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COLLECTING DATA ON DISABILITY PREVALENCE IN EDUCATION PROGRAMS

USAID EDUCATION HOW-TO NOTE

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How-to Notes provide additional design and implementation suggestions not covered in existing USAID Policy documents related to sub-areas of the USAID Education Policy.

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KEY TAKEAWAYS

- USAID’s Office of Education adheres to the social model concept of disability and recommends the use of social model tools to generate disability data.
- Disability disaggregation is now required in all person-level standard foreign assistance indicators for basic education programming that targets learners with disabilities, and for all higher education and education-related youth workforce development programming regardless of the activity’s focus or target group.
- The tools presented in this How-to Note pertain to disability prevalence data only. They are not validated to be used as screening tools.
- There is no single definitive tool to collect disability prevalence data in USAID Education programs. USAID recommends a suite of tools and offers guidance for selecting the right tool.
- There are established tools for collecting disability prevalence data from older youth and adults. However, there is no established tool to collect similar data from children in school settings. A promising new tool for use by teachers in schools is being tested now.
- USAID recommends a set of best practices for generating disability data. Paramount among them is the principle of “Do No Harm” to ensure data is not misused and does not label, stigmatize, or exclude children and youth with disabilities from education settings.

I. INTRODUCTION

USAID's Education Policy prioritizes increased access to quality education for all children and youth. The policy recognizes that by not programming intentionally for children and youth with disabilities, we risk excluding a significant share of the population from acquiring the skills needed to live a productive life. Equity and inclusion for persons with disabilities¹ cut across all areas of USAID's education programming from pre-primary education to higher education, in formal and non-formal education, and everywhere in between. All USAID Education Policy priorities integrate the concept of disability inclusion, recognizing that disability-inclusive education improves learning outcomes for all.

Despite similar commitments by other donor and multilateral agencies such as the United Nations and the World Bank, marginalized children and youth, particularly those with disabilities, remain underrepresented in educational settings.² Even when they are in school, learners with disabilities continue to face barriers. Education settings frequently are not equipped to create learning environments that effectively accommodate and engage learners with disabilities or to engage families and communities appropriately in learners' education. As a result, learning outcomes among learners with disabilities tend to lag behind those of their peers, and dropout rates tend to be higher.³

To track the progress being made in addressing these crucial gaps, identify barriers and approaches to successfully engaging learners with disabilities, and inform programs designed to increase high-quality education among learners with disabilities, it is essential to have information that permits disaggregation of education data by learners' disability status and type.⁴ Through data collection that determines disability prevalence and type, USAID Missions and implementing partners can target programming to the specific needs of learners, disaggregate education outcomes by disability, and understand progress toward increasing access for this group.

Collecting and using **disability disaggregated data** is one way to track disability inclusion. This data alone is not sufficient for measuring Inclusive Education programming. Additional indicators on education system strengthening and policy reform, for example, should be coupled with disaggregated data to show a more comprehensive picture of progress toward Inclusive Education.

The Office of Education recognizes that collecting disability prevalence data for the purpose of disaggregating outputs and outcomes is an initial step in strengthening the systems that serve learners

¹ Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UN Convention on the Rights of Persons with Disabilities).

² UNESCO, 2016, *Education for people and planet: Creating sustainable futures for all: Global Education Monitoring Report Team*. Paris: United Nations Educational, Scientific and Cultural Organization (UNESCO). <https://unesdoc.unesco.org/ark:/48223/pf0000245752>

³ Graham, N., 2014, *Children with Disabilities. Paper commissioned for Fixing the Broken Promise of Education for All: Findings from the Global Initiative on Out-of-School Children*. (UIS/UNICEF 2015) Montreal: UNESCO Institute for Statistics (UIS); Wodon, Q.T., C. Male, C.E. Montenegro, and K.A. Nayihouba, 2018, *The Challenge of Inclusive Education in Sub-Saharan Africa (English). The price of exclusion: disability and education*. Washington, D.C.: World Bank Group: <http://documents.worldbank.org/curated/en/171921543522923182/The-Challenge-of-Inclusive-Education-in-Sub-Saharan-Africa>.

⁴ *Mapping of Tools for Disaggregation by Disability Status Report*, 2019.

with disabilities. Ethical considerations alone demand that efforts to measure disability prevalence end not with validated tools, but with individuals, programs, and systems that are better equipped to improve education outcomes for learners with disabilities. USAID's Office of Education is committed to strengthening such systems around the world even as we strengthen disability measurement.

2. PURPOSE AND USE



This guidance note provides **information** about **tools and approaches** to generate **disability prevalence data** in USAID Education programming. It does not discuss tools and approaches to screen and identify individual learning needs or diagnose disabilities.

This How-to Note on Collecting Data on Disability Prevalence in Education Programming is intended for Missions, local actors, and implementing partners who are committed to improving access to safe, quality, inclusive education⁵ for all children and youth across the USAID Education continuum. Focusing on collecting disability prevalence data only, this Note is applicable to USAID Education programming in pre-primary, primary, secondary, youth workforce development, and higher education, and in formal and non-formal education. Further, this document provides important information on which tools allow an activity to report disability disaggregated data for standard foreign assistance indicators, as required in the Office of Education's [Education Reporting Toolkit](#).

Disability prevalence data, as opposed to individual screening and identification data, quantifies the incidence of disability within a population. In the context of USAID education programming, a population may be an activity population, sampled to allow estimates of disability prevalence that, when aggregated and linked to learning outcomes, can provide crucial information on USAID's effectiveness in reaching and teaching children and youth with disabilities. Disability prevalence data is never used to provide information on or about individuals; it is used only in aggregated form.

- **Missions** should use this document to frame their approach to measuring disability prevalence in programming, to guide investment in further measurement and areas of research as well as budgeting for activities, disaggregating education outcomes by disability status, and as a discussion point with the local actors who drive evidence-generation for disability inclusive education.
- **Local actors** such as ministry officials will find this document useful to understand USAID's approach to generating disability prevalence data in education programming, which can serve as a foundation for mutual understanding and collaboration, and support local efforts to generate such data.
- **Implementing partners** should adopt the perspectives and approaches espoused in this document and use it as a guide to measuring disability prevalence, tracking inclusion and

⁵ The USAID [How-to Note on Disability Inclusive Education](#) offers guidance on USAID's Inclusive Education approach.

identifying opportunities for greater participation in programs, and as a catalyst for their own innovation. Further, implementing partners may use this document to guide their disability disaggregation work for reporting on standard foreign assistance indicators.

The How-to Note is divided into the following sections:

- *The USAID Office of Education’s Vision for Disability Measurement and Systems in Education* positions this note as a next step, not a final step, toward strengthened systems that support disability data-driven programming for all children and youth. This section highlights remaining gaps in disability measurement and outlines the Office of Education’s commitment to further investment.
- *A Call to Action* recommends necessary steps by USAID and partners to achieve the Office of Education’s vision.
- *The USAID Office of Education’s Approach to Disability Measurement* outlines the Office of Education’s adherence to the social model of disability and its emphasis on collecting disability prevalence data through this lens.
- *Integrating Disability Measurement into the Program Cycle* presents guidance for collecting disability prevalence data across the program cycle, including selecting the right tool, best practices in generating disability data, and recommendations for data collection in conflict- or crisis-affected settings.

3. THE USAID OFFICE OF EDUCATION'S VISION FOR DISABILITY MEASUREMENT AND SYSTEMS IN EDUCATION

While this How-to Note captures USAID's current thinking, recommendations, and ongoing investments for generating disability prevalence data to understand and expand the reach of USAID education programming in meeting the needs of learners with disabilities, it does not by itself achieve the Office of Education's vision for disability measurement and strong systems to serve learners with disabilities. A world in which all children and youth are engaged in quality, equitable, and inclusive education—a vision cast by the [2018 USAID Education Policy](#), the [2020 Global Education Monitoring Report on Inclusion in Education](#), and the [International Disability Alliance's Inclusive Education Report](#)—must be supported by administrative data systems that generate data on learners with disabilities to inform budget and program decisions and systems that support early and periodic screening and identification to ensure all children and youth can reach their full potential and achieve desired education outcomes. However, administrative data systems globally do not yet consistently collect disability data, and we are far from such universal access to screening and identification. While we work toward such a world, this How-to Note offers interim guidance to strengthen USAID's ability to determine disability prevalence and disaggregate education outcomes in order to produce the necessary data to strengthen the systems in which we work.

Screening and identification are critically important aspects of ensuring learners have the support they need to succeed in educational settings. Early and periodic screening enables parents, teachers, and health workers to put in place early interventions that can improve chances for learners to reach their full potential and desired education outcomes. Screening may take different forms and be carried out by different professionals at different times. For example, health workers may conduct assessments as early as birth to identify early intervention needs. Health programs may conduct ongoing growth monitoring and nutrition screening to identify children at risk of malnutrition, which could stunt growth and development and lead to disability. Early childhood programs such as playgroups, preschools, pre-primary, or others may monitor young children's development and provide early intervention before the child enters primary school. Schools may also carry out screening assessments that do not require medical expertise to determine students' learning needs. Health workers and teachers may work together to administer hearing and vision screening at school and refer students for medical follow up and provision of services as needed.⁶ Screening and identification may also take place particularly during/after armed conflict or natural disasters as part of school (re)enrollment, education voucher programs, or child protection services, when there may be an increase in disability incidence and existing barriers to participation in education may be compounded.⁷

This Note focuses on disability prevalence data collection and use. It does not provide guidance on screening and identification or the related tools, nor should the tools described in this document be used to screen for disabilities as they have not been validated for that purpose. Other global actors, such as UNICEF and the World Bank, are working toward disability screening and identification guidance. USAID Missions can contact their country UNICEF office directly to learn the status of

⁶ The [Universal Design for Learning to Help All Children Learn to Read Toolkit](#) includes information on the process for carrying out school-based screening and determining qualification for services for learners with disabilities.

⁷ Thomas, Edward, 2018, [Children with Disabilities in Situations of Armed Conflict: Discussion Paper](#), UNICEF.

UNICEF's work in the specific country context. The Disability Identification Tool Selection Guide, described later in this document, includes a placeholder for future guidance as it becomes available.

Ongoing Piloting of Tools

The tools presented in this document are among those currently available that USAID supports for use in Education programming. However, as this Note indicates, these tools may not be a perfect fit for all activities based on factors described further below. The Office of Education continues to invest in further piloting of new and existing tools to fill some of these gaps, such as the need for a disability prevalence tool that can yield data on children and youth under the age of 18 and be implemented with educators in educational settings. A USAID-funded pilot, in addition to pilots led by other donors and non-governmental organizations, of the Washington Group's Child Functioning Module-Teacher Version (CFM-TV) will contribute further information on the reliability and validity of such a tool under what parameters and in which environments.

Remaining Questions

Even with ongoing piloting of tools, additional gaps still exist. Namely, even once a validated disability prevalence tool for use with educators exists, it may not be appropriate for specific settings, such as those with larger class sizes or in which there is a low level of familiarity between educators and learners. This How-to Note does not provide a solution for this gap because one currently does not exist. Instead, **USAID Missions and implementing partners are encouraged to continue to innovate by developing and piloting new tools or validating existing tools for new contexts, purposes, and respondents.** When evaluating the benefit of innovative methods, approaches, or measures, consider using [USAID's How-to Note: Conducting a Data Quality Assessment](#) as a guide. All innovation should do no harm and take best practices for disability measurement into account. Those engaged in innovation and piloting have the full support of the Office of Education, and are encouraged to share plans and findings with the Office of Education to improve upon the guidance contained in this How-to Note. Partners may share information via edulinks@usaid.gov.

Tool validation ensures that a tool is measuring what a researcher intends it to measure in a particular context and with a particular population. There are several types of validity, and proper tool validation is an ongoing process; it is never complete. While new tools require thorough validation through approaches such as cognitive testing and concurrent validity testing, existing tools also often require validation. Whenever an existing tool is implemented for a new purpose, in a new context, with a new population, or with a different respondent, it must be validated for that purpose, context, population, or respondent.

4. A CALL TO ACTION

Innovation, which is crucial for the realization of USAID's Office of Education's vision of a world in which the right data support the right services to allow all children and youth access to inclusive education, comes with a cost. Financial and human resources must be contributed to advancing this vision along with the goal of supporting disability-inclusive programming from the start, and these contributions must be a collective effort by various donors and their networks of partners.

- **USAID Washington Offices** are encouraged to work with a variety of partners to support disability measurement innovation; incentivize programming to measure disability; and work across Bureau lines to learn from each other and strengthen the several systems that affect the lives and learning of children and youth with disabilities.
- **USAID Missions** are encouraged to support disability measurement in the context of their activities and incentivize partners to budget funds for this purpose in their proposals. Further, Missions should engage governments and partners in this effort in order to contribute to strengthened local systems alongside strengthened activity data collection.
- **USAID implementing partners** are encouraged to include plans for disability measurement development and testing in their activity proposals, alongside broader efforts to monitor and evaluate inclusive education progress that go beyond tracking disability disaggregated data.

Only through such three-pronged commitment can USAID advance disability measurement and strengthen systems for individuals with disabilities in the countries in which we work. Further, USAID's [Cost Reporting Guidance for USAID-Funded Education Activities](#) provides information on assessing costs and cost effectiveness, which, when applied to disability measurement and the dividends it can pay, can provide data to further strengthen USAID's case for further, collective investment in disability measurement.

5. THE USAID OFFICE OF EDUCATION'S APPROACH TO DISABILITY MEASUREMENT

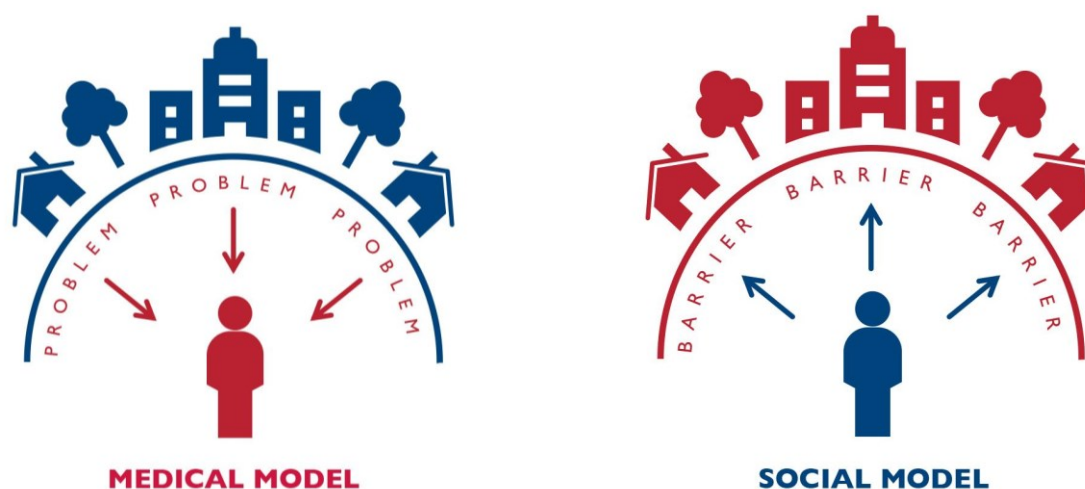
The Social Model of Disability

USAID takes a social model approach to conceptualizing disability, where disability is not inherent to having certain functional conditions like difficulty seeing or walking, but rather results when a person with a physical, mental, intellectual, or sensory impairment is faced with an unaccommodating environment that limits their full and effective participation in society on an equal basis with others.⁸ The social model stands in opposition to the medical and charity models of disability, in which disability is located within the person, not the surrounding environment. The “medical model” typically focuses on “curing” individuals, whether or not they can or wish to be cured. The “charity model” situates persons with disabilities as passive recipients of charity, which can be disempowering and deprive individuals of agency and autonomy. This is not to say that providing charity or medical services is negative per se, but as framings of disability, these models have been rejected by the disability rights community as promoting inequality and failing to address disabling societal barriers. It should be noted that the social model supports access to healthcare and medical services by persons with disabilities on an equal basis with others—indeed, ensuring such access is consistent with the social model approach of removing environmental barriers and promoting full inclusion of persons with disabilities.

A Social Model Approach to Measurement

Most data collection tools derive from either the medical model or the social model of disability.

FIGURE 1. Medical Model and Social Model of Disability



A social model approach to disability measurement allows USAID Education programs to examine how an individual experiences their environment by focusing on difficulties they may have seeing, hearing,

⁸ UN Convention on the Rights of Persons with Disabilities.

moving about, or learning in a particular context. The social model approach to measurement is necessarily tied to context as it focuses on an individual's functioning within that particular environment and the socially constructed barriers (physical, cultural, legislative) that may limit participation.

USAID takes a social model approach because it allows for exploration of the intersection between disability and education systems. Understanding disability as a social construct that arises from an environment that is not structured to include everyone allows USAID's education investments to examine and strengthen the inclusivity of education systems. In an inclusive system, an individual who is defined as having a disability may experience little to no difficulty participating fully in their education because environmental barriers that would otherwise limit participation have been removed.

There are two types of social model disability measurement tools that USAID espouses:

- Functional Questionnaires, which ask respondents questions about their functional abilities or limitations⁹ and individual experiences to produce disability prevalence data.
- Functional Screening Tools, which combine questions about functional abilities with exercises or activities (i.e. vision acuity tests, auditory testing, fine/gross motor skills) to identify individuals with disabilities.

Because this How-to Note focuses on disability measurement for the purpose of determining disability prevalence in order to disaggregate data, only functional questionnaires, not functional screening tools, are discussed in this document.

Using a Social Model Approach to Determine Disability Prevalence

A social model approach to measurement undergirds USAID's emphasis on measuring disability prevalence and disaggregating education outcomes by disability across all ages and stages of education programming. Disability prevalence, as opposed to individual identification, seeks to quantify the incidence of disability within a group for the purpose of disaggregation of education outcomes. Such disaggregation allows USAID and its partners to understand how well programming is reaching persons with disabilities and the differential impacts of programming on children and youth with disabilities in a given environment. Disability disaggregation is now required in all person-level standard foreign assistance indicators for basic education programming targeting learners with disabilities and for all higher education and education-related youth workforce development programming regardless of the activity's focus or target group. Disability disaggregation is one area of measurement that, when coupled with other inclusive education indicators, can elucidate progress toward inclusive education programming for children and youth as well as gaps in education outcomes for certain groups of learners.

⁹ The terms "functional limitations" and "functional difficulties" are only used in the context of the social model disability measurement tools described in this Note. For all other communication purposes, the preferred terminology when discussing persons with disabilities is "persons with disabilities." [USAID's Disability Communications TIPS](#) provides further guidance for communicating with and about persons with disabilities.

6. INTEGRATING DISABILITY PREVALENCE MEASUREMENT INTO THE PROGRAM CYCLE

Generating and Using Prevalence Data

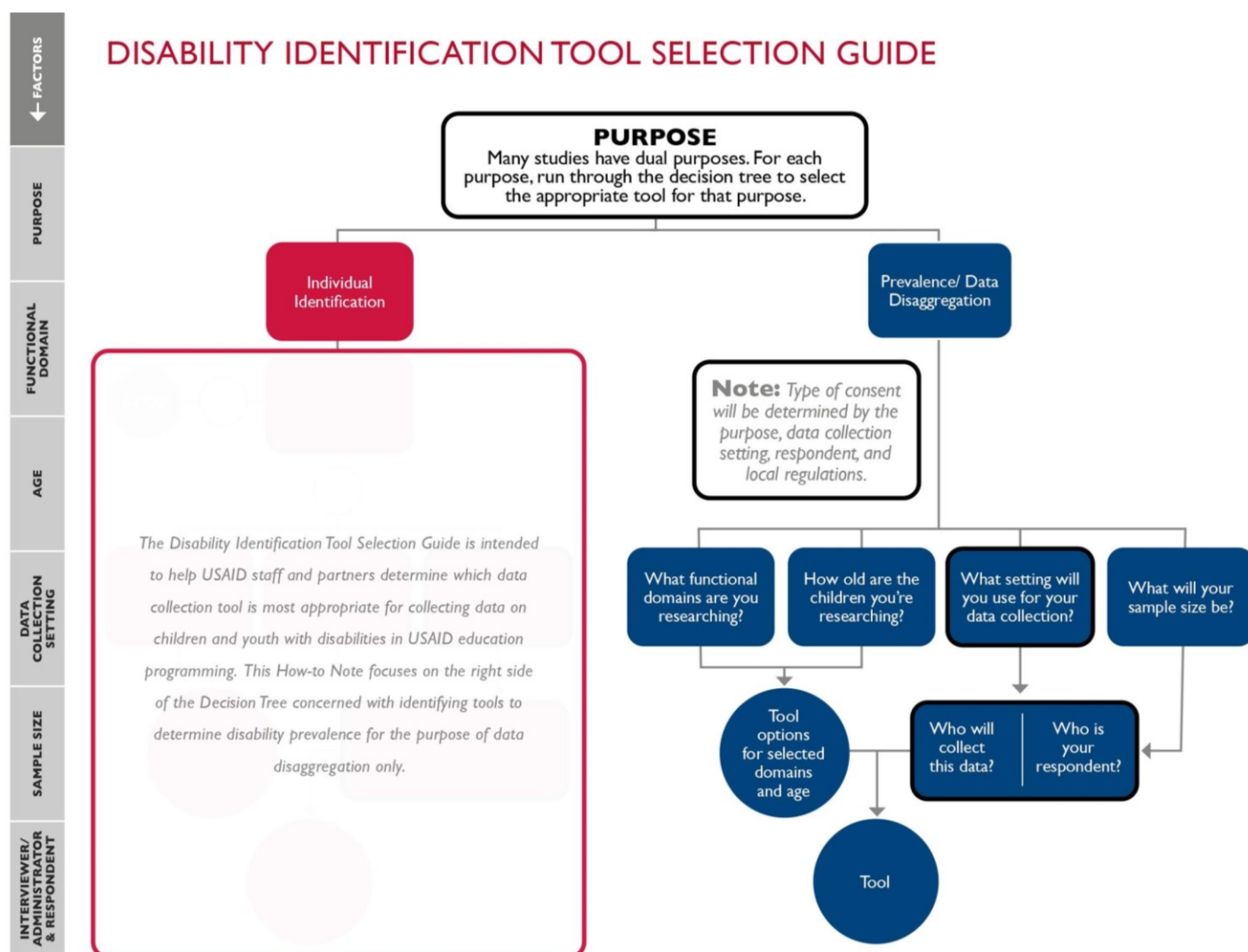
Measurement of disability prevalence is useful at various points of the program cycle:

- Large-scale prevalence studies can be helpful for **country/regional strategic planning, project design and implementation, and activity design and implementation** stages. USAID recommends using household-level data on disability prevalence, when available, obtained through the Demographic and Health Survey and UNICEF's Multiple Indicator Cluster Survey. Missions can use resulting data as a reference point when developing their Country Development Cooperation Strategy and for project and activity designs. Keep in mind that following armed conflict or natural disasters, prevalence studies may underestimate the proportion of the population with disabilities. Additionally, prevalence studies carried out post-conflict or post-disaster should have adequate methods and resources to locate persons with disabilities at the household level because this population is often further marginalized during humanitarian emergencies. More information on this topic is provided later in this Note.
- Missions and partners can use social model disability prevalence tools as part of assessments conducted to inform planned education **project and activity designs**, to identify contextual barriers, as well as to identify local sources of resilience and opportunities for future disability-inclusive programming. Disability-related indicators can be added to baseline studies, which can then be included in midline and endline data collection to determine increased participation and improvements in education outcomes.
- At the **activity implementation and monitoring and evaluation stages**, prevalence data that allows an activity to disaggregate outputs and outcomes by disability status can be useful along with other inclusive education indicators to understand differential program impacts and to improve targeted interventions to reach certain learners. Moreover, disability prevalence data is essential for reporting on disability disaggregates included in the Office of Education's standard foreign assistance indicators for basic education (ES.1), higher education (ES.2), and youth workforce development (EG.6).

Selecting the Right Social Model Tool to Measure Disability Prevalence

While much work is underway to develop new tools to measure disability prevalence in different contexts and with different respondents, a handful of social model tools currently exist to measure disability prevalence data. When implemented for the purpose and with the respondents for whom the tools have been validated, these tools are useful options for activities to measure disability prevalence or to disaggregate data by disability status across the program cycle. The Office of Education's interactive [Disability Identification Tool Selection Guide](#), built around a tool selection decision tree (see Figure 2) is a useful resource to help Missions and implementing partners select the best tool for their purpose and context.

FIGURE 2. Disability Identification Tool Selection Guide Decision Tree



As the decision tree clarifies, Missions and implementing partners must ask questions related to beneficiary age and respondent type in order to select a validated tool. Table 1 illustrates a sample of available social model tools appropriate for beneficiaries of different ages and with different respondents. Hyperlinks to a section on each tool in this How-to Note are included in the table for ease of reference. All of these tools may be used in either a conflict- or crisis-affected setting or a stable context.

TABLE 1: SAMPLE OF AVAILABLE DISABILITY PREVALENCE TOOLS FOR DIFFERENT AGES AND TYPES OF RESPONDENTS

BENEFICIARY AGE ¹⁰	2-4 YEARS	5-17 YEARS		18+ YEARS
RESPONDENT TYPE	Mother/Primary Caregiver	Mother/Primary Caregiver	Teacher/Trainer/ Instructor	Self
VALIDATED TOOL	CFM for 2-4 year olds	WG-SS or CFM for 5-17 year olds	CFM-TV (undergoing validation)	WG-SS or WG-ES

The tools mentioned here do not comprise an exhaustive list, nor do they encompass the myriad tools developed by partner countries. USAID Missions and implementing partners are encouraged to assess the landscape of local tools available, in addition to those listed below, when selecting a tool to measure disability prevalence. USAID guidance will be updated as more tools become available.

Existing Social Model Tools to Measure Disability Prevalence

The Washington Group Short Set for Children and Youth Ages 5-17 or Youth/Adults 18+ years

The [Washington Group Short Set \(WG-SS\)](#) is based on the International Classification of Functioning, Disability, and Health's (ICF) definition of six main domains of functioning, which include vision, hearing, mobility, memory/concentration, self-care, and communication. Respondents are asked whether they have trouble functioning in their environments for each domain, and to what extent. The WG-SS includes one question per domain, as shown below.

FIGURE 3. Washington Group Short Set of Six Questions on Functioning



¹⁰ The age ranges listed in this table correspond to age ranges of USAID Education programming.

The WG-SS was developed and validated as a self-reporting tool for use in national census and household surveys with respondents older than 17 years for the purpose of calculating prevalence rates or disaggregating data by disability. While the tool can provide disability data on children and youth aged 5-17, it is to be implemented with adult respondents (mothers or other primary caregivers) and even then will likely underestimate disability prevalence due to its exclusion of key domains that are important to assess in children. The WG-SS should not be implemented directly to children or youth under 18 years of age.

The WG-SS has many advantages. First, this questionnaire has been extensively tested and validated in many countries around the world. Second, it is supported by a wealth of resources developed by experienced statisticians and practitioners from the Washington Group (WG) on Disability Statistics.¹¹ The tool is simple and inexpensive to add as a module to any population-level data collection and takes less than two minutes to administer. While the WG-SS can identify many children and youth (up to age 17) with disabilities, it is known to severely underestimate the prevalence of children and youth with learning, developmental, and psychosocial disabilities that other measurement tools discussed further below address.

The Washington Group Extended Set for Youth and Adults Ages 18+

The [Washington Group Extended Set \(WG-ES\)](#) contains 35 questions covering each of the ICF's six domains of functioning, plus affect (anxiety and depression), pain, fatigue, and upper body functioning. This tool collects more information on disability status than does the WG-SS, though its purpose is similarly to collect data on disability prevalence or for the purpose of disaggregation by disability status. The tool is to be implemented with adult respondents aged 18+, with these adult respondents responding on their own behalf, or through an appropriately identified proxy respondent who knows them well and can respond on their behalf. The WG-ES should not be implemented with children.

Like the WG-SS, the WG-ES has been extensively tested and validated and is supported by many resources developed by the WG. While it is longer than the WG-SS and therefore takes more time to administer, it provides a wealth of data on disability prevalence and can be amended to household or larger disability surveys.

The Washington Group/UNICEF Child Functioning Module for Children and Youth Ages 2-4 and 5-17

The [Child Functioning Module \(CFM\)](#) was also developed by the WG in collaboration with UNICEF to collect disability prevalence data on children and youth in national household surveys and censuses. Unlike the WG-SS and WG-ES, it contains two modules, one for collecting data on children aged 2-4 and another for collecting data on children and youth aged 5-17. Regardless of age, the tool has been validated for use with parents/caregivers as respondents, and should not be used to collect data directly from children and youth without further validation.

The CFM covers several domains in addition to the ICF's six basic domains. For children ages 2-4, these domains include seeing, hearing, mobility, fine motor skills, communication, cognition (learning), playing, and controlling behavior. For children ages 5-17, these domains include seeing, hearing, mobility, self-

¹¹ <http://www.washingtongroup-disability.com/>

care, communication, cognition (learning, remembering, concentrating), accepting change, controlling behavior, relationships, and affect (anxiety and depression).

The Child Functioning Module-Teacher Version for Children and Youth Ages 5-17

In response to growing demand for a tool that can be implemented in school settings, the Washington Group, in collaboration with UNICEF, drafted the Child Functioning Module-Teacher Version (CFM-TV), a set of questions modeled off the CFM but modified to be used with *teachers* as the respondents. The CFM-TV is a set of 15 questions that covers the same domains as the CFM except for self-care and is designed to obtain data on children aged 5-17. The CFM-TV is still undergoing testing with the intention of validating it for implementation with teachers as respondents, as opposed to mothers or other primary caregivers.

Ongoing piloting of the CFM-TV funded and implemented by various donors and NGOs seeks to determine the tool's validity and reliability for the purpose of determining prevalence in a population or disaggregating activity outcome data by disability. While the CFM-TV is promising and well-suited for implementation in the context of USAID activities, use of this tool should be subject to further piloting for validity and reliability. Key questions, which are the subject of both past and ongoing piloting¹² mentioned above, remain:

- Under what conditions is the CFM-TV a valid and reliable tool?
 - What amount of familiarity (defined as length of relationship, student participation/attendance, and size of class) between educator and learner is necessary for a valid and reliable score on the tool?
 - How, if at all, do different educator perspectives, attitudes, or mindsets regarding disability in general, types of disabilities, or individual learners influence their ratings of learners?
- Is the CFM-TV valid and reliable for determining prevalence of certain types of functional difficulties and not others?

Best Practices for Collecting and Using Disability Prevalence Data

Regardless of the program cycle stage or the tool used, Missions and partners should adhere to key best practices for collecting and using disability prevalence data. The USAID [Best Practices in Generating Data on Learners with Disabilities](#) document provides important supplemental guidance to this How-to Note on the topics listed below.

¹² Past CFM-TV pilots offer initial answers to these questions. Ongoing CFM-TV pilots will provide additional data that will allow USAID and other donors to share best practices, necessary conditions, and limitations for implementing the CFM-TV.

FIGURE 4. Best Practices for Collecting and Using Disability Prevalence Data



Paramount amongst these best practices is to do no harm. Ethical considerations to take into account when collecting disability prevalence data include, but are not limited to:

- Data—even disability prevalence data—should NOT be collected if it will be misused to segregate learners into non-inclusive education settings.
- Proper data security and protocols must be in place to maintain confidentiality and protect individual-level data from being released; disability prevalence data are only for the purpose of aggregate reporting and disaggregation.
- Consent and/or assent must be collected from all respondents.
- Data collection and consent protocols must satisfy in-country requirements and be reviewed and approved or deemed exempt by an accredited U.S.-based institutional review board or equivalent in-country organization.¹³

Collecting and Using Disability Prevalence Data in Conflict- or Crisis-Affected Settings

While the best practices noted above pertain, in general terms, to all education contexts in which disability prevalence data is collected, this note makes some additional recommendations to USAID Missions and partners on collecting and using disability prevalence data in crisis and conflict-affected contexts.¹⁴

¹³ See USAID’s brief on [Ethics in Research and Evaluation in the Education Sector](#) for more information on IRB approval.

¹⁴ The [2018 USAID Education Policy](#) defines “crisis-affected” as “a country, region, or community that is experiencing or recently experienced a crisis, [...including those] indirectly affected by a crisis due to population displacement, reallocation of government resources, or diminished capacity. Crises include natural hazards, health epidemics, lawlessness, endemic crime and violence, and climate vulnerabilities.” The Policy defines “conflict-affected” as “a country, region, or community that has experienced armed conflict and/or recently terminated armed conflict, which is in contention over the control of government and/or territory that results in armed force between two parties, at least one being a government of a state. Conflict-affected also includes countries, regions,

Based on feasibility and reliability, data on disability prevalence can come from a variety of sources.

- **Leveraging education enrollment processes for crisis- or conflict-affected populations to collect disability prevalence data.** Particularly following acute crises (e.g. natural disasters or conflicts), displaced learners within a country will enroll or attend a local school or education/training program. These learners will follow an established enrollment process, and as part of this process, it is recommended to use social model tools to estimate disability prevalence amongst the newly enrolled learner population.
- **Prevalence data may need to be collected at the household-level in targeted areas rather than at the point of education service provision.** In crisis- and conflict-affected settings, the learning environment may be at the home or community level, education services may not yet have resumed, and/or learners with disabilities may not be in school. Prevalence data from inaccessible or exclusive educational services will underestimate the prevalence of children with disabilities within the crisis-affected population.

For national programs or a large-scale emergency, it may not be feasible to collect household-level prevalence data for a variety of reasons. In this case, below are other options for estimating disability prevalence data in order to plan inclusive education programs.

- **Needs assessments outside of the education sector may offer usable prevalence data.** In crisis- and conflict-affected settings, the humanitarian community (including the host government) supports household-level needs assessments across a variety of sectors. These assessments may provide usable estimated prevalence data, particularly at local levels, which may reduce the burden on education resources. USAID Missions may want to coordinate with other USAID or State Department colleagues who more often manage household-level needs assessments (e.g. food security, health) in order to explore whether already planned surveys can adjust their sample and include questions that estimate disability prevalence for children and youth. UNICEF, the World Health Organization, and other multilateral actors may also design and implement large-scale surveys, which could provide usable data.
- **Registration data from within or beyond the education sector may also have usable prevalence data on children and youth with disabilities within the displaced or crisis-affected population.** Social protection programs (e.g. cash transfers), distributions of essential goods and services (e.g. food, non-food items), and camp management providers for refugees or internally displaced people (e.g. camps housing people displaced by natural disasters, protection of civilian sites) typically register beneficiaries. Part of this registration data may include data on disability prevalence at the household or individual level.
- **Use 15 percent as the estimated prevalence of disability if it is not possible to collect primary data and no other reliable estimates exist.** A conflict- or crisis-affected context may ultimately preclude collecting primary data. The 2019 Inter-Agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action recommends assuming that 15 percent of the affected population has a disability in the absence of other robust data. Especially

or communities indirectly affected by conflict due to population displacement, reallocation of government resources, or diminished capacity.”

if an activity estimates the prevalence at 15 percent, plan to collect qualitative data directly from affected learners with disabilities in order to understand the barriers and potential solutions to inclusive education.

Data on disability prevalence should be collected in a way that allows for an understanding of the intersectional challenges learners with disabilities face. Disaggregation by displacement status, sex, ethnicity, religion, tribe, sexuality, gender identity, or other demographics can allow program planners to better understand the ways in which learners with disabilities are marginalized in times of conflict or crisis for reasons other than their disability.

Plan to ask learners with disabilities themselves about the barriers they face to education and what solutions they may suggest. Regardless of whether Missions or partners collect prevalence data firsthand or use an estimated prevalence rate from another data source, interviews or focus group discussions with learners with disabilities, as well as their families or caregivers if needed, will provide critical insight into the barriers they face in education as well as solutions they prefer or are already implementing. Education programs should incorporate feedback loops from learners with disabilities and caregivers at strategic points in project or activity implementation to understand how interventions are addressing education barriers.

Additional resources regarding data collection on disabilities in conflict- or crisis-affected environments include:

- The [2019 Including Everyone: Strengthening the collection and use of data about persons with disabilities in humanitarian situations](#) publication documents progress in policies and guidelines related to disability data in the humanitarian sector; reviews the existing tools and mechanisms for gathering data on persons with disabilities; and presents four case studies.
- [The 2019 Inter-Agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action](#) provides recommended actions for data collection, use, and management in general and specifically for education services; maps common secondary sources of data on disability prevalence available in many countries; and provides do-no-harm guidance most relevant for these settings. This set of guidelines has both measurement and programmatic guidance.

7. CONCLUSION

Collecting and using disability disaggregated data is vital to achieving USAID's Education Policy priority of increased access to quality education for all children and youth. By espousing the social model of disability and social model disability measurement tools, USAID is better able to generate the disability prevalence data needed to strengthen disability-inclusive education systems and improve education outcomes for children and youth with disabilities. When implemented for this purpose and with the respondents for which they are validated, social model disability prevalence tools assist USAID education programming in disaggregating education outcomes for learners with disabilities. Such disaggregated data can be used with other inclusive education indicators to highlight the gaps in programming that can yield improved targeting of learners with disability and improved education outcomes in USAID activity implementation. Disaggregated data, along with other indicators, can also help partner countries make data-informed decisions about education investments, which is crucial in the lower-resource contexts in which USAID education programming is most common.

USAID's Office of Education is not alone in this effort to improve outcomes for learners with disabilities through improved measurement of disability status. Efforts by Missions and partners to validate existing tools for new purposes or to develop new tools are welcome, and USAID's Office of Education would like to learn of such efforts. Please share information about your disability data tool development and validation efforts by emailing us at edulinks@usaid.gov.