



Save the Children



Report

Midterm progress report on the quality of disability data and disability inclusion in countries included in the Norad Framework Agreement 2019-2023

Save the Children Norway, December 2022

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Executive summary

Save the Children Norway (SCN) identified children with disabilities (CWD) as a marginalized group in the 2019-2023 Norad Framework Agreement for effective contribution to fulfilling the “Leave No Child Behind” ambition. To improve the data and identify children with disabilities, SCN employed the globally recommended Washington Group Questions (WGQs). As a result, two sets of WGQs were collected. At baseline, only half of the 12 country offices (COs) collected reliable disability data, indicating a need for comprehensive capacity-building support. To improve data collection, SCN developed a training program for COs needing data collection support. At midline, most countries had improved data collection methods and utilized disability data to enhance programming.

This review aims to inform an active dialog between Norad and SCN on the challenges of identifying children with disabilities and measuring results. To this end, the review serves three specific objectives:

- To document SCN's capacity-building project on disability data and inclusion.
- To document progress on the quality of disability data and the use of data to inform program planning.
- To identify COs' needs for capacity-building support on disability data and inclusion.

Primary data were collected from the COs in Lebanon, Malawi, Somalia, and South Sudan using key informant interviews and focus group discussions with CO staff in the Norad-funded SC programs. A thorough desk review of program documents was also conducted.

Seven of the 12 country offices in the Norad Framework Agreement received capacity-building training consisting of eight modules. Due to Covid-19, the 16 hours of training were provided remotely via Microsoft Teams.

The COs reported that SCN's training modules were relevant, needs-responsive, and practice-oriented, contributing to improving the reliability and use of disability data to adjust programs. The training also contributed to CO planning, decision-making, and the training of additional CO staff and partner organizations.

At midline, most COs had mastered the data collection tools and expressed the need for additional capacity-building support focusing on communicating disability data analysis with thematic advisors and utilizing disaggregated data to improve programs. The following midline results indicate the effectiveness of the capacity-building support provided to COs:

- All countries, except the Mozambique CO,¹ collected reliable disability data.
- The disability prevalence in the data collected for a child protection outcome indicator was reasonably high in Somalia (18 percent), South Sudan (seven percent), and Uganda (ten percent). In addition, the disability prevalence reported for the literacy data and child safety indicators was six and four percent, respectively, compared to almost none at baseline.
- The COs participating in the training demonstrated mastery of disability data collection using the Washington Group Methods. In addition, staff members reported training colleagues, partner staff, external enumerators, and teachers based on SCN's training modules. For instance, the Somalia CO conducted ten rounds of such activities; the Malawi CO trained 593 teachers (320 male, 273 female) on WGQs data collection and disability inclusion.
- SCI Lebanon has collected reliable data each school year.

¹ The Mozambique CO experienced challenges translating the WGQs into the local language, adversely affecting midterm data quality.

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- The COs demonstrated the ability to modify disability-inclusive program activities based on disaggregated midterm data. However, using data to inform programming was found to be an area that needs to be made more effective.

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Introduction

Disability is understood as health-related impairments, activity limitations, and participation restrictions adversely affecting the interaction between the individual with functional difficulties and that individual's context, including environmental and personal factors. The International Classification of Functioning, Disability, and Health (ICF) categorizes human functioning into (a) functioning at the body or body part level, (b) the whole person, (c) and the whole person in a social context. Disability, therefore, involves dysfunction at one or more levels, including impairments, activity limitations, and participation restrictions.² According to World Health Organization (WHO), around 15 percent of the world's population and five percent of children aged five to 15 are expected to suffer moderate or severe disabilities.³ The WHO's conceptualization of disability deals with disability from a human rights perspective and adheres to the United Nations Charter on Rights of Persons with Disabilities (UNCRPD). As stated in Save the Children's Disability Inclusion Policy, Save the Children works to fulfill the rights of adults and children with disabilities.

Save the Children and partner organizations were concerned that binary disability data collection methods which ask respondents: *"Do you/does your child have a disability?"* led to underreporting and incompleteness of disability data. To overcome this challenge, SCN adopted the Washington Group Questions (WGQs) to collect baseline data for the 2019-2023 NORAD Framework Agreement. The outcome indicators agreed upon with SCI COs disaggregated by disability include:

- The percentage of children meeting the expected proficiency level in grade X in literacy by gender and disability.⁴
- The percentage of children attending school who have been physically punished by a teacher during the last 12 months, by gender and disability.⁵
- The percentage of children who report feeling well and/ or safe within the school by gender and disability.⁶
- The percentage of children between the ages of one and 17 who experienced physical punishment and/or psychological aggression by parents/caregivers in the past month, by gender and disability.⁷

The Washington Group Short Set (WGSS) questions were used to collect disability data in a school setting and asked learners to self-report the types and levels of functional difficulty experienced. In addition, the Child Functioning Module (CFM) questions for the age group five to 17 were administered in a community data collection setting. These questions asked the caregivers of children to identify children with disability in the communities targeted by the NORAD-supported SC programs.

Purpose and method of the review

This review responds to an ongoing dialog between Norad and SCN on the challenges of reaching children with disabilities and measuring results for children with disabilities. The specific objectives of this review are:

- To document progress made from 2019 to 2021 on the quality and use of disability data to inform program and planning decisions by SC COs.
- To document SCN's capacity-building program on disability data and inclusion conducted between 2019 and 2021.

² More explanations of the concept of disability available in the WHO's document entitled as Towards a Common Language for Functioning, Disability and Health.

³ WHO's Global Disability Action Plan 2014-2021.

⁴ All 12 countries included in the Norad Framework Agreement 2019-2023.

⁵ Lebanon, Malawi, Palestine, South Sudan, Myanmar, Guatemala, and Uganda

⁶ Palestine, Myanmar, Malawi, South Sudan, Guatemala, and Nepal

⁷ Myanmar, Nepal, Somalia, South Sudan, Uganda, Guatemala, Lebanon, Mozambique and Palestine

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- To identify gaps in the COs' capacity to collect and utilize disability data.

Primary data were collected using key informant interviews (KII) and focus group discussions (FGD) from four Save the Children COs in Malawi, Somalia, South Sudan, and Lebanon. The first three COs were selected for in-depth analysis and detailed data collection using KII and FGD at midterm, as these COs experienced difficulties collecting disability data at baseline. In addition, SCN sought to examine if its training modules helped address challenges and improve the quality of disability data. Lebanon was included to assess if a CO that collected quality disability data at baseline (2019) could maintain its practices for collecting reliable disability data at the midline (2021). Finally, a desk review of program documents was conducted to collect secondary data.

Capacity building support for SCI Country Offices (COs) on administering WGQs and disability inclusion

Based on the lessons learned at baseline, SCN developed training materials consisting of two packages (a) materials for training SC program staff (five modules) and (b) materials for training enumerators (three modules). While the general purpose of the training was to develop the COs' capacity to collect reliable and comparable disability data using the Washington Group/UNICEF Questions, the specific objective was to enable COs to implement the NORAD Framework to collect quality disability data for the midterm. In addition, the COs in Somalia, Malawi, Uganda, South Sudan, and Mozambique received capacity-building support, as they did not collect quality disability data at baseline in 2019. Therefore, along with the COs in Guatemala and Colombia, these COs received training consisting of 16 hours in 2020. Due to COVID-19, the training was provided remotely through Microsoft Teams.

The COs reported that SCN's training modules were relevant to specific CO needs, as the training material was well-developed and provided good illustrations. The participants also stated that the training sessions promoted active participation, including interactive discussions and group work. In short, the training met the expectations of COs needing capacity training.

Several areas for improving the training modules were also identified. For example, participants asked SCN to allocate additional time for more practical exercises. The training schedule should also allocate time for deeper discussions on Module 3 and Module 4. Participants also recommended integrating concrete examples and scenarios from participating COs and including the experiences of a person with a disability in each cultural context.

The COs in Malawi, Somalia, and South Sudan reported that the training enabled staff to collect more reliable data and generate disability disaggregated data at the midline. Malawi and Somalia also adjusted program contents based on disaggregated midline data. Moreover, participating COs conducted training on disability data collection for additional CO and partner organization staff and external enumerators. For example, SCI Somalia arranged ten training rounds for its staff and partner staff; SCI Malawi trained 593 (320 male, 273 female) teachers and 15 (nine male, five female) CO staff working on Youth Empowerment Project after the COs received the training from SCN.

SCI **Lebanon** did not participate in SCN training modules in 2020 but was nevertheless able to collect reliable and comparable disability data. SCI Lebanon also provided continuous refresher training to colleagues and received MEAL technical support from SCN. The sound practice by Lebanon CO is that it collects disability data on each learner in Norad-supported schools using the WGSS tool during the school registration period at the beginning of each school year. This practice has helped the CO solidify its skills in administering the WGSS questions. However, the CO needs to be trained on all training modules, as its skills are mainly limited to administering the WGSS.

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After midline data collection, the COs participating in focus groups and interviews were encouraged to rank the priority level of competency areas as high, medium, or low based on the need for further capacity-building support. The ranking is recorded in the table below.

Somalia	South Sudan	Malawi	Lebanon	Competency areas for capacity building support
High	High	Medium	Medium	Understanding the WGQs and skills of administering the tool
Low	High	Low	Low	Translation of WGQs
Medium	Medium	Low	High	Training of enumerators
High	Medium	Medium	Medium	Data quality assurance and data quality control
Low	Medium	Medium	High	Disability data analysis
High	Medium	High	High	Communicating disability data analysis results and data with data users (thematic advisors)
Medium	High	High	High	Utilization of disability disaggregated data to inform programming, planning, and budgeting
Medium	Medium	High	High	Disability-inclusive thematic program

“Training on Administering the WGQs and Introduction to Disability Inclusion” was a commonly desired capacity-building support in the first years of the NORAD Framework Agreement. However, successful implementation transitioned many COs into higher-level capacity-strengthening needs, including disability data utilization and disability-inclusive programming. For example, the Lebanon CO, which did not receive the full package training, has indicated five of eight competency areas as the highest priorities for capacity support. The two types of skills most of the COs are interested in being supported for further capacity building are (a) the skill of communicating disability data analysis results with thematic advisors that are users of disability disaggregated data and (b) the skill of utilizing disability disaggregated data to inform programming, planning, and budgeting.

Reliability of disability data collected at midterm

A plan was developed for collecting data from school and community settings in countries where schools re-opened after COVID-19 closures. However, COs in countries where schools were closed during the Norad midterm data collection could only collect disability data on some outcome indicators in a community data collection setting. Save the Children defines reliable disability data in terms of the disability prevalence computed based on the data collected from a sample of respondents. The data gathered about children aged five to 15 is expected to show about five percent or higher of the children as children with disabilities. This practice aligns with the [Washington Group estimates](#) and [global-level estimates documented by World Health Organization](#). Thus, the COs reporting disability prevalence lower than five percent were considered COs with less reliable disability data. Furthermore, these COs were not encouraged to disaggregate outcome indicators by disability, as the number was too low to serve disaggregation purposes. Other factors influencing data reliability include the quality of the translation of WGQs into local languages, adequacy and appropriateness of training of enumerators, and processes of administering the WGQs.

The lessons learned from the baseline enabled SCN to identify COs⁸ needing capacity-building support. For example, at midterm, **Malawi** reported a disability prevalence of six percent and four percent of learners in its literacy samples (N=634) and child safety (N=691) assessments. On the other hand, **Somalia** and **South Sudan** reported a disability prevalence of two percent in literacy samples of 396 and 427 learners, respectively. A high proportion of school-age children in general, and most children with

⁸ Malawi, Somalia, Uganda, Mozambique and South Sudan

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disabilities in particular, were out-of-school children in Somalia and South Sudan, which explains the low disability prevalence in schools. A [USAID report 2017](#) indicated that only 40 percent of school-age children are enrolled in Somalia schools. In the case of South Sudan, the [World Bank's report](#) stated that about 62 percent of school-age children were out of school in the country in 2015. This indicates that identifying and enrolling out-of-school children with disabilities should be considered a priority for SC's education program, especially in such countries as Somalia and South Sudan.

The caregivers who responded to the Parenting without Violence (PwV) Caregiver Questionnaire provided data about children's disability, enabling disaggregation of a child protection outcome indicator⁹ by disability. At midterm, the disability prevalence in samples¹⁰ used to measure progress on this indicator was 18 percent in Somalia, ten percent in Uganda, and seven percent in South Sudan, compared to almost none at baseline. In addition, the disability prevalence documented at the midline indicates that four¹¹ of the five countries that could not provide reliable data have greatly improved the reliability of one or more outcome indicators at the midline.

On the other hand, of the six COs¹² that collected reliable disability data at baseline, three¹³ did not collect disability data due to COVID-19 closures or internal conflicts in the country that prevented the collection of comparable data at the midline. Of the remaining three COs that collected disability data at midline, only Lebanon could document an acceptable disability prevalence of eight percent in the literacy assessment sample (N=1237) at midline compared to the prevalence of ten percent reported at baseline.

Continuous refresher training on WGQs that the CO provides to its education and child protection staff enabled the CO to maintain good quality disability data. However, the Nepal and Palestine COs that documented disability prevalence ($\leq 2\%$) at midline was substantially lower than reported at baseline neither received the SCN training on Administering WGQs nor provided evidence of continued refresher training to its staff.

In Palestine, the authorities allowed midline data collection to be conducted under a specific program activity known as a "summer camp," where only a limited number of learners with health-related functional difficulties attended. Therefore, disability data collected from the camp did not enable documentation of a realistic disability prevalence at midterm.

The challenges noted in the collection of disability data at midterm include:

- The Malawi CO stated that learners with severe hearing or communication difficulties were not sampled for data collection because the CO team did not have a specialist to communicate effectively with such challenges.
- The challenge of translating WGQs into local languages and its effect on the quality of disability data collected was noted by the Mozambique CO.

Progress in utilizing disability data to inform programming and planning decisions

The capacity to collect reliable and comparable disability data is the first step for evidence-based effective disability-inclusive programming and planning. The disability disaggregated outcome indicator prompted active discussions and questions among program staff in the COs regarding why children with disabilities performed differently on some outcome indicators compared to their peers without disabilities. Such discussions enabled adjusting program activities. Examples of program activities that were introduced as

⁹ Percent of children aged 1-17 years who experienced any physical punishment and/or psychological aggression by parents/caregivers in the past month.

¹⁰ Sample sizes in Somalia, Uganda, and South Sudan were 834, 656, and 387 children, respectively.

¹¹ Malawi, Somalia, South Sudan, and Uganda.

¹² Colombia, Lebanon, Palestine, Nepal, Myanmar and Guatemala.

¹³ Colombia, Guatemala, Myanmar

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new or modified to be more disability-inclusive through the 2022 annual planning are presented below by country.

Somalia

New activities included in the education program in 2022 are listed below. Other disability-inclusive activities that were implemented in previous years were also retained in 2022. These activities focused on:

- Identifying and addressing barriers preventing children with disabilities' enrollment and access to education, participation, and decision-making.
- Building the capacity of child clubs to raise awareness of and advocate for the right of children with disabilities at the school and community levels.
- Assessing the provision of appropriate assistive devices and/or technology to children with disability as necessary.

The Somalia CO has also adjusted one child protection program activity. The activity conducts sessions on positive discipline for parents and other caregivers. The CO implemented this activity in 2019 but adjusted programming in 2022 when it started to target the parents of children with disabilities as program beneficiaries. As a result, the activity is expected to benefit between 25 and 30 percent of the families of children with disabilities.

A child rights disability activity newly included in SCI Somalia's annual plan 2022 was "building the capacity of child clubs to advocate for children with disabilities at school and community level." In addition, the implementation of additional disability-inclusive child rights activities that were implemented in previous years was also continued.

Malawi

Except for a few existing program activities that were adjusted to be more disability-inclusive in 2022, all education, child protection, and child rights program activities listed below were added to the Norad-funded program in 2022 based on the disability data collected for midterm review. These activities focused on:

- Offering refresher training to teachers on disability-inclusive literacy and numeracy teaching methods, including sessions on attitude barriers among teachers to improve the teachers' ability to use teaching methods suitable for learners with functional difficulties. This aligns with the National Strategy on Inclusive Education 2017-2021.
- Conducting sensitization meetings with teachers and parents/guardians of children with disabilities on the care of assistive devices to improve shelf life and efficiency.
- Supporting the Ministry of Education by allocating NOK 125,926 to procure and distribute school teaching and learning materials adapted to meet the needs of children with disabilities.
- Supporting the Ministry of Health in training relevant stakeholders in targeted districts on using paper-based technology to produce assistive devices for children with disabilities.

In 2022, the Malawi CO deliberately targeted the families of children with disabilities in its program known as "Responsible, Engaged and Loving Fathers Approach (REAL)" to make the child protection program more disability inclusive. The approach aims to create a supportive relationship and engagement between fathers and their children to protect the child from early pregnancy and child marriage. In addition, the following new child rights activities were added to the program content in 2022. These focused on:

- Orienting child parliamentarians on disability issues and knowledge enables participants to engage in constructive and informative debates on disability issues.

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- Involving children with disabilities in district and community-based advocacy platforms, child-centered social accountability, commemorating the Day of African Child and the International Day for the Girl Child.

Lebanon

The Lebanon CO collected disability data at midterm after submitting the 2022 annual plan and could not use its midterm data to inform this plan. However, the CO introduced new disability-inclusive education activities after program implementation started based on collected disability data for the midline. These activities focused on:

- The provision of assistive devices for visual, hearing, and physical disabilities and implementation of rehabilitation activities. The activity started in 2020.
- The creation of individual education plans and functional and risk-informed school plans were more disability inclusive. This activity started in 2021 and will continue until 2023.

South Sudan

Due to midterm data collection that was delayed until after submitting the 2022 annual plan to Save the Children Norway, SCI South Sudan could not inform its 2022 plan with findings from the midterm review. However, the South Sudan CO has identified activities it included in its detailed implementation plan for the year 2022, finalized after all midterm data were collected. In addition, the implementation plan has revised some educational activities to be more disability-inclusive and focused on:

- The current activity, "Training of PTAs on their roles and responsibilities and make follow-up on their support to schools," which included four sessions on the Student Needs Assessment Plan (SNAP) to increase awareness of inclusive education.
- Teacher training on protecting children with disabilities and positive discipline practices has been integrated into the existing teacher learning cycle activities in 2022.
- Conducting disability-inclusive Back to School Campaigns in targeted communities.

In the case of child protection, the South Sudan CO revised activities to be disability inclusive using the detailed implementation plan for 2022 and any subsequent annual plans as a means for such adjustments. These focused on:

- Training of children with disability and their caregivers on positive parenting. This includes making disability-inclusive adjustments in the existing parenting without violent activities.
- Training of community-based structures on inclusion and disability to enable them to identify and refer children with disability to service providers for assistance.

The South Sudan CO also intends to include in its subsequent child rights plans an activity to celebrate the UN Disability Day with persons with disability as an awareness-raising and campaigning strategy to understand better the Convention of the Rights of Persons with Disabilities at school and community levels. To sum up, while noting the merits of the disability disaggregated data in supporting evidence-based planning, the COs have also stated that the lack of technical guidance documents regarding how to effectively utilize the collected data to inform programming and planning decisions was mentioned as a factor that needs to be addressed. In addition, the need to do more disability-focused qualitative studies to inform programming and planning decisions was also noted.

Recommendations

Recommendations for further capacity-building support by SCN

- Organization and facilitation of face-to-face or remotely facilitated workshops and discussion forums should be done among thematic and MEAL advisors from COs that implement NORAD-

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supported SC programs based on lessons learned from disability data collection at baseline and midline.

- Provision of technical guidelines and technical backstopping by SCN MEAL and thematic advisors regarding detailed analysis and utilization of disability disaggregated data for more disability-inclusive programming, planning, and budgeting.
- Support COs for disability-inclusive child rights situation analysis and assessment of Children with disabilities.

Recommendation for COs to improve the collection and utilization of the disability disaggregated data

- The leadership in the COs needs to give clear instructions and support for using the WGQs regardless of whether a donor requires the WGQs.
- Country offices must plan in consultation with a Save the Children member country to conduct a more in-depth qualitative study focusing on barriers children with disability face.

The Way Forward

In partnership with the Washington Group, SCN is pilot-testing the Child Functioning Module-Teacher Version (CFM-TV) in Norad-supported SC programs implemented in Somalia and Nepal to address the issue of a small number of children with disabilities enrolled and reported by schools. The CFM-TV is a set of WGQ questions designed by the Washington Group and UNICEF to be administered by teachers to identify children with disabilities in schools. Other Washington Group partners pilot testing the CFM-TV tool include UNICEF, Humanity and Inclusion, USAID, and Sight Savers. The CFM-TV tool will be rolled out to SC programs if the pilot studies find it a reliable disability data collection tool.