Save the Children

TECHNICAL GUIDANCE NOTE

On the use of Washington Group Question Sets for Disability Disaggregated Data

SAVE THE CHILDREN INTERNATIONAL

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CONTENT

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Abbreviations

CFM	The WG/UNICEF Child Functioning Module
CFM-HV	The WG/UNICEF Module on Child Functioning Humanitarian Version
CFM-TV	The WG/UNICEF Module on Child Functioning Teacher Version
CRC	The United Nations Convention on the Rights of the Child
CRPD	The United Nations Convention on the Rights of Persons with Disabilities
DHS	Demographic and Health Surveys
FGD	Focus Group Discussion
IPTT	Indicator Performance Tracking Table
KII	Key Informant Interview
LFS-DM	The WG/ILO Labor Force Survey Disability Module
MEAL	Monitoring, Evaluation, Accountability & Learning
MICS	UNICEF Multiple Indicator Cluster Surveys
NGO	Non-Governmental Organization
OPDs	Organizations of Persons with Disabilities
TWG	Technical Working Group
WG-ES	The WG Extended Set on Functioning
WG-IEM	The WG/UNICEF Inclusive Education Module (IEM)
WG-SS	The WG Short Set on Functioning

1.Introduction

Save the Children's mandate is based on the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD) and therefore recognizes that every child has the same and equal rights irrespective of their different identities or characteristics. Save the Children's Policy on Disability Inclusion[1] outlines the discrimination and inequality often faced by children and adults with disabilities and commits Save the Children to support these groups realizing their full and equal rights.

Data disaggregated by disability is fundamental to understanding the inequality and discrimination that persons with disabilities face and the gaps in humanitarian aid distribution and development programmes. With data disaggregated by disability, we can ensure that our programmes reach and benefit all children and families and that we deliver impactful and purposeful advocacy work towards duty bearers and other responsible stakeholders. Recognizing the importance of disability disaggregated data, the 2030 Sustainable Development Agenda affirms that data should be disaggregated by disability in addition to age, gender, income, ethnicity, race, geographic location and other characteristics to ensure that no one is left behind.

Rights-based, needs-responsive and disability inclusive programmes rely on reliable evidence and comparable data which makes visible the inequities between persons with disabilities and those without. Therefore, disability disaggregated data must become a regular and integrated part of our research and evidence culture and data systems. This means that, whenever we gather and analyze evidence and data from any community or group, we need to understand both how many of the respondents that may have a disability and to what extent and in which way their responses and experiences in any way may differ from the responses and experience of those without disabilities.

1.1 About this document

This guidance note aims to provide Save the Children and partners with **condensed information and practical guidance on how to apply disaggregation by disability status to programme data, using the different Washington Group Question Sets (WGQ)**. These question sets are the best known, most widely used and recommended tools for disaggregating data by disability status alongside gender and age. In this guidance document, we cover what the WGQs are, their added value and limitations, when we should or should not use them, and finally a step-by-step guidance on how we should use them.

The target audience for this guidance note is **all Save the Children and partner staff** working in and with Global Teams, Country and Member Offices, especially those engaged in implementation and support of programmes and advocacy, such as Programme Quality and Impact teams, Technical Advisors, Research and Evidence teams, Monitoring, Evaluation, Accountability and Learning staff and Project Management teams. The guidance applies to both **development contexts and humanitarian action.**

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[1] For internal policy documents in different languages and child-friendly versions access here Disability Inclusion Community of Practice - 1. Save the Children Disability Inclusion Policy –

This guidance document builds on work by Save the Children Norway and has been adapted to a broader Save the Children context by the Disability Inclusion Technical Working Group and its Disability Data Task Team.

It serves as a deep-dive into disability disaggregated data using the Washington Group Question Sets as referred to in SC Recommended disaggregation for programme guide. It also expands the short SCI Brief on Disability Disaggregated Data with more details and guidance.

Due to the evolving learning of applying disability disaggregated data within Save the Children's projects and new insights and complexities of what works and not, it has taken several years to complete this guidance, and it will remain a living document as tools are refined, updated and applicability keeps shifting across programmes.

1.2 Why do we need disaggregated disability data?

Disaggregating data is done to detect and compare differences and inequalities between respondents with different demographic characteristics and their responses in any type of research and data. We particularly use it when trying to analyse and understand participation, access, needs, use of services and overall impact of our programmes. If we, in any data or evidence uptake want to understand if the needs, experiences, access, use or impact differ for adults and children with disabilities, we must disaggregate data by disability when we collect it. Depending on the purpose of our study or the data we collect, disaggregated data can also help us identify differences and similarities between people with different combinations of demographic characteristics such as age (adults/children), gender (men/women, mothers/fathers, girls/boys/others), and disabilities (children with /without disabilities).

Disaggregated disability data is necessary to;

a) Determine the disability prevalence in our research sample, project participants or programme.
b) Understand to what extent our programmes benefit children with disabilities and how they perform on various programme indicators compared to their peers without disabilities.
c) Use statistics and data to inform project and programme design, annual planning and budgeting decisions aiming to reduce the inequity faced by children and adults with disabilities.
d) Use statistics and data for carrying out effective awareness raising and advocacy towards duty bearers and other relevant stakeholders.
e) In some cases, identify children or adults who have difficulties in one or more functional domains and, therefore, *may have a disability* and refer them to appropriate screening or diagnostic services.

In practical terms Save the Children programmes as well as our partners', should collect data disaggregated by gender, age and disability whenever relevant and possible. This includes, but is not limited to the following situations:

- Child Rights Situation Analysis
- Thematic needs assessments
- Programme baseline, midline and endline

- Evaluations
- Regular programme monitoring data collection activities, such as indicators relating to learning outcomes, safety in school, child protection case management, child clubs, Child friendly space attendance etc.
- Larger research designs and analysis.

SCI recommends using disability disaggregated data on relevant programme indicators, and using the Washington Group Question Sets when doing so. Save the Children should not use other ways of disaggregating disability data unless it is non-data driven methodologies such as Developmental Delay Screening and Assessment tools or professional diagnostic screenings. In very exceptional circumstances for urgent rapid needs assessments in humanitarian settings, the **Humanitarian Disability Needs Estimation Screening Tool (HD-NEST)** can be used but keep in mind that it cannot be used to determine disability status nor should it be used to disaggregate findings, it is simply a needs assessment tool.

1.3 How we define and understand disability?

According to the UN Convention on the Rights of Persons with Disabilities, "**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*".[2]

In plain language, we can distinguish between impairments and disabilities in the following way:

- **Impairments are** any loss or difference of psychological, physiological, or anatomical structure or function and are based on WHO's International Classification of Diseases (ICD-11) or the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR)
- **Barriers are** things that hinder a person from participating in society on an equal basis with others. Barriers are often categorized into the following types: attitudinal, environmental, institutional, financial, or communicational.[3]

According to this definition, disability arises from the interaction between a person's impairment and the barriers they experience daily when carrying out activities and using services in society and at home. Barriers are removed by accessibility and reasonable accommodation or universal design principles and the more they are removed the less the person experience barriers regardless of their impairment. This in turn determines a person's level of participation and ability to enjoy their rights on an equal basis to others without disabilities. Thus, two people with the same impairment can experience very different levels of disability, depending on how many and severe barriers they experience in any said activity or location.

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[2] UN General Assembly (2006) *Convention on the Rights of Persons with Disabilities (CRPD)* Article 1.

[3] For more on barriers please see SC Disability Rights Terminology Standard 2024 | Save the Children's Resource Centre page 17.

Save the Children's approach to disability inclusive programming focuses primarily on **removing barriers and applying enablers, so that adults and children with disabilities can participate in and benefit from our programmes on an equal basis as those without disabilities. To real more about disability and terminology please read our Disability Right Terminology Standards.**

The Washington Group (WG) does not use the word "disability" in its question sets, due to the negative connotations of this word in many communities, societies and cultures. Instead, the WG has translated and operationalized the word disability into **"functional difficulties**" aiming for more neutral, less sensitive and more practical terminology. According to International Classification of Functioning, Disability and Health (ICF), *"functioning is an umbrella term for body function, body structures, activities and participation. It denotes the positive or neutral aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors)."*[4]

2. Washington Group Question Sets

2.1 What is the Washington Group on Disability Statistics?

The Washington Group on Disability Statistics (WG) was established by the UN Statistical Commission in 2001 with the mandate to develop a methodology for collecting **statistical population data on disability** that is internationally comparable. After more than five years of extensive testing and validation across countries and cultures, the Washington Group Short Set (WG-SS) of questions was finalized and adopted in 2006. Over time, the WG, at times in collaboration with UNICEF and ILO, has developed an additional seven sets/modules of questions, some of which include two questionnaires. These sets consist of different questionnaires (question sets and Modules) often collectively referred to as the **Washington Group Questions or more accurately the Washington Group Question Sets and Modules (WGQs).**

The WG tools were designed for **use in national censuses or surveys** to primarily estimate disability prevalence and to assess progress on various programme/service indicators disaggregated by disability. While Save the Children and other non-governmental organizations rarely conduct these large-scale data collection projects, the WGQs have been increasingly adopted and used in data collection in programmes both in development and in humanitarian contexts and have been found to provide more accurate disability data compared to other methodologies.

2.2 How is disability measured by the Washington Group?

The Washington Group Question Sets (WGQS) does not measure impairments or diagnoses but rather the extent of "**functional difficulty"** a person may have within one or more **"functional domains".**

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[4] The ICF- An Overview: available here: https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf

Disability is best understood as a continuum. In terms of **difficulty functioning**, the 'difficulty' is divided on a continuum from no difficulty at all, through some difficulty and a lot of difficulty to completely unable to carry out the action. Each of these levels represents a cut-off or threshold in the determination of a final disability identifier; for example, to define those with and without disability. These levels of functioning are also represented in the **response categories** to the majority of the WG Question Sets.

- "*No difficulty* ",
- "*Some difficulty* ",
- "*A lot of difficulty*" or
- "*Cannot do at all* "
  Some sets may have additional answer options depending on Module and focus.

The different sets or modules include a set of questions designed to identify (in a census or survey format) people with a disability. The questions ask whether people have difficulty performing basic universal activities in so called **"functional domains".** Functional domains are categories based on health-related function and builds on the ICF classifications. A few examples of a functional domains used by the Washington Group on Disability Statistics include "*seeing*", "*hearing*", "*mobility*", "*self-care*", "*communication*" "*remembering*", and "*coping with change*".

As a standard cut-off or threshold in the determination to define which respondents have or do not have a disability, Save the Children should count any respondent who has replied "*a lot of difficulty* ", or "*cannot do at all* ", in at least one of the functional domains as a person with disability and everyone else as a person without disability. When presenting data the terminology used should be child/adult/person with disability and child/adult/person without disability.

2.3 Why not just ask people "Do you have a disability?"

The WG strongly advices against mentioning the word "disability" and instead asks questions on functional difficulties as explained above and in accordance with the different WGs questionnaires without adding to it. But why is it so important to never ask people if they have a disability, even as a screener question?

1) Depending on the person or the context, the question can be seen as offensive or stigmatizing. This can make respondents unwilling to answer the question, or to give an incorrect answer.

2) The question can be misunderstood or understood across different contexts and by different individuals, which will give you incorrect data.

3) The question can come with assumptions which lead to respondent bias, either that answering yes may come with additional support or that answering "no" may mean losing out on support or have other implications.

The WGQ sets were originally developed to be used for collecting and analyzing population data such as censuses, Multi Indicator Cluster Surveys (MICS) and Demographic Health Surveys (DHS). To use the tools for programme data, specifically smaller project data can therefore include some challenges relating to sample size, statistical significance and purpose. It is therefore important to understand which set to use and how to use it. Many sets are still being tested within programmes by actors such as Save the Children.

2.4 When to use or not use the WGQs?

Do not use the WGQ's:

- **To determine who needs medical services and what type of services those should be.** This type of data is difficult to collect with non-specialized staff and tests. The WGQs cannot be used to collect this type of data.
- **To establish disability/impairment type or diagnosis.** None of the WGQs sets or modules provide a medical diagnosis or determine eligibility to program benefits.
- **Individual-level purposes**, including for first-stage screening purposes, or to determine accessibility needs, reasonable accommodation or other individual service needs assessments.
- **To determine individual need for rehabilitation or assistive technologies.**
- **To generally identify barriers experienced by children or adults with disabilities or their caregivers, especially qualitatively.** The only exception is the Inclusive Education Module (IEM) tool and the Labor Force Survey Disability Module (LFS-DM). These two tools do capture barriers and other matters. Questions about barriers can be included in a quantitative survey which uses WGQs for disaggregation and are useful when the sample size includes a general cohort. But to assess barriers, persons with disabilities or their family members are often specifically selected for more in-depth qualitative methods such as in-depth interviews or focus group discussions and then the WGs do not add much value as interviewees would have already been confirmed to have disabilities through other means or OPD memberships.

Do use the WGQs:

- **When you want to know how many, or what percentage, of your respondents in a study sample have a disability.** For example: Midline Evaluation Report: Literacy empowerment alliance for a resilient new generation (LEARN) project
- **When you want to understand how respondents with disabilities answer in comparison to those without disabilities.** This can be both child or adult respondents with disabilities, children of respondents with disabilities or parents of children with disabilities. For example: The Hidden Impact of COVID-19 on Child Poverty
- **When you need to determine who is excluded from programmes, services or spaces or at risk of being excluded** For example: Baseline report increased accountability to eliminate violence and discrimination against children with disabilities (AVAC)
- **When you want to understand the situation of families or persons with disabilities compared to those without disabilities**, for example in household surveys or multi-sectoral needs assessments. For example: Household with Disability in Afghanistan: Multi-sectoral needs assessments

Remember that the WGQs are not a disability diagnostic tool but one that measures functional difficulties based on a cut-off point which serves as a proxy for disability.

2.5 Why use the WGQs for disability disaggregated data?

- WGQs are extensively tested worldwide, across income levels and regions.
- WG-SS is most used/tested; others like CFM-HV are new and unpiloted.
- Developed with OPDs, in line with UN CRPD article 4.3 and "Nothing About Us Without Us".
- Provide self-reported data on functional difficulties from respondents' perspective.
- Integrate easily into existing surveys, adding only minutes to data collection.
- Recommended by the International Disability Alliance (IDA).
- Most sensitive way to ask about disabilities and preferred by persons with disabilities.
- Most internationally recommended tool for disability disaggregation (used in in UNICEF Multiple Indicator Cluster Surveys (MICS), Demographic and Health Surveys (DHS), and censuses done by National Statistics Offices).
- Data is comparable across locations, contexts, and cultures.
- Enumerators need no medical knowledge—just follow simple guidelines.
- Methodologically robust; can correct common underestimation of disability prevalence.

3. Using the Washington Group Question Sets

3.1 How to use the Washington Group Question Sets

The vast majority of the WGQs Sets consist of **several questions which are to be inserted into an already existing survey questionnaire** form within the **demographic section.**[5] This would be the same part of the survey where respondents are asked about age, location, education level, sex, number of children, school grade etc.

The **questions and accompanying response categories should be inserted as they are,** preferably in already approved translated versions (rather than translated together with the rest of the questionnaire or the researcher), and only by changed or revised according to strict rules and conditions when absolutely necessary. The order of the questions should not be altered in any circumstance.

Before data is collected, **enumerators must be trained on how to administer the questions**, especially since it is important to avoid the word disability, but also since some sets have a skip logic which the enumerator who collects the data must follow.

The recommended respondent of the questions depends on the set and the purpose of the study and what is possible in the context and location of the data collection moment. As a rule, **all adults should respond themselves** to questions about their own functioning (i.e., the adult's or parent/caregiver's disability status)**. For children we should always use the Child Functioning Modules sets.** And when

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[5] The questions should not be added to a binary question about disability. We should never ask about disability in the form of do you/ does your child have a disability?

we ask about functioning in children (i.e. the child's disability status) and especially when using the CFM modules, the questions should be **directed to and answered by the parent/caregiver as a rule**[6]. Only when conducting the CFM-TV, should the questions be answered by a teacher.

If by any circumstance and exception the **adult sets**, such as the WG Short Set (WG-SS) or the WG- SS Enhanced or the Washington Group Extended Set (WG-ES), **are used on children under 18 years of age** and there is no parent/caregiver around, it can be administered to the **child directly to respond** but it should **not be used on children under the age of 12 and the child must be sufficiently mature** for and fully consenting to the study, and all ethical protocols must have been followed.

In exceptional circumstances, we may need to **interview proxies/intermediaries for adults** as well as for children (for example when collecting data from people with more complex or multiple impairments).

3.2 What are the different Questions sets?

Contrary to what many believe, the WGQs are not just one set of questions but **eight different sets of the Washington Group Questions (and one enhanced set)**. All sets have **similar response categories** as mentioned above, but the **number of questions**, the **intended respondent or subject** and the **functional domains** that they measure vary between the sets.

In the following pages, we will go through the different WGQs sets with a focus on those most relevant for Save the Children and our partners. The choice of WGQs sets will depend on the target group (i.e. whose disability status we want to measure), time availability and context.

1. The WG Short Set on Functioning (WG-SS) and
   The WG Short Set on Functioning Enhanced (WG-SS Enhanced)
2. The WG Extended Set on Functioning (WG-ES)
3. The WG/UNICEF Child Functioning Module Age 2-4 (CFM)
4. The WG/UNICEF Child Functioning Module Age 5-17 (CFM)
5. The WG/UNICEF Module on Child Functioning Teacher Version (CFM-TV)
6. The WG/UNICEF Child Functioning Module Humanitarian Version (CFM-HV)
7. WG/UNICEF Inclusive Education Module (IEM)
8. WG ILO Labor Force Survey Disability Module (LFS-DM)

Table 1 – All the WGQs Sets and summary details

Name of Set	To assess disability in	No of Qs	Intended respondent	Functional domains covered	Summary	Resources
The WG Short Set on Functioning (WG-SS)	Adults 18+ years	6	Adult themself	Seeing, hearing, mobility, remembering/	Shortest and most used in large surveys/census,	Find full set here (WG) and approved translations to

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[6] Remember that for young married girls, their husbands are not their caregivers.

				concentrating, self-care, communication	great for adults but not suitable for children as domains are limited and fail to take into consideration child development.	other languages here (SCI) or here (WG)
The WG Set - Enhanced (WGSS-Enhanced)	Adults 18+ years	12	Adult themself	Seeing, hearing, mobility, remembering/ concentrating, self-care, communication, upper body functioning and affect (depression and anxiety).	As the Short Set but also includes domains relating to mental health.	Find full set here (WG)
The WG Extended Set on Functioning (WG-ES)	Adults 18+ years	34+ 3 optional	Adult themself	Seeing, hearing, mobility, remembering/ concentrating, self-care, communication, upper body functioning and affect (depression and anxiety), pain, fatigue.	Same as above but includes more functional domains and common assistive technologies.	Find full set here and approved translations to other languages here
The WG/UNICEF Child Functioning Module Age 2-4 (CFM)	Children aged 2-4 years of age	16 with skip logic	Primary caregiver	Seeing, hearing, mobility, fine motor skills, communication/comprehension, learning, playing, controlling one's own behavior	Produced by WG and UNICEF, targeted at children considering stages of child development	Find full set here (WG)

The WG/UNICEF Child Functioning Module Age 5-17 (CFM)	Children aged 5-17 years of age	24 with skip logic	Primary caregiver	Seeing, hearing, mobility, self-care, communication, learning, remembering, concentrating, accepting change, controlling one's own behavior, making friends. anxiety, depression,	Same as above, targeted to older age group of children	Find full set here (WG)
The WG/UNICEF Module on Child Functioning Teacher Version (CFM-TV)	Children of school age 5-17 years of age	20	Teacher or school staff closest to the child	seeing, hearing, mobility, fine motor, communication/comprehension, learning, remembering, attention and concentrating, coping with change, controlling behaviour, relationships, and affect (anxiety and depression).	Aimed at identifying children with disabilities **in a school setting.** Developed to take advantage of EMIS data. All questions are prefaced with “‘***Compared with children of the same age…***’, “ Cannot be administered at the enrolment, teachers must know students, high respondent bias risk.	Find all resources here
The WG/UNICEF Module on Child Functioning Humanitarian Version (CFM-HV)	Children 2-4 or children 5-17	10 -14 with skip logic so only 7 asked per child	Mother or primary caregiver	Age 2-4 Seeing, hearing, mobility, fine motor skills+ comprehension, controlling one's own behavior Age 5-17 Seeing,	For humanitarian settings. This is the newest set and exists in three different tiers depending on situation: at the onset or later. Each tier has its own questions except	Find all resources and questionnaires here Contact CO and UNICEF directly for available translations.

				hearing, mobility, fine motor skills + communication, concentration, controlling behavior, affect (anxious, nervous, worried)	the third which is the standard CFM questions.	
The WG/UNICEF Inclusive Education Module (IEM)	Children of school age	74 with skip logic, without CFM.	Mother or primary caregiver		**Cannot be used to disaggregate** or detect prevalence without **combining with CFM.** Full survey, which captures school environment, school attendance determinants, reasons for not attending school. Structure follow MICS	Find full set and resources here
The WG/ILO Labor Force Survey Disability Module (LFS-DM)	Adult 18+ years	17 with skip logic	Adult themself	Seeing, hearing, mobility, cognition/remembering, self-care, communication, anxiety, depression, barriers, accommodations, attitudes, social protection.	A full survey which covers more than status. It has 5 sections, whereof the first is the WG-SS. The LFS-DM was intended for inclusion in Labor Force Surveys and is also suitable for use in population-based surveys that collect data on employment.	Find full set here (WG)

3.4 Limitations to the WGQs

Although the WGQs are the recommended tool for disability disaggregation by Save the Children and the disability movement at large as well as major institutional donor, keep in mind that there are some methodological restrictions:

Disclosure:
Although the WGQs are known to be less stigmatizing, depending on the training of enumerators and context in which data is collected, respondents may not be willing to disclose or admit their own or their children's functional difficulties due to fear of being stigmatized or discriminated against although the WGQs are formulated to be non-stigmatizing and to address this issue.

Over-reporting:
Some respondents may overreport functional difficulty with the expectation of receiving benefits or material support.

Proxy respondent unawareness:
Not all caregivers who respond to the WGQs on behalf of their children may have accurate understanding of the type and level of health-related information they observe in their children. However, pilot test results and documented experienced on the use of WGQs have proved that these methodological restrictions do not cause significant data quality issue provided that the data collectors are well trained and the WG/UNICEF guidelines for administering the question sets are adhered to properly.

Gendered biases
Depending on the set used and maybe particularly when using a proxy respondent there may be some gendered biases in some communities where men are less involved in caregiving and child rearing and therefore may not know as much as about their child's functioning. This can easily happen for example in Household surveys where questions are often asked to the head of the household, which in many societies usually are men.

Misalignment with national disability categories:
There is still a large discrepancy between the functional domains covered in the WGQs sets and most country's national categorisation of disability meaning that it often cannot be used to determine eligibility for disability cards or social protection schemes without individuals going through more robust and professional assessments and screenings.

Impossible to use for children under 24 months:
Since infants and toddlers under 24 months often have varying paces to achieve developmental milestones none of the WGQs sets are possible to use for this group of children. The only way to assess disability status in these young children is through Developmental Delay Screening tools or medical diagnosis.

Risk of collecting poor data:
Although the WGQs sets are developed to be administrated by anyone, meaning non-professionals, without training of enumerators, translations which follow the recommended guidelines and quality

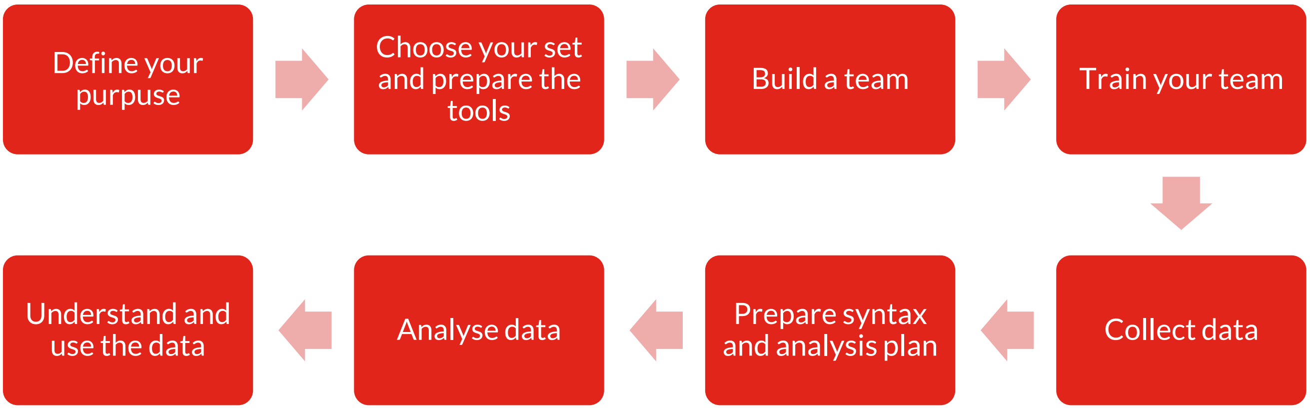
monitoring, there is a risk of interviewer bias which can lead to errors in the data. For this reason, it is strongly recommended to allow time and resources to train enumerators, pilot the tools and use the same enumerators for different studies once trained.

Use of WGQs for programme level data and donor demands:
Almost all tools have been developed for national population data collection purposes and to apply them to programme or even project level is operationally and analytically challenging, mainly because of the high number of data collection initiative which happens within a project cycle, coupled with the reality of low capacity and few to no opportunities for preparation phases or trainings. This is particularly the case in humanitarian contexts or when it is not a donor demand. This is something donors fail to understand. Save the Children is one of the organisations that is continuously testing and learning about the use of WGQs for programmes but sometimes we have to also push back to donors when collecting the data is either not feasible, in case we do not have authority to, programme scope is too large for our ability, or if the data is not going to be used in a meaningful enough way compared to the time and effort it takes to collect it. Collecting data needs to serve a purpose and we should only collect it when we intend to use it. However, not collecting disability disaggregated data risks making people with disabilities invisible in Save the Children programmes, policy, underfunded in budgets, excluded from services, and unprotected in crises—ultimately reinforcing systemic inequality and exclusion from our programmes.

Not identifying barriers:
The questions on their own do does not say anything about barriers. To understand which barriers respondents face, questions about such must be added to other relevant sections of the questionnaire. Disaggregation by the WGQs can then help understand if respondents with functional difficulties experience these to a greater extent than respondents without.

4. Practical step by step operational guidance

4.1 Process Overview



4.2 Define your purpose

Before you can develop your research protocol, sample, survey tool or know which WGQs set to use you must be clear on the purpose of the data collection and what type of data you want to include in your report. The most common ways to collect data on disability is if you want to:

- Know how many children with disabilities (functional difficulties) are among the respondents
- Know how many adults with disabilities (functional difficulties) are among the respondents
- Know how many children of parents with disabilities (functional difficulties) there are among the respondents
- Know how many parents of children with disabilities (functional difficulties) there are among the respondents

You decide this by looking at the overall purpose of the study, is it about children and literacy, about parents' attitudes, household needs assessments, or a study which includes questions for both children and adults. In some cases, you may need two sets of questionnaires, one to capture disability status in the adult and another to capture disability status in the child.

The data you collect and the set you include will determine the extent to which you can cross-tabulate survey responses in your final analysis. Presenting results as in the examples below is only possible if the data is collected.

- *A higher proportion of the households headed by a person with disability reported having been separated from their children (15%) than those without disability (10%).*
- *47% of adult respondents with a disability were 'in crisis' compared to 35% of adult respondents without a disability (35%).*
- *Around half (51%) of the child respondents from households where the parent/caregiver respondent had known disability reported needing help and having no one to help, compared to 37% of child respondents from households where the parent/ caregiver respondent did not report disability.*

- *60% of children with disabilities reported "not having someone to help them", compared to 36% of children without disabilities*[7]

4.3 Choose your set and prepare the tools

Your first step is selecting which questionnaire to include in your survey tool. The table below aims to help with this.

What age are those you want to know disability status from?	Is parent/caregiver available to respond?	Is teacher trained on CFM-TV available to respond?	Where is the data collection setting?	The recommended question set is:
0–2-year-old	Not applicable	Not applicable	Anywhere	You cannot use any of the WGQs sets for children this young, please refer to our M-GAD tool or other developmental delay screening tools or medical diagnosis. Innovations in Healthy Start in Life or World Bank Document
2–4-year-old	Yes	Not applicable	Anywhere	CFM 2-4 Years
2–4-year-old	No	Not applicable	Anywhere	We suggest to not collect the data unless there is another permanent carer available.
2–4-year-old	Yes	Not applicable	In humanitarian contexts with limited time	CFM- HV 2-4 Tier one or Tier 2
5–17-year-old	Yes	Not applicable	Community/Home	CFM-5-17 Years
5–17-year-old	No	Yes	School	CFM-TV
5–17-year-old	No	No	School	We suggest training the teachers and use CFM-TV. If impossible WG-SS can be asked to children over the age of 12 in exceptional cases
5–17-year-old	Yes	Not applicable	In humanitarian contexts with limited time	CFM- HV 2-4 Tier one or Tier 2

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[7] Examples taken from The Hidden Impact of Covid-19 on Children: A Global Research Series

Adults	N/A, Adults respond themselves	N/A, Adults respond themselves	Anywhere	WG-SS, WG-SS Enhanced or WG-ES

Translate and test your Question set

Ensuring the use of correct translations of the WGQs is essential and is a prerequisite for retaining the meaning and for allowing valid and comparable data. Deviating from these standards risks misinterpretation, response bias, and loss of data quality. Whichever WGQ set you choose, **you must use the correct and approved translations**. If English is not the most appropriate language in your context, you have two options:

Use an official translation

The WG-SS, WGSS-Enhanced and WG-ES have been translated into some of the most widely spoken languages including Arabic, Chinese, English, French, Portuguese, Russian, Spanish, and Vietnamese. Here you can find the translations into official UN languages tested and approved by the WG, as well as unofficial translations done by different NGOs. SCI has some more translated WG-SS versions available here.

The CFM modules have also been translated into the UN languages in addition to Khmer, Slovak, Swahili and Ukrainian, available here and under respective link in the table above.

If you still cannot find a translation in your language, contact your National Statistical Office, national or local Organizations of Persons with Disabilities (OPDs) or other stakeholders (for example Humanity and Inclusion, UNICEF, Christian Blind Mission or Light for the World) to determine if a translation already exists. You contact the Washington Group Secretariat directly to ask for a language here or UNICEF here.

Translate the WGQ set yourself:

If no previous translations exist in your chosen language, you must commission your own translation. **You will need to follow the WG translation guidance (available here) and the guidance from UNICEF for the CFMs (available here).** The WG recommends either the (a) Forward-Backward Translation method or (b) the Conceptual or Team Translation method. The description of these two translation methods is available here. To ensure correct understanding of the concepts, terms and words used in the WGQs, both Washington Group and UNICEF have provided clarification on each individual question. These clarifications, also known as Translation Cards, should be used by translators, disability inclusion advisors, MEAL advisors, and trainers of enumerators. They are available here:

- WG-SS Question Specifications
- WG-SS Enhanced Question Specifications
- WG-ES Question Specifications
- CFM sets Question Specifications is available in the Manual for Interviewers.
- CFM-TV set has its own question specification

- CFM- HV set has its own question specification

Finally, it is important that **translations capture the concepts** that are being asked about and that respondents clearly can understand without the interviewer having to explain or probe. This is called **cognitive testing** and is mandatory part before determining final translations. Find guidance here.

When planning a translation, keep in mind the guidance set by the WG or UNICEF:

1. If you are translating a larger questionnaire that includes the WGQs, **don't translate the two through the same process**. Instead, translate the WGQs following the WG and UNICEF guidance and then attach the questions to the questionnaire.

2. When you select your translators, make sure they are fluent in **both the source language and the target language**, and that they understand both cultural contexts as well as the subject matter of functional difficulties. The WG Secretariat has a partnership with **Translators Without Borders**, who might be available to support if needed. We also advise you to engage with other disability expert organizations in your country, OPDs, the national statistics office, and other relevant actors.

3. Once the translation is done, **test/pilot the questions and the survey process in local communities.** Conduct a **validation and reflection workshop** to see what the findings of the pre-test were and to agree on any changes to the translations.

4. SC MEAL staff, programme staff, disability TE staff, OPDs, government officials must **review and agree on the final versions** to be used.

5. Once your translation is finished, **share it** with the WG Secretariat, partners and other stakeholders, including the Disability Inclusion Technical Working Group.

6. Contact the Disability Inclusion Technical Working Group. if you need to contact the Washington Group Secretariat for more technical advice and support.

4.4 Build a team

Any study which includes the WGQs must follow SC's Ethics & Evidence Generation Policy and Procedure and accompanying templates[8]. However, in addition to engaging MEAL staff, programme staff, operational staff, enumerators etc. your team must include **persons with disabilities, and their representative organizations (OPDs). This is a prerequisite for a rights-based approach.**

Depending on your context, this can mean different things. We recommend considering the following strategies to engage persons with disabilities and OPDs throughout the process, especially if the purpose of collecting data is centered around disability rights:

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[8] See here SCI's Procedure on Research, Evaluation and Assessments

a) Collaborate with OPDs in designing the study: Agree on what to achieve; the methodology and WGQ set, and which group of respondents to include.
b) Involve OPDs in assessing and adjusting Safeguarding policies, procedures and practices.
c) Engage OPDs in training the enumerators, the SC and partner staff (see next page)
d) Include OPDs in any data collection task force, working group or advisory committee.
e) Identify and hire enumerators also with disabilities
f) Engage OPDs in awareness raising in local communities to discuss functional difficulties (well in advance or after the data collection activities)
g) Collaborate with OPDs who can receive referrals of children or adults with disabilities if the study is not anonymous and confidential.

If there are no OPDs available to collaborate on this data collection initiative, we recommend collaborating with persons with disabilities living in the target communities and/or identifying other organizations (governmental or non-governmental) working for children or adults with disabilities.

4.5 Train the Team

The people designing, administering, analyzing and reporting on the data collection must have a good understanding of the WGQs sets and how they should be administrated and analyzed. Different persons and teams may need different parts of the training depending on their roles and prior capacities, **but all people involved should have a basic understanding of the rights of persons with disabilities**, the barriers they face, and the importance of inclusion. This is particularly important if the study is specifically related to disability rights. Enumerators, data entry staff and analysts in particular need training and pilot testing (as part of the training) to be successful in collecting and disaggregated data by using the WGQs sets. Keep in mind that all involved in data collection activities with children, adults and families with disabilities have to be familiar with Save the Children's Disability-Inclusive Child Safeguarding Guidelines. It is also recommended to review the UNICEF Working Paper on Ethical Involvement of Children with Disabilities in Evidence Generation and Use

Consult the table below to see who should receive what training:

Topic	Program staff/ thematic leads	MEAL staff	Disability inclusion staff	Enumerators (including teachers for CFM-TV)
The concept and definitions of disability, barriers, the rights of persons with disabilities, enablers and in general disability inclusive programming for all involved	✓	✓	✓	✓
Advantages and limitations of WG Method for collection and analysis of disability data	✓	✓	✓	
What the different WGQs sets and modules are, and what they are not and when to use which		✓	✓	✓

Translation of WGQs		✓	✓	
Practically administering the chosen WGQs set or Module questionnaire		✓	✓	✓
Data entry and analysis training for relevant MEAL and program staff, including sharing of syntaxes		✓	✓	
Understanding, presenting and using disability disaggregated data to inform program design and planning decisions	✓	✓	✓	[9]

Your enumerators are the ones who will have direct contact with those responding to the surveys and their training is particularly important. Make sure that all enumerators receive the same type of training and exhibit the same degree of understanding using the chosen set/s to avoid errors in data and bias that might arise from different enumerators doing the interviews differently. Make sure your enumerators **are sensitized to disability rights**, as harmful beliefs and attitudes can lead to safeguarding breaches during data collection. All trainings, particularly those that target people who will be in direct contact with children, must include components related to child safeguarding. Please refer to Save the Children's Disability Inclusive Child Safeguarding Guidelines. All interviewees must feel safe and well-treated.

4.6 Collect the data

Determine the sample size

The sample size and sampling technique are not determined by either of the WGQ Sets we use. The most ideal sample size and sampling technique are instead determined on the larger purpose and scope of the study into which we integrate the WGQs. Thes size and technique should be part of the overall study design. In some cases, a large sample size may be needed, especially if we are trying to present fundings in a statistically significant way, but in other cases it may suffice with a smaller sample size.

If data collection targets respondents with pre-identified disabilities

In some cases, a study may intentionally want to include children or adults with disabilities as respondents, and it may be tempting to identify respondents which already we know or think have disabilities. This is often done through one of the following ways:

1- Select a sample size from existing data bases (programme participants) which already indicates disability status (even if not determined by WGQs)
2- Sample from existing programme participants which we know have disabilities
3- Ask OPDs or other organisations to identify respondents with disabilities by word of mouth

As any of these methods may include previous identification by binary questions about disability, observation, OPD membership or assumption it is recommended to still use the WGQs within the

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[9] Teachers who collect data using CFM-TV should ideally be the primary owners and user of the data and use it to integrate the data with the EMIS and improve services based on the data. Therefore, it is important that also teachers understand how to present and use the data.

demographic section of the survey, especially if the sample aims to include both respondents with disabilities and as well as without. By doing this the data collected is reliable and prevalence of functional difficulties confirmed. It is not unusual that persons pre-identified as not having functional difficulties in fact do have difficulties, and that those who are pre-identified as having a disability do not have any functional difficulties as per the WGQs,

If a sample size exclusively consists of children with confirmed disabilities or parents of children with confirmed disabilities and you therefore have no part of the sample to compare findings to, you may not need to collect disability disaggregated data using the WGQs as it may have any added value. The exception may be if you want to know prevalence in each functional domain or if the sample size is so large that responses can be disaggregated by functional domains.

Determine and abide by your safeguarding routines

All organisations working with children are responsible for ensuring that their programmes and interventions, including data collection, are safe for children. Safeguarding means the set of policies, procedures and practices that mitigate and manage risks, and for effectively reporting and responding if harm does occur. Adults and children with disabilities are in general at greater risk of abuse, and it is particularly important to implement rigorous safeguarding processes, adhere to ethical best practice and carry out risk assessments. SCI global and country specific safeguarding procedures may need to be adjusted to be applicable for people with different types of disabilities, including making sure that everyone can report issues. As disability data is considered sensitive personal data, adequate data protection mechanisms are required during data collection, storage, processing, transfer and reporting. Make sure you abide by the SC's Child Safeguarding Protocol, Disability Inclusive Child Safeguarding Guidelines, and Data Protection Policy.

Strictly follow the guidelines!

Practical guidelines on **DOs and DON'Ts** are available in the guidance How to Ask WGQs, and in UNICEF's Manual for Enumerators. Below are some of the most important considerations for Save the Children:

- The WGQs set should **fit into another main data collection questionnaire**, and not vice-versa. Thus, never ask the WGQs on their own but always as part of other main data collection tools (e.g. literacy test, child protection case management forms, household survey questionnaire, situation analysis survey, rapid needs assessment etc.).
- Place the WGQs set in the beginning of the questionnaire, **as part of the demographic section**. This is because the WGQs should be understood as personal information (alongside with age, name of town, name of school etc..) and not as part of the main survey questions.
- **Do NOT ask about disability status in any other way** anywhere in the survey, i.e. do not also use a binary yes/no questions about disability.
- **Include all questions**: The enumerator must **say out loud all standard questions and their answer categories for each question** in your chosen set of WGQs. There are very limited exceptions to this rule. For example, if hearing aids are not available or used in your context, the clause *"…even if when using a hearing aid"* can be removed from the question, or if it is very culturally sensitive to ask about '*self-care*' in your context, then that question can be removed.

However, any such changes must be agreed during the design phase and adjustments reflected in each questionnaire.

- **Do not edit, amend, clarify the questions, or interpret or translate them on the spot.** Do not add, remove, or change anything. Do not provide a time frame for functional difficulty when asking questions. If the question is not understood, repeat it.
- **Listen to the respondents but stay neutral** and detached when you ask your questions and record your responses, to avoid influencing the respondents.
- **Ensure confidentiality** - make sure to ask the WGQs where the conversation cannot be overheard by others.

Adapt to your setting

If you are asking the WGQ sets at a service point, for example health clinic, nutrition center, child protection office or MHPSS location, you should include the WGQs (WGSS for adults and CFM for children where possible) as part of the demographic section of the standard registration form. This data will help us understand how many persons with disabilities use the service points, who might be excluded from basic services or programme interventions, and how their issues might differ.

If you are doing surveys with individual respondents, such as learning assessments, formal and close ended interviews, you can include the chosen WGQs set in the demographic section of the questionnaire. This also applies to Focus Group Discussions but only use it if relevant and if the data will be used.

If you are asking the WGQs sets as part of a household survey, you have two options:

1. To ask the appropriate set of questions about **each** of the household member i.e. the WG-SS or WG-ES to each adult in the household and the CFM (use relevant age set) **about** each child in the household. This way you have disability data about all members of the households, if you intend to use it. We advise **doing one questionnaire at a time** rather than one question at a time for all members.
2. To have a sample system where you ask the responding adult the WG-SS to know the functional difficulties of the adult and you can select one child to ask about (first born, second born, of school age, project participant, child club participant or other) for functional difficulties in a child. This way you get an indication and a fair sample, but you cannot exclude that there are other members of the households with disabilities which may impact the responses.

The choice depends on the collaboration willingness and levels of expected fatigue in the respondent.

Avoid asking questions in the form of; *Are there any adults/children/persons in the household who have difficulties (…)?* Or, *How many people in the household have difficulty (…)? Does any other member of the household have a disability?* This will not give accurate data when cross tabulated with other responses.

If you are using the WGQs in a humanitarian setting, you can apply the WGQs to assess the extent to which children and adults with disabilities have access to and benefit from our humanitarian programmes. In sudden onset emergencies you can use the WG-SS for adults or the CFM-HV Tier 1 for children. Whenever there is a survey with general population administered in humanitarian settings, the WGQs may be used for disaggregation as in other settings. If you cannot collect data from individual surveys, make sure that a more community focused questionnaire on needs includes questions about the situation for persons with disabilities (See Disability-Inclusive Situation Analysis). In exceptional cases where service and support needs are more relevant than disability status, the Humanitarian Disability Needs Estimation Screening Tool (HD-NEST) can be used.

4.7 Prepare your syntax and analysis protocol

The following section is intended for **disability experts, data analysts, and staff members who will conduct the practical data analysis**. As such, it may be challenging for colleagues without prior knowledge of MEAL processes and routines to fully utilize this section. If you need support, please seek out a designated MEAL advisor, or reach out to the Disability Inclusion TWG.

Design your data analysis plan

Prior to data collection, ensure you have a clear data analysis plan that adheres to data protection and ethics guidelines. Please note that all studies must receive data ethics approval from the ethics review in Cayuse. To minimize data quality issues, use a standard data entry and data analysis program. You can use
(a) the data entry and analysis excel templates available in SCI's Disability Inclusion Technical Working Group share point. These can be accessed from here for WG-SS, and from here for CFM question sets.
(b) use data analysis syntaxes for different statistical software (SPSS, STATA, SAS, etc.) that are available on the WG website here, or UNICEF website here.
(c) develop own analysis templates and/or syntaxes following WG guidelines.

There are two steps of analyzing data collected using WGQs.

The first step is to categorize all data subjects (respondents, although in some questionnaires there may be data about more subjects than the respondent) into either a "person with disability" or a "person without disability" based on the chosen cut-off point/threshold for disability. Save the Children's standard cut of point/threshold is anyone responding '*a lot of difficulty*' or '*cannot do at all*' within any one of the domains. [10] Thus, the first level of analysis is a *disability status identifier* analysis that enables us to create a dichotomous disability variable. The syntax templates provided below will help you with this.

The second step is using the calculated dichotomous data that was obtained from the first level of analysis, to calculate indicator value disaggregated by disability, gender, age, geographical area etc. depending on the intersectional relevance.

Insert/develop appropriate data analysis syntaxes

When entering the data or through the data collection tool, each data values (response categories) collected as text data in the form of "*no difficulty*", "*some difficulty*", "*a lot of difficulty*", or "*cannot do at all*" with **numerical data as 1, 2, 3, or 4 respectively.** Likewise, the text data values on anxiety collected as

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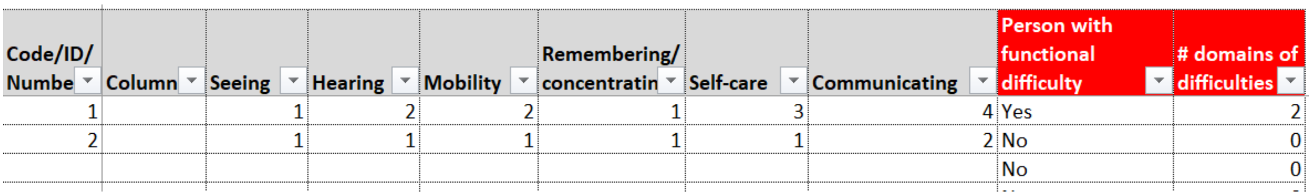
[10] Look at the notes on cut-off points/threshold for "disability" that is available at the end of the section on data analysis.

"*daily*", "*weekly*", "*monthly*", "*a few times a year*", or "*never*" **have to be replaced with 1, 2, 3, 4, or 5** respectively to do the quantitative analysis using the analysis syntaxes.

Make sure to insert/develop correct data analysis syntaxes in the selected data entry and analysis template before or after data entry into the template is done. Such syntaxes are developed as *disability status identifier* to create a dichotomous disability variable having "person with disability" and "person without disability" categories (as per the first step above) and are available from the WG website here or UNICEF website. The SCI Disability TWG has also prepared data entry and analysis template with excel syntaxes to generate the dichotomous disability variable. This data entry and analysis template also automatically produces analysis results in summary tables and charts that can be used in narrative reports or presentations of prevalence of disability within the sample. These excel analysis templates are available for analysis of data collected using WG-SS, CFM set for age group 5-17 years, and CFM set for age group 2-4 years. These can be accessed here for WG-SS and here for CFM Modules.

The syntaxes automatically calculate which respondents (data subjects) which have disability or not by assigning anyone with a 3 or 4 in any one or more domains with the value of Yes or No. The Syntax also helps you see in how many domains a person has function difficulties above the cut-off point / threshold (person with disability). See below for example from Excel Syntax for WG-SS.



Code/ID/ Numbe	Column	Seeing	Hearing	Mobility	Remembering/ concentratin	Self-care	Communicating	Person with functional difficulty	# domains of difficulties
1		1	2	2	1	3	4	Yes	2
2		1	1	1	1	1	2	No	0
								No	0

Clarification on cut-off points/thresholds for "disability"

The cut-off point/threshold for disability recommended by the WG for all data collected by different WGQs sets is *"a lot of difficulty"* or *"cannot do at all"* in any domain/question in a specific WGQs set. Save the Children strongly recommends using "**a lot of difficulty" or "cannot do at all**" in any domain as a standard threshold for disability, regardless of which WGQs set or CFM question set is used. For questions on **anxiety and depression**, the recommended cut-off point for disability is "**daily**".

For reference we want to mention that the WG has also provided four cut-off options for data collected using the WG-SS which produces four disability identifiers. **Only Disability 3 can be used for any other set than the WG-SS.**

Disability1: This is the least restrictive cut-off, including anyone who reports "*some difficulty*", "*a lot of difficulty*" or "*cannot do at all*" in any one domain or more. This cut off point will increase the prevalence of respondents with disabilities and include a higher level of uncertainty.

Disability2: This cut-off identifies those with more significant difficulties and includes anyone who reports **either** "*some difficulty*" in at least 2 domains or "*a lot of difficulty*" or "*cannot do at all*" in any one domain or more.

Disability3: This is the cut-off point recommended by the Washington Group for international reporting and cross-country comparability and the standard cut-off point for Save the Children. It includes anyone who reports "*a lot of difficulty*" or "*cannot do at all*" in any one domain or more.

Disability4: This is the most restrictive cut-off, identifying those with the most severe difficulties and includes those reporting "*cannot do at all* in any one domain or more.

In rare circumstances, in case we want to identify everyone within a population who may be at a risk of being excluded from program services/activities due to any level of health-related functional difficulties, we can use "Disability 1" or for "Disability 2". The Disability 4 threshold can be used when an organization wants to make a more conservative estimate of disability prevalence by counting only those who report a "*cannot do at all*" level of functional difficulty as persons with disability.

The cut-off point used in the analysis and the reason for using that specific cut-off point (if other than Disability 3) should be clearly stated in the study report or in the analysis methodology section.

Review and quality control the data

When data is entered into the data entry and analysis template, conduct data quality control by cleaning the data to prepare for correct analysis. Do this by ensuring there is no missing or incorrect entries with each column representing a functional domain.

If a respondent has partly answered the WGQs causing missing data on one or more domains, make sure to replace the missing values with a 0 (zero) so that the respondent will be counted in the denominator when doing disability prevalence calculation. If, for some reason, any respondent did not answer the questions from a WGQs for a specific data subject, leaving all questions (domains) with missing data, take out the data subject and all data related to them from the data analysis template.

After having all the data in the form of numerical data values in the data analysis template, correct any incorrect values such as those outside the expected answer codes of 1-4 or 1-5 for a specific WGQs set. For example, if a cell has the number 7 or each domain from the same respondent has a 4 you can assume there is something wrong with the data. A numerical data value of 0 should only exist if there is no answer to the domain in question. If the data set appears unrealistic, make sure you examine possible explanations, correct data problems, and if necessary, re-do data collection and analysis even if using a smaller sample size. Examples indicating that data is wrong:

- An extremely low prevalence (%) of respondents with disabilities
- An extremely high prevalence (%) of respondents with disabilities
- A high proportion of respondents with disabilities with functional difficulties in several domains.
- A disproportionate difference in prevalence between data collection sites.
- A high level of missing data

Avoid double counting: When calculating general disability prevalence, be careful not to double count persons who may have functional difficulties above the cut-off point in more than one domain. A person who has answered option three "*A lot of difficulty*" (3) for both seeing and communicating is still just one person with disabilities, although the person may have multiple disabilities. You can reference these respondents or data subjects as '*respondents with functional* *difficulties in more than one domain (or the number of domains)*' when writing your report and presenting results. Using available syntax is the best way to control this.

4.8 Analyse the data

Different types of analyses

There are four types of analyses that can be done based on the disability disaggregated collected using WGQs sets. These are presented below.

a) Calculation of general (non-domain specific) **binary disability prevalence (with disability or without disability)** is done based on the sample size in the dataset. The disability prevalence value calculated based on data from a sample of data subjects can be used to estimate disability prevalence in the relevant population.
b) Calculation of **disability prevalence by functional domain.** This can provide very useful information for decision making when a large sample size is used. It is less relevant and useful for a small sample size often used in programme or project level.
c) Calculation of **indicator value disaggregated by disability**. This provides evidence of how children with disabilities are performing on a specific indicator (e.g. literacy indicator) compared to their peers without disabilities. Please note that, in such analysis the performance of children with disabilities should be compared against the performance of children without disabilities and **not** against the performance of all children in the dataset that also includes children with disabilities. In very large sample sizes or for population data this can even **be disaggregated by functional domain** although it is rare Save the Children uses such large sample sizes for it to be statistically relevant.
d) Calculation of **indicator value disaggregated by intersectional characteristics** at least by both disability and gender, disability age and gender or disability, gender, age and school attendance. This provides evidence of intersectionality of disability with other demographic and socio-economic situations.

For Save the Children it is often interesting to compare;

- **children with disabilities to children without disabilities**
- adults with disabilities to adults without disabilities preferably by males and females
- children of parents with disabilities compared to children of parents without disabilities
- parents of children with disabilities compared to parents of children without disabilities.

The more a report's result section tells us about differentiation and possible inequalities the more interesting it is and the more it helps us address gaps in programming and services and child rights. When writing the report, remember to always present the findings from respondents or subjects with disabilities **in comparison** to those without making the data relevant and interesting.

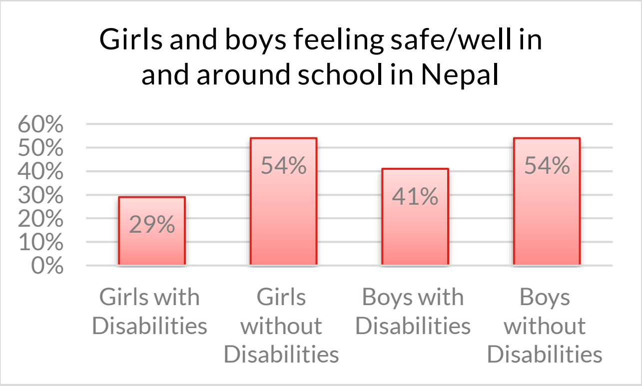
Many Save the Children studies have begun to collect disability data using the WGQs but very few present any findings by using disaggregated analysis. If reports present the data at all it is often limited to a quick mention of the prevalence in the study sample and nothing else. Good analysis and technical interpretations of the findings are key.

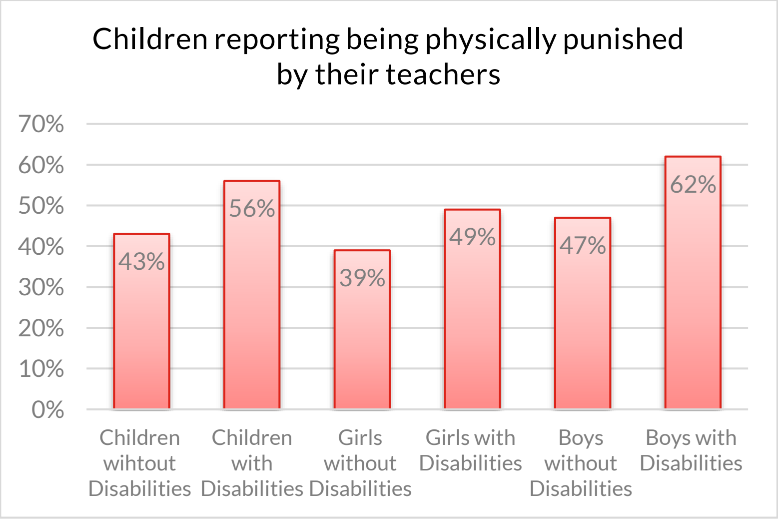
Document learnings

Always document the lessons learned to properly document data collection challenges and identify improvement. Consider sharing lessons learned with the Disability Inclusion TWG, Save the Children MEAL and Research and Evidence Community and possibly with the relevant government entity and/or donor to ensure Save the Children contributes to the evidence of using the WGQs sets and modules for programme data. This is particularly important since the question sets were originally developed for population data and there are several operational challenges in using them for programmes, especially across such broad purposes, themes and settings in which Save the Children works.

4.9 Understand and use the data

Data on how many persons have different kinds of disabilities can be used to simply report prevalence in a sample or a population but also provide statistical and numerical evidence about how adults, children and families with disabilities may face different realities and challenges in comparison to their peers without disabilities. The WGQs alone will not tell us this story but when cross-tabulated and presented in a disaggregated way with the other data from the study in question it will. This data can in turn help us make visible barriers, inequalities and gaps which need to be addressed in future programme design, or which areas require further investigation and research.





By including a WGQs set in situation analysis surveys, rapid needs assessments, baseline surveys etc. you can during the;

Design Phase

- use disaggregated findings to inform programme activities or interventions necessary to reduce inequalities or to ensure that children, adults and families with disabilities can equitably benefit from Save the Children activities.

- use findings to design a more in-depth barrier analysis with targeted respondents with disabilities to tailor your activities.
- use the findings to finalise outcome and output indicators and determine which to prioritise for disability disaggregation.
- share data with partners and others to complement each other's interventions.

Implementation phase

- analyse monitoring data to assess whether the project is having the desired impact for children, adults or families with disabilities, identify areas of improvement/activity adaptation if any, and track their implementation.
- use comparative data to assess whether children, adults or families with disabilities participate in your projects/programme activities to the same extent as those without or in the same numbers of available population data would assume.
- in case respondents are not anonymous, identify individual children and adults with disabilities who should be specifically targeted by a programme.
- in case respondents are not anonymous and you have consent from the participants, use the data to refer or link respondents or data subjects identified with disability through the survey with relevant services. Referrals should not be made based on assumptions but based on requests from and discussions with the respondent(s).

End of project/transition phase

- evaluate the impact of the programme/project on the project participants, comparing if the impact of the programme differs by gender, age, disability, and other factors.
- document best practices and lessons learned, make available beyond the project team.
- provide future recommendations to address any gaps in equitable impact for children, adults and families with disabilities.

Campaigns

- use the findings to raise awareness among program communities about the rights of persons with disabilities, importance of disability inclusive services and activities, and identification and support of persons with disabilities in general and children with disabilities in particular. This **awareness raising should take place after data collection** so that it will not affect the data or the results, and target service providers including teachers, child protection case management workers, CSOs, local government staff, religious and traditional leaders.

Advocacy phase

- use your (anonymized and confidential) data in advocacy to advocate for policies, budget allocation and resources for people with disabilities in your area of advocacy, if relevant using the Disability Data Advocacy Toolkit.

- Use the data to inform human rights reports such as the alternative reports to the Convention on the Rights of Persons with Disabilities, the Convention on the Rights of the Child, Universal Periodic Report (UPR) and other international, regional and national human rights monitoring and reporting mechanisms.

Resources

Example Questionnaires

1. Example of inserting WG-SS into a questionnaire
2. Baseline report of Increased Accountability to Eliminate Violence and Discrimination Against Children with Disabilities Project (AVAC) Annex 2
3. Endline Evaluation Report: Increased accountability to eliminate violence and discrimination against children with disabilities with children questionnaire and parent questionnaire.
4. Midline Evaluation LEAN Caregiver Survey Thailand
5. Mid-term Evaluation Report for the Pathways to Wellbeing, Empowerment, and Resilience for Adolescents and Youth (POWER4AY) Program, Uganda 2024 Appendix II
6. The Hidden Impact of COVID-19 on Children: Research design and methods – Annex A
7. SCN Parenting Without Violence Caregiver Questionnaire CFM
8. SCN Literacy data collection tool for grade 3 WGSS

Examples Studies

1. Baseline report of Increased Accountability to Eliminate Violence and Discrimination Against Children with Disabilities Project (AVAC)
2. Endline Evaluation Report: Increased accountability to eliminate violence and discrimination against children with disabilities
3. Midline Evaluation Report: Literacy empowerment alliance for a resilient new generation (LEARN) project IDELA
4. Mid-term Evaluation Report for the Pathways to Wellbeing, Empowerment, and Resilience for Adolescents and Youth (POWER4AY) Program, Uganda 2024
5. Norad Leaving No Child Behind Progress Report 2019-2021

6. Norad Progress Report 2019 - 2022 Leaving No Child Behind
7. The Hidden Impact of Covid-19 on Children: A Global Research Series (10 reports)
8. The Hidden Impact of COVID-19 on Children and Families with Disabilities
9. U FIND Project Baseline Report Sri Lanka

Videos

- The WG has produced a series of videos in partnership with the Center for Inclusive Policy
- Introduction to the importance of disaggregating data by disability, and on the WG-SS.
- **The Child Functioning Module – Teacher Version & the Inclusive Education Module**

Learning briefs

- Using the WGQs on disability data in development programs: A learning brief (CBM 2023)
- The Data Collection Tools Developed by the Washington Group on Disability Statistics and their Recommended Use (2020)
- Producing disability-inclusive data – Why it matters and what it takes (UNICEF 2020)
- Disability Data Collection – A summary review of the use of the Washington Group Questions by development and humanitarian actors (2018) (Leonard Cheshire and HI)
- Everybody Counts - Sightsavers' disability data disaggregation project (Sightsavers 2017)
- Collecting Data on Child Disability - Companion Technical Booklet (UNICEF 2014)

Trainings

- Collecting Data for the Inclusion of Persons with Disabilities in Humanitarian Action on KAYA

Annex 1. Checklist for effectively administering Washington Group Questions

Checklist for collecting Disability Disaggregated data using the WGQs sets	Done
A. Planning the use of Washington Group Questions	
Disability TA or inclusion advisor has been involved in the process of study design?	
Partner OPDs have been informed and consulted prior to data collection about the general study design?	
Confirmed that the purpose of the study and use of WGQs is to detect prevalence of children, adults or households with disability within respondents and/or to disaggregate response data and findings by disability?	
Confirmed that the data will be collected on an individual person (one person at a time) and not on an entire household or community groups?	
The correct WGQ Set is embedded in the study design, data collection tools and analysis plan, for each relevant indicator that calls for disaggregation by disability?	
MEAL staff has completed the SC designated training, as a minimum technical competency requirement, and read all manuals related to the selected set or module? For a more effective and efficient administration of WGQs, more rigorous and practice-oriented training is required. SCI Disability Inclusion Working Group can be contacted for advice on this.	
Confirmed and agreed where the data collection is to take place? Door to door, parents' sessions, community meetings, in school, at service delivery point, through OPDs, humanitarian response (rapid onset or later), online etc.	
Confirmed and agreed whose disability status the study aims to collect (data subject)? Children 2-4, children 5-7, several children within a household, adults, parents/caregivers, all adults in a household?	
Confirmed and agreed from whom the data is collected (who the survey respondent is)? A child (above 12), an adult, a parent/caregiver, a teacher? Is respondent answering for themselves or as a proxy for a different data subject?	
The right WGQ set is identified to achieve the planned outcome of the data collection and data use intended?	
The main data collection tool in which the WGQs set will be inserted is identified, and the intended overall respondent correlates to the intended subject for disability status	

as well as respondent type relevant for the chosen set. (adults, children, teachers, caregivers, learners in school setting)?	
The relevant Guidance Note accompanying the chosen WGQs set is being followed to ensure the set is used correctly regarding if the respondent should answer for themselves or as a proxy?	
Approved and existing language versions of WGQs questionnaires identified by talking to disability team and stakeholder before any attempt at translation is made?	
If translations are planned, this is done following the WG guidelines on translations and includes a selection of stakeholders, language and cognitive testing before the study can commence data collection?	
Are any new translations of WGQs sets shared with the SCI Disability Technical Working Group, for filing and sharing with the WG Secretariat?	
Enumerators and other staff involved in translation, collection, data entry and analysis have been trained on disability sensitization and the chosen set or module in detail, including how to administer those questionnaires with skip logic?	
Questionnaires have been adapted to include the chosen WGQ set questionnaires and the introductory sentence without mentioning disability anywhere?	
B. Check preparations for and progress during data collection	
Data collection supervisors from programme staff (preferably MEAL advisors) who can supervise data collection processes and provide immediate technical support to enumerators are deployed to do so?	
A printout of the “DOs and DON’Ts” is handed out to each supervisor and enumerator to inform them all that they must adhere strictly to those rules when administering the part of the questionnaire which is the WGQs set with respondents?	
Each enumerator is provided with a notebook, asking them to note down any challenges and lessons they learned from administering the WGQs to submit to the lead MEAL advisor for learning?	
Each supervisor is instructed to make sure s/he has good overview each of the enumerators conducted the administration during the first half of the first data collection day? This helps to correct any errors observed in administering the WGQs before it is too late to correct inappropriate use of the questions.	
Each supervisor is instructed to hold a feedback session at the end of data collection day to deal with issues that emerge during the data collection process?	
A mechanism for verification of data quality during the data collection time has been agreed and is carried out? For example, a supervisor can randomly select a few completed questionnaires and go back to the respondent (or call the respondent) to verify that the data collected by an enumerator was correct. Or a few questionnaires can be entered to note any errors or bias.	
C. Check preparations for proper data entry, data cleaning, and analysis	

Data analysis syntaxes for the chosen WGQs set and the chosen data analysis software/program are shared and understood by those doing the data entry?	
The analysis protocol is clear on how to cross tabulate questions throughout the survey and how to present the results and findings in a disaggregated way?	
Report writers and programme managers know how to embed the data on prevalence and cross tabulated (disaggregated) results/evidence for each relevant question being presented into the written report?	
The presentation of disability disaggregated results is comparing response from children/adults/households/caregivers with disabilities against the responses from children/adults/households/caregivers without disability, and NOT against results of all children/adults/households/caregivers in the sample?	
Evidence/results are disaggregated by disability, and by both disability and gender as a mandatory results documentation requirement? In addition, decide if additional disaggregation factors can be recommended together with disability; for example, disaggregation by both disability, gender and region/age.	
D. Check if sufficient preparations are done to utilize disaggregated evidence and results to inform program/planning decisions to promote the rights of children and adults with disabilities.	
A Disability Technical Advisor has been consulted to make sense of the data thematically and provide recommendations?	
Relevant thematic advisors have developed a plan for using disability disaggregated evidence/results to develop or revise program design/plans/budgets?	