rate of disability than the general population, and their exclusion from data collection efforts can be a significant source of undercoverage. This population is often the most challenging for data collection due to their mobility and isolation from social services.

When an inclusive sample design is not possible, data collected from partial samples need to be presented with a caveat indicating that they are representative of only a portion of the total population of persons with disabilities.

DATA COLLECTION PROCEDURES

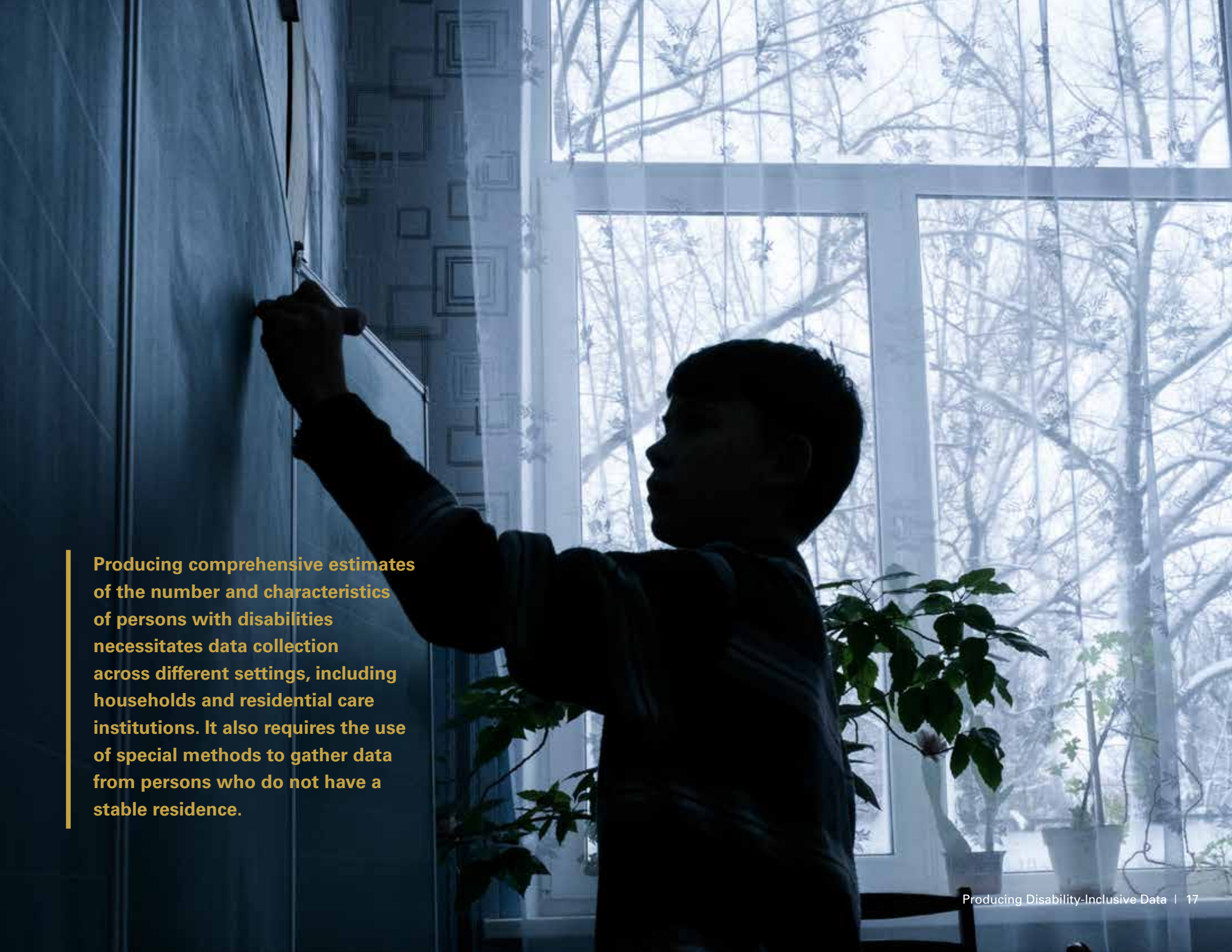
Representative data require not only a good sample design but also correct implementation. In addition to generic limitations and possible bias, which can affect any data collection effort, particular risks of exclusion exist when tools and procedures are not adequately designed to gather information from persons with disabilities. Failure to include such persons in the sample of a survey artificially lowers the disability prevalence rate; it also underestimates the severity of disability in the population since severe cases are more likely to be excluded from the final statistics. What follows are some recommendations that can facilitate the inclusion of every respondent wishing to participate in a survey.

Identifying eligible respondents

Inclusive data collection implies that data are collected from and about all persons, irrespective of their disability status. Too often, however, persons with disabilities may not be seen as valid respondents by interviewers or by family members.

Situations in which a respondent with a disability is prevented from participating in the interview should be coded in such a manner that s/he is included in the calculations of the overall disability prevalence rate. This will ensure that the data are representative of the entire target population of persons with disabilities, and not just persons who are able to participate in the data collection. Alternatively, a proxy respondent needs be identified to provide information on behalf of eligible respondents with certain impairments. Protocols for these situations should be developed during the design stages of data collection, and interviewers should be trained to handle such cases without hesitation and in a standardized way.

In some cases, persons with disabilities may be underreported in the listing of household residents due to shame or because the household head acting as respondent assumes that such persons should not be listed. Specific probing can be used to encourage the disclosure of information about all household residents, including persons with disabilities.



Producing comprehensive estimates of the number and characteristics of persons with disabilities necessitates data collection across different settings, including households and residential care institutions. It also requires the use of special methods to gather data from persons who do not have a stable residence.

TIPS FOR INTERVIEWING PERSONS WITH DISABILITIES

- Treat persons with disabilities and their caregivers with the same respect as any other respondents.
- Read the questions exactly as written – this includes not only the question text, but the response categories as well.
- Do not make assumptions about a person's capabilities.
- Record the response given by the respondent and do not make any assumptions about what the response should be.
- Accommodate persons with hearing difficulties by finding a quiet, well-lit space, or using a sign language interpreter if needed.
- Accommodate persons with communication difficulties by speaking slowly, if necessary, speaking clearly, and being prepared to repeat questions or answer categories as needed.
- Accommodate persons with vision difficulties by making it clear when you are addressing them.
- Accommodate persons with intellectual disabilities by not treating them like children, making sure they understand you, repeating questions and answer categories if necessary, and being patient and respectful.

Source: Adapted from 'Training on How to Ask "Disability" Questions on Censuses and Surveys', <www.washingtongroup-disability.com/washington-group-blog/training-ask-disability-questions-censuses-surveys>.

Levels of interview assistance

In some cases, enabling a selected respondent to participate in an interview will require assistance. This could include personnel with certain skills (such as sign language interpreters) and assistive technology. Accommodating individual needs means making necessary and appropriate modifications and adjustments to questionnaires and interview techniques to ensure that persons with disabilities can participate in the data collection process on an equal basis as other members of the population. All fieldwork personnel should receive standard training on general survey administration guidelines, and on any specific protocols related to interviewing persons with disabilities.

- Direct personal interview: Respondent participates directly. However, it may require interviewers who are able to communicate in a way that meets respondents' abilities. In-person interviews may require assistance if a respondent has communication or cognitive difficulties. Interviewers who can use sign language or alternative accommodations for persons with hearing impairments need to be provided. Involving organizations of persons with disabilities in all phase of data collection is key to identifying personnel who can use sign language or prepare accessible materials.
- Interpreted interview: Someone interprets the questions to the respondent and interprets the responses back to the interviewer; the interpreter acts as an intermediary. It is important to note that this can introduce bias and a breach in confidentiality. In such cases, the questionnaire needs to be designed in a way that only certain questions are asked.

TRAINING INTERVIEWERS

Training interviewers and sensitizing them to issues related to disability is critical since stigma may be a challenge in itself among enumerators. The importance of inclusion must be clearly communicated to the teams that will be collecting the data. These teams are central to the production of accurate data since they influence the participation of individual cases. For example, if an interviewer decides that administering a questionnaire to a person with severe difficulties in communication is going to take too long, the interviewer may decide to exclude that person from the data collection. In doing so, s/he would also introduce bias into the results because they would be less representative of those most in need of support.

Training enumerators in the importance of systematically including all persons – as well as the attitudes and behaviours that can encourage participation – is essential. Additionally, interviewers need to be competent in providing different levels of assistance when interviewing persons with certain functional difficulties.

REPRESENT THE EXPERIENCE OF PERSONS WITH DISABILITIES IN DATA ANALYSES

Data collection and analyses should be framed within a research rationale that easily links findings with specific results for persons with disabilities and fills knowledge gaps.

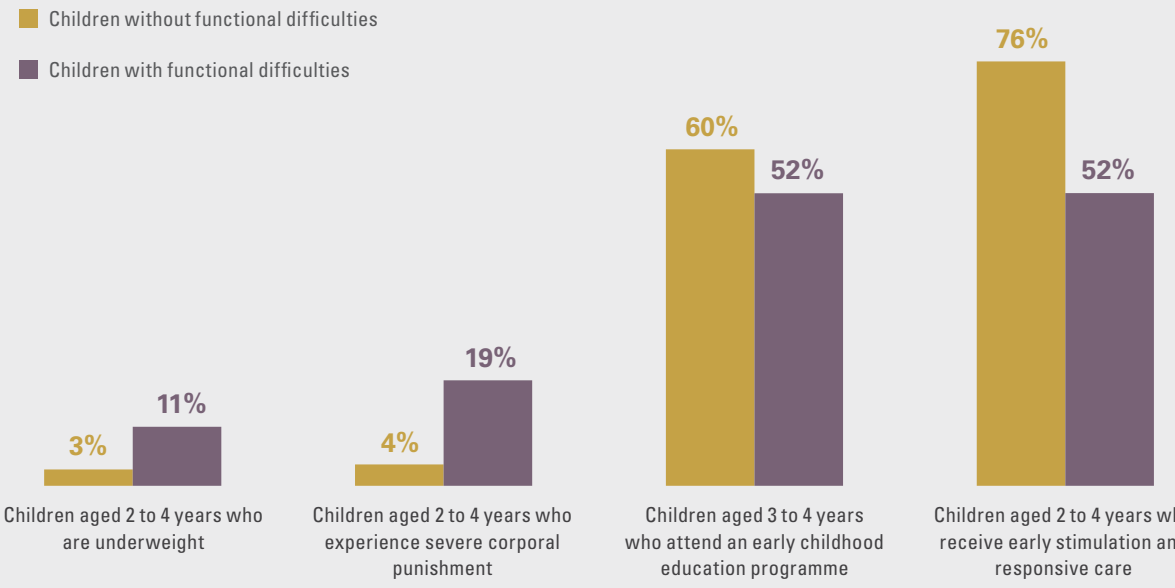
Addressing the needs of persons with disabilities is complex because they are not a homogenous group and their experiences may vary. Persons with similar impairments may experience different barriers. Moreover, certain barriers may not affect persons with different impairments to the same extent.

Disaggregating data according to disability should thus be a standard practice. Because there are direct and indirect ways in which disability can impact families, for certain indicators disaggregation might be more useful when done at the household, rather than at the individual, level.

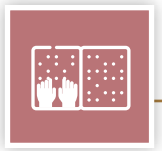
An analytical plan should be developed early in the study design process to ensure the required information will be collected. Data analysis should provide answers to questions that have the potential to positively impact the lives of persons with disabilities. Therefore, such analysis should take place in consultation with the disability community, government departments, and data users to ensure that all the relevant outputs are available and described in the final report.

UNCOVERING INEQUITIES IN THE LIVES OF CHILDREN WITH DISABILITIES IN MEXICO

Mexico's national survey of girls, boys, and women (ENIM 2015) was implemented to generate information on the situation of children and women. It was based on a large number of indicators, some of which were presented for the first time in that country, including information on the proportion of children with functional difficulties. The results allowed the identification of disparities in key indicators and were used to generate a policy brief summarizing the situation of children with disabilities in the country.



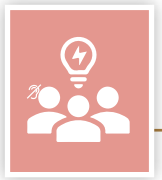
Adapted from: National Institute of Public Health (Mexico) and UNICEF Mexico, 'Que nadie se quede atrás. La situación de niños y niñas con discapacidad en México', Mexico City, 2017.



ENSURE THAT REPORTING AND DISSEMINATION ARE INCLUSIVE

The lack of accessible statistical material for persons with disabilities has been a persistent issue. Policy guidance and mandatory standards for the dissemination of statistics have rarely included specific provisions to ensure the production of material that can be easily accessed by persons with certain impairments.

Infographics and other visual tools are becoming popular vehicles to release data. Increasingly, podcasts, videos and the use of various social media platforms have become tools for building interest and engagement. However, such tools are often not accessible and other means of distributing the information should be developed to ensure that it reaches the entire population.



PROMOTE DISCUSSION, LEARNING AND REFLECTION ABOUT DISABILITY AND USE EVIDENCE TO GUIDE INCLUSIVE POLICIES

The availability and dissemination of inclusive, high-quality statistical reports are key to empowering persons with disabilities to participate fully in all stages of monitoring and evidence-based programme development. At the same time, active discussion of the issue is needed to communicate how persons with disabilities may benefit from newly generated evidence. Even the highest-quality data, the most robust results and the most comprehensive reports have limited utility in the absence of active discussion, learning and reflection on required action points.

Discussion and consultation processes can exclude persons with disabilities if materials, content and exchanges are not facilitated using assistive methods. These may include language interpretation or captioning or other required accommodations. Persons with cognitive and psychosocial disabilities are the most likely to be excluded from informed discussion processes. Including persons with disabilities in the process also means ensuring that they can contribute to the discussion. This may require some form of capacity building to empower them to participate.

Once evidence is available and extensive consultations and discussions have taken place, further advocacy strategies are needed. These should be targeted at key stakeholders to encourage the direct use of evidence in the development of programmes and interventions. The successful uptake of evidence into tangible results should be the ultimate goal of any data collection programme and is the culmination of all the strategies described in the previous sections. Relevant, high-quality data that address critical issues affecting persons with disabilities have a higher potential to shape policymaking and of resulting in concrete interventions and programmes. This, in turn, increases ownership of evidence and builds a rationale for additional data collection and methodological advances.

INCLUDE PERSONS WITH DISABILITIES AT EVERY STEP OF THE DATA CYCLE

Inclusion needs to go well beyond consultation at various stages of data collection. Rather, it must seek out opportunities and synergies to share ownership and foster broad engagement.

Steps in the process of breaking the cycle of invisibility are facilitated and accelerated by partnering with organizations of persons with disabilities. Obtaining such support requires intentional engagement from the earliest stages of a project, which encourages buy-in and involvement through successive stages. What's more, working with persons with disabilities or representatives of organizations that do so can oftentimes facilitate data collection due to their familiarity with the local context.

Inclusion is often erroneously thought of as a disability-specific issue that is prohibitively expensive and impractical to implement – and therefore unsustainable. Correcting these misconceptions requires robust data and studies to help identify which investments are needed and which are most effective, not only to benefit persons with disabilities but also their families and communities, and society as a whole.

OVERCOMING BARRIERS TO THE INCLUSION OF PERSONS WITH DISABILITIES IN MONITORING EFFORTS

TYPES OF BARRIERS	HOW THEY AFFECT MONITORING	INCLUSION STRATEGIES	CROSS-CUTTING STRATEGIES
INSTITUTIONAL AND STRUCTURAL BARRIERS Insufficient priority and insufficient funding available for inclusive data collection and monitoring	Planning and design do not consider persons with disabilities: • Sample design or eligibility rules exclude or underrepresent persons with disabilities • Data cannot be disaggregated by disability status	Develop study designs to collect key data across all residential settings, including households and residential care facilities Ensure persons with disabilities are not excluded from enumeration	Ensure data are collected and used to inform improvements in inclusive practice
ATTITUDINAL BARRIERS Negative attitudes about the capabilities of persons with disabilities	Measurement tools reflect ideas about disability that foster exclusion or stigmatization Persons with disabilities are not listed as household members due to stigma or shame	Use adequate data collection tools to allow for disaggregation according to disability status Intentional probing should be used by interviewers to encourage the disclosure of information about all household residents, including persons with disabilities	Engage with organizations of persons with disabilities during all stages of data collection
COMMUNICATION BARRIERS Lack of materials in accessible formats or the lack of sign language interpreters during data collection and dissemination of results	Persons with disabilities are excluded from data collection due to the lack of accommodation instruments and protocols Dissemination of results is not accessible to persons with disabilities	Adapt data collection protocols and adequately train fieldworkers to use such protocols Follow standards for inclusive dissemination of statistics, which can entail the production of materials for persons with vision, hearing and cognitive impairments	Empower persons with disabilities to become active stakeholders

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