



# BEST PRACTICES IN GENERATING DATA ON LEARNERS WITH DISABILITIES



Despite calls for equitable and high-quality education for all children and youth by the United Nations (UN), the United States Agency for International Development (USAID), and all other major donor organizations, marginalized children and youth<sup>1</sup> remain underrepresented in schools throughout the world. This underrepresentation is particularly pronounced among children and youth with disabilities.<sup>2</sup> In order to monitor progress and identify ways to strengthen the quality of education for these learners, reliable, accurate, and comparable data is needed.

USAID's Office of Education is committed to collecting, analyzing, and using disability data in USAID education programming to ensure that efforts are inclusive of learners with disabilities and meet the Agency's Education Policy priority of "expanding access to quality education for all, particularly marginalized and vulnerable groups."<sup>3</sup>

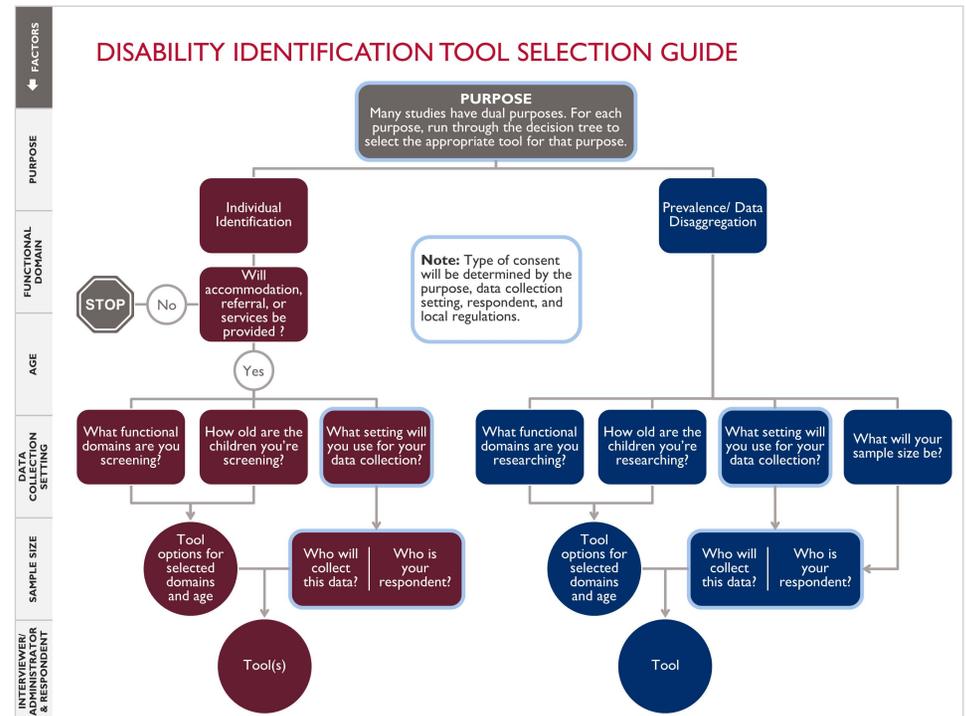
This brief summarizes best practices in collecting data on learners with disabilities that USAID's Data and Evidence for Education Programs (DEEP) project gleaned through a [tool mapping study](#) and expert and implementing partner consultations.<sup>4</sup> The selection of appropriate data collection tools and the use of appropriate protocols in their application affect the quality and relevance of any resulting data. Given the sensitive nature of individuals' disability status data, additional considerations must be born in mind when collecting and using them. The following points describe these considerations.

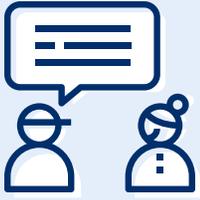


## USING THE RIGHT TOOLS

It is important to select a validated data collection tool whose purpose aligns with the purpose of your data collection. Any misalignment between the chosen data collection tool and the purpose could result in inaccurate information or conclusions. The interactive *Disability Identification Tool Selection Guide*, another resource provided by USAID, can help researchers select tools that most closely align with their data collection purpose. Before applying a data collection tool for any purpose, researchers should allow time for pilot testing and analysis to confirm the tool's validity.

The decision tree graphic below illustrates the questions researchers should consider when determining which tool to use. The separate interactive *Disability Identification Tool Selection Guide* will walk you through these questions and direct you to the best tool for your context.





## SELECTING RESPONDENTS AND INTERVIEWERS

Once a proper tool or set of tools has been selected, it is essential to work with respondents and interviewers for which the chosen tool has been validated. Failure to do so can result in inaccurate data. For example, the Child Functioning Module (CFM) has been validated for use with trained interviewers and with parents or legal guardians as respondents. The CFM should not be used with children and youth as respondents unless it is first pilot-tested with this group. The *Disability Identification Tool Selection Guide* provides information regarding respondents and the tools that have been validated for them. When possible, recruit persons with disabilities as interviewers.



### RESOURCE LINKS

- [Cross-Cultural Survey Guidelines | Interviewer Recruitment, Selection, and Training](#)
- Please see the M&E section for recommendations on making assessments accessible to interviewers with disabilities.
- Please see the SINTEF studies for examples of surveys where people with disabilities and their organizations play an active role in study design, data collection, and implementation of the results of the studies.



## SAMPLE SIZE

Researchers should make sure they have a sufficiently large sample size to permit disaggregation by disability status. The ability to further disaggregate by type of disability, sex, or other factors may be limited if the sample size is not large enough. In order to fully understand marginalization and its effects, these disaggregation analyses may be important.

## SETTING CONSIDERATIONS

When collecting data at the school level for prevalence purposes, researchers should also consult evidence from household-based surveys, which can capture information on out-of-school children and youth not captured in school-based surveys.



### RESOURCE LINKS

- [Washington Group on Disability Statistics | Basic Guide to Sampling for Disability Surveys](#)
- [Practical Recommendations for Equity Analysis in Education](#)



## TRANSLATION AND ADAPTATION

Selected tools may need to be translated and adapted so that they are appropriate to respondents' language and culture. Researchers must take care in translating and adapting these tools, however, to make sure that questions retain their original meaning and that resulting data are comparable and accurate. The Washington Group on Disability Statistics provides guidance<sup>5,6</sup> to ensure that translated questionnaires maintain equivalence of measurement across languages and dialects.

Several recommendations should be kept in mind when translating or adapting tools:

1. When adapting questionnaires, consider the appropriateness and relevance of questions for local culture, setting, respondent, and interviewer. If a question cannot be adapted to make sense in a given context, then, after careful consideration, consider dropping or modifying it.
2. Include local disabled persons' organizations (DPOs) in the translation and adaptation process to ensure that language captures what is intended and appropriate. DPO participation can also help researchers avoid terminology that could perpetuate misconceptions of disabilities or result in stigmatization of respondents.
3. Maintain continuity of concepts in questions rather than attempting to produce a literal translation.
4. Translate and make available questionnaires in all main languages likely to be encountered to avoid on-the-spot translations in the field.
5. Ensure that the interviewer and/or interpreter has a strong grasp of the questions' original meaning and comprehends key terminology<sup>7</sup> in case they encounter an unanticipated language or a language that has no written form and must work with an interpreter.

6. Apply a consensus or committee approach to translation and adaptation. Consensus approaches to translation are considered superior to forward/back-translation. Never rely on tools such as Google Translate.
  - » For example, consider the TRAPD approach to translation—**t**ranslation, **r**eview, **a**djudication, **p**retesting, **d**ocumentation.<sup>8</sup> This approach involves a team of translators who each develop an independent translation. The translators and a reviewer compare translations to develop an accepted translation. An adjudicator compares the final version to the original questionnaire prior to approving the final version.
7. Conduct cognitive testing on each translated and adapted version of the questionnaire prior to pilot testing. Cognitive interviewing will ensure that interviewers use language respondents understand, that questions are understood as originally intended, and that there is no bias in questions.
  - » Ensure that target populations are included in both cognitive interviewing and pilot testing.



### RESOURCE LINKS

#### TRANSLATION

- Translation of the Washington Group Tools
- The TRAPD Method for Survey Translation
- Cross-Cultural Survey Guidelines | Translation: Overview

#### COGNITIVE INTERVIEWING

- Cognitive Testing Interview Guide
- Washington Group Cognitive Testing of Translated Questions (Forthcoming, 2020)



## TRAINING

Those involved in data collection should receive proper training. As with the application of any survey, training content and duration can vary considerably. To obtain well-trained interviewers and high-quality data, key elements should be incorporated into training:

- I. An introductory module that ensures that interviewers:
  - a. Have a clear sense of the purpose and importance of this data collection.
  - b. Are familiar with disability concepts and proper terminology that reinforce a human rights-based/social model concept of disability.
  - c. Are familiar with ethical considerations, such as maintaining respondent privacy/confidentiality and obtaining consent and assent.
  - d. Know how to interact with the expected respondent populations, including those with disabilities.
  - e. Are prepared for challenges they may encounter in the field.
2. A module on the use of the tool that provides opportunities for trainees to:
  - a. Learn about questionnaire content and administration.
  - b. Learn general interviewing techniques and approaches to obtaining consent.
  - c. Flag any additional revisions to questionnaire translations prior to fieldwork.
  - d. Participate in:
    - i. Mock interviews in the training facility.
    - ii. Supervised practice interviews with respondents in the field.
  - e. Learn how to work with local translators in case in-the-field translation is needed.
  - f. Learn strategies for interviewing respondents who are deaf or hard of hearing. These may include:
    - i. Working with an official sign language interpreter.
    - ii. Utilizing a team member who uses a sign language to carry out the interview.

- iii. Working with a family member who can interpret.
- iv. Using methods to communicate directly with a respondent without an intermediary.

- g. Participate in assessments to ensure they have mastered training content.

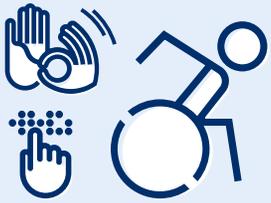
As training is developed, a few other best practices should be followed:

1. Train more interviewers than you anticipate needing so that only those who successfully complete training assessments go out to the field.<sup>9</sup>
2. Include representation from DPOs in training to provide guidance and address disability-specific questions that may arise during training.<sup>10</sup>
3. Despite the need to secure well-trained interviewers, don't instill anxiety among interviewers. Disability may be complex, but the questions used to identify disability are straightforward and require little advanced understanding. If interviewers carry doubt or uncertainties into the field, they are likely to transfer those to the respondent.
4. Adapt your training based on the type of interviewer you use, their level of data collection experience, and their prior familiarity with disability-related issues. For example, training length and content will be different if you work with seasoned interviewers, first-time interviewers, or teachers who will complete forms regarding students in their classes.



### RESOURCE LINKS

- [Module on Child Functioning: Manual for Interviewers](#)
- [Cross-Cultural Survey Guidelines | Interviewer Recruitment, Selection, and Training](#)
- [Enumerator Training](#)
- [Doing Research with Enumerators](#)



## ACCOMMODATIONS

Researchers should provide accommodations as needed, such as sign language interpreters, interviewers who can sign, or large script and/or braille questionnaires to ensure equal participation and representation of persons with disabilities. Reasonable accommodations should be made available for both respondents and interviewers with disabilities. Where identified respondents are unable to respond even with the provision of reasonable accommodations, researchers may, on a case-by-case basis, attempt to identify an appropriate proxy respondent who knows the respondent well and can answer on their behalf, consistent with data privacy protections and IRB approval.



### RESOURCE LINKS

- [HHS.gov | Special Protections for Children as Research Subjects](https://www.hhs.gov/ohrt/special-protections-for-children-as-research-subjects)
- [HHS.gov | Research with Children FAQs](https://www.hhs.gov/ohrt/research-with-children-faq)



## ETHICAL CONSIDERATIONS

Given the sensitive nature of data on individuals with disabilities, researchers should take into account particular considerations regarding consent and assent requirements and the use and dissemination of resulting data. These requirements may differ when data are being collected for individual identification versus prevalence or data disaggregation purposes and depending on who the respondent is. Below are a few guiding principles regarding data use and dissemination.

- Data for individual identification **should only be** collected when 1) it can be kept confidential and secure and 2) there is a plan to use it to provide referral services, accommodation, grants, or other government incentives to those individuals identified as having a disability.
- Data **should not be** collected if identification of children and youth with disabilities will cause harm to individuals, such as segregating learners into non-inclusive education settings. Data collection should always be underpinned by the social model of disability and with intent to improve inclusive education outcomes for learners with disabilities.<sup>11,12</sup>
- Data collection and consent protocols must satisfy in-country requirements and be reviewed and approved or deemed exempt by an accredited US-based IRB or equivalent in-country organization.<sup>13</sup>
- Aggregate-level findings should be shared with ministries of education and health because they can flag patterns of prevalence that may indicate the need for government intervention. Data can be uploaded to Education or Health Management Information Systems and used to guide policy and funding allocation decisions.
- Results of individual child identification should be shared with parents/caregivers.

Below are a few guiding principles regarding consent and assent.

- For individual identification of children or youth under consenting age, prior parental/caregiver consent is always required.
- When a teacher provides data through a data collection instrument for prevalence or disaggregation purposes and individual children and youth are not identified, individual parental consent may not be required, but follow local IRB guidance to make this determination. When prior consent is not required, parents should be notified of this data collection and its potential benefits to the school system in advance of collection, and be given the option to exclude their children from the study.
- When prevalence or disaggregation data are collected in school directly from children and youth under consenting age, both individual parental consent and child assent are required even though individual respondents are not identified.

## ENDNOTES

- 1 USAID defines marginalized and vulnerable children to include children with disabilities, girls, children affected by or emerging from armed conflict or humanitarian crisis, children in remote or rural areas (including those who lack access to safe water and sanitation), religious or ethnic minorities, indigenous peoples, orphans and children affected by HIV/AIDS, child laborers, married adolescents, and victims of trafficking, or those who are denied, or have very limited access to, privileges enjoyed by the society-at-large. *USAID Education Policy 2018*.
- 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 USAID. 2018. *USAID Education Policy 2018*. <https://www.usaid.gov/documents/1865/2018-usaid-education-policy>
- 4 Mulcahy-Dunn, A., Martin, A., Mont, D., Venetis, E., Rizzo, T., & Jarvis, J. L. 2020. *Mapping of tools for disaggregation by disability status: Report*. Rockville, MD: EnCompass LLC. Prepared for USAID. <https://www.edu-links.org/resources/mapping-tools-disaggregation-disability-status>
- 5 Washington Group. 2017. *Translation of the Washington Group Tools*. Washington Group on Disability Statistics. <http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-3-Translation-of-the-Washington-Group-Tools.pdf>
- 6 Washington Group. 2006. Appendix 3: *Cognitive Testing Interview Guide*. Washington Group on Disability Statistics (October 2); Forthcoming Washington Group. 2020. Cognitive Testing of Translated Questions.
- 7 Translators without Borders. 2018. *The words between us: How well do enumerators understand the terminology used in humanitarian surveys?* <https://translatorswithoutborders.org/the-words-between-us-how-well-do-enumerators-understand-the-terminology-used-in-humanitarian-surveys/>
- 8 Harkness, J. A., Edwards, B., Hansen, S. E., Miller, D. R., & Villar, A. 2010. "Designing questionnaires for multipopulation research." In J. A. Harkness, M. Braun, B. Edwards, T. P. Johnson, L. E. Lyberg, P. Ph. Mohler, B-E., Pennell, & T. W. Smith (Eds.), *Survey methods in multinational, multicultural, and multiregional contexts* (pp. 33-58). Hoboken, NJ: John Wiley and Sons.
- 9 Vaessen, M., Thiam, M., & Le, T. 2005. "Chapter XXII: The demographic and health surveys." In United Nations Statistical Division, United Nations Department of Economic and Social Affairs (Eds.), *Household surveys in developing and transition countries*. New York, NY: United Nations. Retrieved March 26, 2010, from [http://unstats.un.org/unsd/HHsurveys/pdf/Household\\_surveys.pdf](http://unstats.un.org/unsd/HHsurveys/pdf/Household_surveys.pdf)
- 10 See SINTEF report for example surveys that included DPOs in design and implementation of data collection on people's functional limitations: <https://www.sintef.no/en/projects/studies-on-living-conditions/>.
- 11 GLAD. 2019. Global Action on Disability Network Infographic on Inclusive Education. <https://gladnetwork.net/search/resources/glad-infographic-inclusive-education>
- 12 IDA. 2020. *What An Inclusive, Equitable, Quality Education Means To Us*. International Disability Alliance (IDA). <http://www.internationaldisabilityalliance.org/ida-inclusive-education-2020>
- 13 See USAID's brief on Ethics in Research and Evaluation in the Education Sector for more information on IRB approval. <https://www.edu-links.org/sites/default/files/media/file/IRB%20Policy%20Brief%20FINAL.pdf>

## REFERENCES

- Altman, B. M. (ed.) 2016. *International measurement of disability: Purpose, method and application* (Vol. 61). Springer.
- Miller, K., D. Mont, A. Maitland, B. Altman, and J. Madans. 2011. *Results of a cross-national structured cognitive interviewing protocol to test measures of disability*. *Quality & Quantity* 45(4): 801-815.
- United Nations. n.d. *Convention on the Rights of Persons with Disabilities – Article 1 – Purpose*. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html>
- USAID. 2018. *How-to Note: Collecting Data on Disability in Education Programming*. Education Links. <https://www.edu-links.org/resources/how-note-collecting-data-disability-education>.
- Washington Group. 2017. *Translation of the Washington Group Tools*. Washington Group on Disability Statistics (October 23). <http://www.washingtongroup-disability.com/wp-content/uploads/2016/12/WG-Document-3-Translation-of-the-Washington-Group-Tools.pdf>
- Washington Group. 2016. *Child Functioning*. Washington Group on Disability Statistics (December 18). <http://www.washingtongroup-disability.com/washington-group-question-sets/child-disability/>
- Washington Group. 2016. *Extended Set of Questions on Functioning*. Washington Group on Disability Statistics (January 18). <http://www.washingtongroup-disability.com/washington-group-question-sets/extended-set-of-disability-questions/>
- Washington Group. 2006. *Appendix 3: Cognitive Testing Interview Guide*. Washington Group on Disability Statistics (October 2). [http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/appendix3\\_cognitive\\_test.pdf](http://www.washingtongroup-disability.com/wp-content/uploads/2016/01/appendix3_cognitive_test.pdf)
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