Fafo

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Tracking disability inclusion in multilateral organizations

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Acronyms

CRPD	Convention on the Rights of Persons with Disabilities
DAC	Development Assistance Committee (OECD)
DPO	Disabled Persons' Organization
ECOSOC	Economic and Social Council (UN)
FCDO	Foreign Commonwealth and Development Office
GDS	Global Disability Summit
GDPR	General Data Regulation Production
IDA	International Development Alliance
IEI	Inclusive Education Initiative
IFL	Identity First Language
ILO	International Labor Organization
OECD	Organization for Economic Cooperation and Development
PFL	Person First Language
PIDB	Program Information Database
SIC	Specific Intervention Code
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
UNDIS	United Nations Disability Inclusion Strategy
WB	World Bank

Foreword

This report was commissioned by the Atlas Alliance—an umbrella organization for Norwegian stakeholders involved in international development work with and for disabled persons. The report is part of the Atlas Alliance's preparations for the Global Disability Summit in Oslo in February 2022. We are grateful that Fafo was entrusted with the task of exploring how multilateral organizations track and monitor work on disability inclusion.

We take this opportunity to thank the disability-inclusion experts and local field officers at UNICEF, the UNHCR, and the World Bank for taking time to share their knowledge, expertise, and experience with us.

Finally, we are thankful to, Anne Kielland, our colleague at Fafo who shared with us her impressive knowledge and experience from working with persons with disabilities, and who provided very useful comments on a draft of the report.

As always, the report remains the sole responsibility of its authors.

The authors, Oslo, February 21, 2022

Summary

This report investigates the developments in efforts to monitor the inclusion of persons with disabilities in the programs and activities of the United Nations High Commissioner for Refugees (UNHCR), the United Nations Children's Fund (UNICEF), and the World Bank, in the years between the first (2018) and the second (2022) Global Disability Summits (GDSs). The report is based primarily on information from, and the experiences shared by, the staff of these three multilateral organizations. It asks if and how the recent polices, guidelines, and accountability frameworks of UNHCR, UNICEF, and the World Bank have led to an improvement in the monitoring of the inclusion of persons with disabilities. Although the three organizations serve as case examples, in this report we have not carried out a comprehensive study of the organizations per se, but rather explored how the organizations currently track efforts toward disability inclusion.

Chapter 1 presents the central concepts related to disability inclusion and identifies some of the methods currently used to identify persons with disabilities. We briefly discuss the concept of inclusive education and explain the methodology adopted in our study.

Chapter 2 describes some of the main tools and approaches used by the three organizations to track and monitor disability inclusion, including the Washington Group questionnaire modules for use in national censuses and household surveys. We also present the OECD-DAC marker that was developed to facilitate the tracking of disability inclusion in development and humanitarian aid, because it is an important tool despite not being used by the three organizations.

The three organizations have all developed strategies and accountability frameworks that include commitments to the inclusion of persons with disabilities at all levels of the organizations' work, as well as obligations to track and monitor such efforts. We present the UN Disability Strategy and the World Bank Disability Inclusion and Accountability Framework and discuss their implications for tracking and monitoring disability inclusion. We also present UNICEF's program performance management system: inSight. This connects UNICEF's strategic plan to work on the ground at the implementation level through an intricate system of indicators, tags, and codes, including for disability and inclusion. The system provides managers with detailed information on program implementation and results; links information from activities, results, and expenditure at the program and country levels to policy areas, goals, and targets in the strategic plan; allows the production of reports based on detailed data; and lets donors produce their own reports in accordance with their own specific needs, interests, and policy requirements through a portal.

Chapter 3 discusses in some detail the experiences staff at both the headquarters and local level of the organizations have with using these tools to track disability inclusion in the field. For example, how the Washington Group questions, which were mainly developed to measure disability prevalence, can also be used to identify persons with disabilities for program participation in certain contexts and to then monitor their inclusion. We address experiences with the OECD-DAC marker for disability inclusion and find a modest interest in using the marker among the three multilateral

organizations. We discuss the field experiences of using UNICEF's inSight system and find that knowledge about disability and the promotion of inclusion as well as competence in the usage of the system may be insufficient. Finally, we turn to other challenges in tracking disability inclusion, with a particular focus on stigma. Stigma was an issue raised by many of the informants. We discuss stigma as presenting a challenge to identify disabled persons and thus to include them in local programs, as well as the implications of stigma on monitoring and tracking efforts.

When summarizing the main findings at the end of the report, we address how there are currently a variety of initiatives, programs, and practical efforts on the ground aiming to include persons with disabilities. We identify several challenges that remain for the successful monitoring of the inclusion of persons with disabilities. Current tracking and monitoring efforts are still far from providing sufficient documentation on how many persons with disabilities are being reached by both targeted and mainstreaming programs aiming for disability inclusion. We conclude that it remains difficult for stakeholders to make well-informed choices on where to most efficiently allocate available funding to best contribute to meeting the rights to inclusion of persons with disabilities. Finally, the report ends with a set of recommendations.

1 Introduction

Is it possible to accurately document whether multilateral organizations include persons with disabilities in their activities? That is the question this report seeks to answer through examining the situation in the programs and activities of the World Bank, the United Nations Children's Fund (UNICEF), and the United Nations High Commissioner for Refugees (UNHCR). We ask if recent polices, guidelines, and accountability frameworks specify the activities contributing to disability inclusion, with a focus on inclusive education, and to what extent and how inclusion is monitored and tracked. The report identifies some challenges to such efforts in all three organizations. These organizations were selected for this study because they have diverse mandates and thus can bring different perspectives to a discussion on the efforts to track and monitor disability inclusion.

In this chapter, we present the background and aims of the present study, the central concepts used in this report, and outline the methods currently applied to identify persons with disabilities.[1] We also briefly discuss the concept of 'inclusive education' and present the methodology used for producing the data for this report. Chapter 2 describes the main tools and approaches the organizations use for tracking and monitoring disability inclusion. Chapter 3 discusses some of the experiences that staff at both the headquarters and local level of the organizations have with tracking disability inclusion, including with the practical application of the tracking tools. Finally, Chapter 4 concludes the report.

1.1 Background and aims of the study

In recent years, disability inclusion has received increasing attention, as exemplified by initiatives such as the World Bank's Disability, Inclusion, and Accountability Framework to support mainstreaming disability inclusion in its activities (World Bank, 2018a), the development of the UN Disability Inclusion Strategy (UNDIS) (United Nations, 2019), the 2019 OECD-DAC disability marker for tracking disability inclusion in Official Development Aid (OECD, 2020), and UNHCR's Emergency Handbook with a separate chapter on disability inclusion (UNHCR, 2021). Also, UNESCO's annual Global Education Monitoring report had disability-inclusive education as the main topic in its 2020 edition (UNESCO, 2020).

The overarching question is if the increased attention to disability inclusion in the studied organizations—including the good intentions, ambitions, policy declarations, strategies, and guidelines—has led to the increased participation of persons with disabilities in projects and activities, and whether there are adequate monitoring and tracking tools in place to produce reliable evidence that this is happening.

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[1] We aim to use language respecting the dignity of persons with disabilities following the recommendations of the American Psychological Association (APA, 2020). The social definition of disability places the person first, while the human rights definition puts more emphasis on identity, putting disability first. In this report, we use both 'persons with disabilities' and 'disabled persons' to vary our language.

This report looks at the developments in the years between the first Global Disability Summit (GDS) in London in 2018 (GDS, n.d.), and the second GDS in Oslo in 2022.

The report takes as its starting point the findings of the 2017 report 'Tracking inclusion in Norwegian development support to global education' (Jennings, 2017). Some of the main concerns highlighted in that report were the broad, vague, and non-binding efforts toward disability inclusion in education development programs, rendering accountability difficult. The report also found that disability inclusion was not significantly mainstreamed into the global development agenda, and that the data required to assess disability inclusion were scarce. Several years on, is there evidence that disability inclusion policies in humanitarian and development assistance not only have improved in more recent years, but also that the implementation of these policies is materializing and reaching persons with and without disabilities equally?

The GDS, established in London in 2018, has been described as a milestone for disability-inclusive development (GDS, 2018a). Governments, civil society, the private sector, the donor community, multilateral agencies, and Disabled Persons' Organizations (DPOs)—amounting to 171 institutions in all, from all over the globe—attended the summit. The aim was to share experiences, ideas, and aspirations for more disability-inclusive development and humanitarian work. The summit generated almost a thousand commitments to strengthen disability inclusion. The concluding document, 'Charter for Change', was signed by a long list of stakeholders, including the three multilateral organizations discussed in this report. The charter's Article 8 commits signatories to put the furthest behind first, specifically mentioning these as, 'the most underrepresented and marginalized persons with disabilities'. The summit's secretariat has since published two progress reports on the commitments from GDS18 (DFID 2019; FCDO/IDA, 2021). The most recent report is based on a survey of 57 percent of the GDS18 participants and some case studies of processes related to reaching these commitments, including UNICEF, UNHCR, and the World Bank.

1.2 Understanding disability and inclusion

Disability definitions have evolved over time, but three paradigms can be highlighted as particularly important for the current understanding of the concept of disability. The earlier *medical model* of disability used disability as being synonymous to an individual's impairment, effectively a bodily error that needed to be prevented, treated, or fixed (Tiberti & Costa, 2020).[2] This impairment focus was radically challenged by the sociological *social paradigm*, which turned the focus toward how the physical and social surroundings of individuals with impairments disabled their functioning (Oliver, 1996). On the policy side, the social definition led to a broadening of the programmatic scope from targeted welfare programs toward identifying and reducing the physical and social barriers to functioning. The social model sharply differentiates between impairment and disability; the first being a condition of the body and mind, while the latter is a product of how society responds to such impairments.

The *rights-based approach* adds to the social definition by enhancing the focus on human dignity and worth over mere equality (Degener & Quinn, 2002). The rights-based model maintains the focus on identifying and removing the barriers to inclusion but adds an acknowledgment of the variations in physical functioning as a valuable part of human diversity that is open to disability identity development, which

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[2] The World Bank operates with two medical models in its definitions: the medical model of the 1980s and the bio-social model of 2001 (Tiberti & Costa, 2020).

had become challenging under the sociological paradigm (Degener, 2016). One policy implication of this paradigm change has been the increased relevance of anti-discrimination laws, as part of a broader search for the social mechanisms of exclusion. In some countries, the term disability is understood more in legal terms, as a person who qualifies for public benefits under national welfare programs. Such definitions are often country specific and combine an individual assessment of impairment and the practical functioning of an individual.

The terminology used is a sensitive issue in writing about disability, and the legitimacy of the terms used change with the changing paradigms. In this report, we use identity-first (IFL) and person-first language (PFL) interchangeably. Under the social paradigm, IFL was associated with the medical paradigm, and therefore was considered by many to be derogatory. IFL is, however, making a return under the human-rights paradigm, but with new connotations. We refer to the American Psychological Association's publication manual (APA 2020, Section 5.4), and underscore that when using identity-first language, we follow the recent trend associated with the human-rights paradigm, where the disability identity is reclaimed by disabled persons, and is associated with empowerment and pride (also see footnote 1).

Persons with disabilities are often referred to as though the persons involved represent a homogenous group. In program documents, this very diverse group is often listed among a range of other sub-groups of presumably 'vulnerable populations'. However, the heterogeneity of the challenges faced by persons with disabilities is often trivialized by such broad terms. Persons with disabilities face challenges related to physical, sensory, cognitive, and neurodevelopmental functional variations, as well as different grades and combinations of these. This diversity implies challenges of e.g., adapting accommodation and lifting barriers to enhance inclusion and equal participation, but exposes different exclusion mechanisms.

Consequently, the variations represent challenges to the efforts made toward monitoring and tracking inclusion. Also, counting and tracking can become biased by the type of functional variations perceived as being easier to program for. For example, one of the lowest hanging fruits could be to count ramps constructed in schools, whereas a more challenging but attainable one could be the staffing of schools with teachers who know braille. Tracking and monitoring efforts can be affected when identification remains challenging—and program solutions even fewer—for persons with cognitive and neurodevelopmental functional variations. So, do tracking programs make the extra effort to monitor groups we don't really know how to include?

The Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol, adopted in 2006, is a result of decades of work by the UN to change the attitudes and approaches to persons with disabilities (Degener & Begg, 2019). The CRPD integrates elements of the three disability models (medical, social, and human rights) in defining persons with disabilities as 'individuals who have long-term physical, mental, intellectual, or sensory impairments, which, in interaction with various barriers, may hinder their full, effective, and equal participation in society.' It aims 'to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity' (CRPD, Art. 1.12).

The purpose of *inclusion* is to promote equal access to meaningful participation in a project or activity and represents an important step toward a rights-based understanding of disability (Skarstad & Stein, 2018). 'Disability inclusion' denotes the participation of persons with disabilities in all their diversity, promotion of their rights, and the consideration of disability perspectives, in compliance with the CRPD

(United Nations, 2019:20). Disability inclusion thus addresses not only social inclusion and equity but also policies and practices related to persons with disabilities, and their rights to social benefits as well as protection under anti-discrimination law. This aligns with the shift toward the human-rights approach, which includes adequate support, the identification and removal of barriers as well as exclusion mechanisms, and universal design. The latter entails designing products, environments, programs, and services to be usable and accessible for all people without the need for further adaption (United Nations, 2019:20).

UNESCO (2020) views inclusion in education as a process and as a tool to achieve the larger goal of social equality. UNESCO distinguishes between equality, as a state of affairs that can be observed and measured, and equity, as a process of actions to obtain equality. The inclusion process involves actions that embrace diversity and build a sense of belonging and is guided by the principle that every person has value and potential. An inclusive society is a normative standard that provides direction for all development policies and programs (UNESCO, 2020).

The focus on inclusion as a process makes its tracking extra challenging. Targeted initiatives are more visible and more often aimed at producing short-term results that can be easier counted and measured. Mainstreamed inclusion initiatives, on the other hand, tend to encompass longer-term objectives and efforts in a larger development perspective. The end goal of providing sustainable results through universal access for disabled persons is clearly more difficult to assess (Ingdal & Nilsson, 2012; Larsen & Nilsson, 2021). So, it is often easier to document the results of targeted disability-inclusion initiatives than the results of mainstreamed approaches. In short, targeted charity and welfare programs make counting easy — mainstreaming does not.

1.3 Identifying persons with disabilities

Two decades ago, WHO developed a statistical classification system for disability based on the responses to a survey questionnaire. Still, the questionnaire was complex and too comprehensive to be included in broad, multi-topic household surveys and censuses (WHO, 2001).

In 2001, a group of experts at the UN statistical office, together with statisticians from other international institutions and national statistical offices, gathered in Washington D.C. to develop methods for collecting comparable international disability statistics, and hence the Washington Group on Disability Statistics was established.

Whereas the WHO's classification system was based on a comprehensive identification tool, the Washington Group developed several much more limited questionnaire modules to identify activity limitations that could put people at risk of exclusion. Further, while the WHO questionnaire takes around 120–150 minutes to complete, the Washington Group Short Set on Functioning Questions takes merely one and a half minutes to administer and can easily be included in national censuses and household surveys. The Washington Group Short Set of Questions is today used by statistical agencies in around 80 countries and by various national and international institutions when conducting surveys. The Washington Group Short Set of Questions can also be used by organizations in screening processes to identify persons with disabilities for their inclusion in interventions, projects, and programs.[3]

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[3] Additional information on disability questions developed by the Washington Group on Disability Statistics is found in Chapter 2.

Countries that have used the Washington Group Short Set of Questions have found that 6–12 percent of the population have a disability (Christensen, 2020). The threshold for being classified as disabled according to this tool is higher than in the WHO questionnaire, which implies that the prevalence becomes higher when the latter survey instrument is used. For example, data from the World Health Survey implemented in 70 countries in 2002–2004 led to an estimate of 15.6 percent disabled persons worldwide (WHO, 2011).

This figure for the global prevalence of disability, i.e., around 15 percent, is now the commonly accepted one. Yet, due to the considerable differences in how disability is defined and counted, national figures vary considerably. For example, the use of direct questions, such as 'Do you have a disability?'—previously often used in national surveys—can result in an underreporting of the prevalence due to the stigma associated with disability. The use of medical categorizations of impairment can also produce a similar result (World Bank, 2020a).[4]

At the same time, overreporting may be an issue in areas where the population thinks that program access may be conditional upon disability. For instance, in a survey of disabled children in Niger, pediatricians found that only one-half of the children listed by local informants as potentially qualified for the survey were ultimately screened as disabled according to the Child Functioning Module. Also, among those children screened as disabled, only two-thirds reached the threshold for a disability classification based on the pediatrician's more thorough clinical examination (Kielland, 2021).

UNHCR has reported that forced displacement disproportionately affects persons with disabilities, as violent conflict can heighten the risk of violence, increase exposure to injuries, and limit access to medical service. Further, refugees may be vulnerable toward exploitation and abuse, and may face barriers to accessing most basic services (UNHCR, 2019b). Persons with disabilities are also at risk being left behind during emergencies. A study on Syrian refugees in Lebanon and Jordan found a disability prevalence of 22.8 percent, while 61.4 percent of the households in the study reported having at least one person with disability in the household (HI & iMMAP, 2021). Yet, there may be also a risk of overreporting in the hope of accessing targeted services among populations eligible for humanitarian aid.

1.4 Disability inclusion in education

The right to equal education for all is stated in many recent declarations and conventions, including in the Sustainable Development Goals (UN, 2015). In a rights-based paradigm, inclusive education is the normative standard and points out the target direction for a process embedded in the global struggle for more inclusive societies. The opposite of inclusion is exclusion, and the process toward inclusivity involves identifying, disclosing, and counteracting any exclusion mechanisms at work while at the same time removing the more practical barriers to equal participation. According to UNESCO, inclusive education is a means of responding to the diversity of the needs of all learners through increasing participation in learning and reducing exclusion from education. The goal is to facilitate learning environments where teachers and learners embrace the challenges and benefits from diversity, and where individual needs are met to give every student an opportunity to succeed (UNESCO, 2011). Systems must open up to variations in learning styles and provide support to disabled

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[4] Collecting data on individuals with disabilities is not enough. Data on the barriers and accessibility improvements is also needed to understand and assess disability inclusion.

children based on their individual needs. Inclusive education values the unique contributions that students of all backgrounds bring to the classroom.

In 2016, the CRPD committee stated that inclusive education 'focuses on the full and effective participation, accessibility, attendance, and achievement of all students, especially those who, for different reasons, are excluded or at risk of being marginalized' (CRPD, 2016:3). Among a series of elements that may constitute inclusive education are:

> …the content of education and learning materials, teaching and teacher preparation, infrastructure and learning environment, community norms, and the availability of space for dialogue and criticism involving all stakeholders (UNESCO, 2018:2).

In its concept note to the 2020 Global Education Monitoring Report on Inclusion, UNESCO notes that there are two existing unresolved conflicts regarding education for all, both associated with the practical implementation of the normative standards for inclusivity. First, the idea of equal learning for absolutely *all* children is by some argued to be too idealistic. This argument necessarily raises the uncomfortable question of where to draw the line for what 'all' would mean in a practical setting. The second dilemma inevitably concerns the financial constraints and the practitioner's need to prioritize activities considering the resources at hand. UNESCO proposes that the gap between normative standards and the reality on the ground can be bridged by a focus on achieving gradual progress through an ongoing process of identifying and changing the mechanisms of exclusion more broadly (UNESCO, 2018).

Rights-based inclusive education is the primary goal and indicates the direction for action. To be able to document results on inclusive education reliable baseline data on the school enrolment of children with disabilities is required before any action is taken. According to UNESCO, some 33 million children with disabilities are not in school in low and middle-income countries, while those who attend school tend to score lower in reading and math tests than children without disabilities (UNESCO, 2021). Trustworthy national and local data are in many places missing. A study using census data from 19 countries suggested that the gaps in educational outcome between children with and without disabilities is increasing and that children with disability are 10–17 percent less likely than children without disabilities to enroll in school, complete primary or secondary education, and become literate (Male & Wodon, 2017).[5]

Currently a set of shared challenges prevent disabled children in most countries from attending mainstream schools. In addition to local exclusion mechanisms, these include adequately identifying children with disability and their individual needs, promoting more universal designs and removing barriers to access by accommodating such needs, the assignment of enough adequately trained teachers, the adaptation of appropriate physical infrastructure and learning materials, and, more generally, a mobilization of the necessary resources.

The main concern of this report is accountability of disability inclusion. We investigate if the current monitoring systems are capable of documenting that the inclusion efforts supported honor Article 8 of the 2018 Charter for Change of placing the furthest behind first, so that no one is left behind.

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[5] Few censuses included in the Male & Wodon study used the Washington Group questions on disability, and hence they probably underestimated the prevalence of children with disability, while perhaps only capturing the most severe disabilities. With the increased use of the Washington Group questions in censuses, this picture might change in the future.

1.5 Methodology

In illustrating the progress, achievements, and challenges concerning accountability, this report examines how three major multilateral actors in the humanitarian and development field are tracking inclusion: the UNHCR, the World Bank, and UNICEF. We ask to what extent the organizations can document that they include disabled persons in their operations and programs. We look at how programming towards disability inclusion is monitored across all the organizations as well as disability inclusion in education. Our analysis is derived primarily from interviews with staff in the three organizations' headquarters and at their country offices in Uganda and Niger.

At the headquarters level, persons responsible for disability-inclusive work were interviewed, sometimes together with education experts and technical staff involved in the development and management of the organizations' data collection as well monitoring and performance management systems.

At the country level, we interviewed local staff, including country office personnel, personnel operating in the field, and, a few times, staff from implementing partner organizations. While the headquarters had disability inclusion experts, the country offices lacked such expertise, although most had a focal point for disability inclusion in accordance with the UN Disability Inclusion Strategy (UNDIS). We also interviewed representatives of DPOs, the director and other staff at the Atlas Alliance, and consulted an expert who had participated in the development of the Washington Group questionnaires.

We discussed disability inclusion with country officers in Niger and Uganda to understand how central policies and commitments for disability inclusion are implemented at the country level. We decided to consult the experience from these two countries mainly because of Fafo's broad experience and solid networks from working in both countries. Further, they are two of the six 'Together for Inclusion' (TOFI) countries supported by the Norwegian Government's initiative for disability inclusion.[6] However, it should be noted that this report is not a case study about disability and disability inclusion in these two countries. Local informants provided us with insights on the ground level implementation and input on the available monitoring systems.

The interviews were semi-structured. The main topic was the organizations' efforts to include persons with disabilities in their operations, including regarding inclusive education. We asked how they track and monitor these efforts, and how they report on the results to donors, governments, and the wider public. The interviews explored the possible challenges in the organizations' inclusion work, particularly concerning monitoring and tracking, and enquired about any plans to overcome such challenges.

Two, and sometimes three, Fafo researchers attended the interviews. COVID-19 restrictions meant all the interviews were conducted on the Teams virtual platform. We recorded and transcribed the interviews for accuracy. In line with standard academic practice, we anonymized our sources and do not always provide information about the informants' positions and, when the information is sensitive, we do not mention the place or country of employment. Because we interviewed mainly three organizations, some informants are potentially vulnerable to identification. We

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[6] Together for Inclusion is a partnership that started in 2019, in which seven Norwegian DPOs and nine Norwegian NGOs work with local partners to promote the rights of disabled persons in six countries (Ethiopia, Mozambique, Niger, Somalia, South Sudan, and Uganda. https://www.atlas-alliansen.no/en/home).

promised full anonymity to all our informants and have taken full precautions to do so in our publication. This was an important approach which facilitated our informants to speak freely about sensitive topics.

In addition to the interviews, the report draws on the three organizations' documents regarding their polices, guidelines, and accountability frameworks, as well as various other reports and documents. Such policies and frameworks are usually developed at headquarters, and in our interviews at the country level, we explored how such institutional normative standards were perceived and understood by country-level and local staff. We investigate if the policies and monitoring systems are known and followed locally? Are they easy to implement, and can progress and results be documented? What challenges do field staff meet, and how do they resolve them? Finally, we draw on some articles from international journals, although our literature search yielded little academic writing of direct relevance to the topic at hand.

2 Measuring disability and monitoring disability inclusion

Drawing on the three organizations' reports, strategies, and information from our interviews, this chapter presents some of the tools, systems, and practices used to track disability inclusion. First, we consider the Washington Group's Sets of disability Questions, which are important tools for all three organizations included in this report. Second, we present and discuss the OECD-DAC marker for disability inclusion. This tool is frequently used in bilateral cooperation but has not been adopted by the multilateral organizations in our study. Third, we present the UN Disability Strategy, which all UN agencies relate to, and the World Bank's Disability and Accountability Framework. These are central strategies for disability inclusion, which are important binding documents for the organizations in our study. Following that, we present the monitoring systems and practices based on examples from the organizations. We present UNICEF's recently developed monitoring system, inSight, which has indicators for tracking disability inclusion. Finally, we examine the available public reports on expenditures to disability inclusion.

2.1 The Washington Group's disability questions

The Washington Group on Disability Statistics, a 'city group of experts' established under the UN Statistical Commission, involves statisticians from across the world who are tasked with developing disability measures suitable for inclusion in censuses and national household surveys. Its secretariat is located at the National Center for Health Statistics in Washington, DC, USA. The aim is to provide tools that can provide information on disability that is comparable throughout the world (Washington Group, 2022).

   Information and statistics on impairments are regarded as sensitive personal information, and therefore protected by international regulations, such as the EU's general data protection regulation (GDPR). Importantly, the GDPR can apply to countries outside the EU if funding and persons from GDPR partners are involved. Impairment status is often associated with stigma and discrimination, and access to impairment and disability data can put individuals at risk. Stigma and trauma can also make questions about disability uncomfortable and even be perceived as offensive in contexts where the features of impairment and disability may be associated with shame. Considering this, and in line with the social and human-rights models of disability, the Washington Group questions places particular emphasis on toning down the focus on medical impairment at the individual level, and instead tries to identify barriers and challenges related to social functioning. An informant who had participated in the Washington Group work since the beginning said:

> The main challenge was to ask questions about disability, which is a charged subject, without offending anybody. We came up with questions that we think are universal and non-judgmental.[7]

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[7] Interview with a former statistician in the Washington Group, December 2021.

The solution was to ask questions about disability without mentioning the word disability. The resulting Washington Group short set of questions consists of only six questions and assesses functionality in the following domains: vision, hearing, mobility, cognition, self-care, and communication (Washington Group, 2022).[8]

A slightly longer version of the module was developed to allow capturing further details and to better capture psychosocial functioning. As the Washington Group Short Set of Questions failed to identify some child disabilities, especially, in children under five-years old, the Washington Group in collaboration with UNICEF added a separate Child Functioning Module. The Washington Group is currently testing a combination of the Child Functioning Module together with a special module on inclusive education. The Inclusive Education Module particularly addresses the social, physical, and economic barriers to education. In collaboration with the International Labor Organization (ILO), the Washington Group also developed the Labor Force Survey Disability Module.

The Washington Group questions were developed for use in general, comprehensive household surveys and censuses to help assess the prevalence of disability, but can also be used to survey a particular population, such as refugees or students participation in an education program. In the latter contexts, the Washington Group questions can go beyond mere prevalence mapping, and can be used to also assess inclusion. We return to this in Chapter 3.

2.2 The OECD-DAC marker for disability inclusion

The Organization for Economic Cooperation and Development's Development Assistance Committee (OECD-DAC), an international forum for the largest aid providers in Europe, developed a marker system to facilitate the monitoring and comparison of activities in support of different policies in Official Development Assistance areas, such as gender equality and environmental protection. A marker for disability inclusion was adopted in 2018, in line with Article 32 of the CRPD, which emphasizes the inclusion and accessibility of persons with disabilities in international cooperation programs, and reinforces the ambitions in the 2030 Agenda for Sustainable Development to 'leave no one behind'. The OECD-DAC marker is a tool to monitor and account for the amount of aid aimed at including disabled persons.[9] It has been adopted by bilateral donors in the EU, but is also used by a few non-EU states, such Australia, Canada, and Norway.

The disability policy marker is a tool for holding donors accountable to commitments in the CRPD and the Sustainable Development Goals (UN, 2015). Also, it allows

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[8] The Washington Group short set of functioning questions: (1) Vision: Do you/Does he/she have difficulty seeing, even if wearing glasses? (2) Hearing: Do you/Does he/she have difficulty hearing, even if using a hearing aid? (3) Mobility: Do you/Does he/she have difficulty walking or climbing steps? (4) Cognition (remembering): Do you/Does he/she have difficulty remembering or concentrating? (5) Self-care: Do you/Does he/she have difficulty with self-care, such as washing all over or dressing? (6) Communication: Using your/his/her usual language, do you/does he/she have difficulty communicating, for example understanding or being understood? The questions can indicate if disabled persons are included if the answer to the question is 'a lot of difficulty' or cannot do at all'.

[9] The criterion in the OECD-DAC marker is that the activities/projects must deliberately aim to benefit persons with or without disabilities in equal measure and promote inclusion and accessibility to disabled persons in international cooperation programs. The marker has a scoring system where a score of 2 (principal) is given to projects with the inclusion and empowerment of persons with disability as its main activity (targeted). A score of 1 (significant) is given to projects where disability inclusion is important, but not the main objective of the development activity (inclusive). A score of 0 (not targeted) is given to projects lacking targets for disability inclusion.

for comparisons between donors on such commitments and encourages efforts to share knowledge on different approaches to disability inclusion, as well as aiding the collection and sharing of data on disability inclusion.

Reporting on the disability policy marker is *voluntary*, unlike other policy markers for which reporting is mandatory (e.g., gender). Additionally, the disability marker only tracks *intentions* or *commitments* in program and project plans. It does not inform on actual spending or whether allocated funds actually have reached persons with disabilities, and if so, how many, and with what impact. One informant suggested that the disability marker could be complemented with other tools, such as data collection efforts to monitor results disaggregated by disability.[10] It is out of the scope for this report to investigate this further.

There can be several challenges preventing the multilateral organizations from using the disability marker. One might be that the marker was developed for bilateral donors, mainly in Europe. One informant suggested that the governments using the disability marker could share experience of its usefulness to the multilateral organizations, to improve comparative data and accountability towards the CRPD.[11] Another informant said that '*there are some reservations about having one tracking system working for everybody. [I think] this is related to a variance of roles.*'[12] The informant explained that the bilateral donors were accountable toward policy commitments and that such commitments often alter with change of governments, along with funding priorities. However, multilateral donors are not restricted by the same political guidance and restrictions, according to this informant, they thus could keep their focus on their own development mandate. As we explain below, UNICEF's monitoring system can align to the OECD-DAC marker.

2.3 UN Disability Inclusion Strategy

With the 2030 Agenda for Sustainable Development's call to leave no one behind, inclusion in general, and particularly for persons with disabilities, has become a stronger priority for the UN. Work to develop a strategy for disability inclusion started in 2018. The aim was to mainstream and improve the rights of persons with disabilities in all UN work. The resulting UN Disability Inclusion Strategy, adopted in 2019, has two main components: an accountability framework with common indicators for all agencies, and a scorecard for disability inclusion for country teams. The aim is that adopting a human-rights-based approach to disability will make the concerns and experiences of persons with disabilities an integral dimension of the design, implementation, monitoring, and evaluation of policies and programs throughout the UN system, and assure equality for all persons with disabilities (United Nations, 2019).

The system-wide accountability framework for the implementation of a disability-inclusive policy is the key to making the strategy operational. The framework includes indicators, timetables, technical guidelines, and the distribution of responsibilities for implementing the policy. There are 15 indicators to monitor implementation of the strategy, which focus on four themes: leadership, strategic planning, and

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[10] Interview with a disability expert, December 2021.
[11] E-mail correspondence with disability expert, February 2022
[12] Interview with a disability expert, November 2021.

management[13]; inclusiveness[14]; programming[15]; and organizational culture[16]. All UN entities should report on these indicators annually, and it is expected that all UN staff will understand their role in promoting and facilitating the inclusion of persons with disabilities. The latter requires training to strengthen capacity and competence, which is part of the strategy (United Nations, 2019).

The strategy acknowledges that the lack of high-quality and disaggregated data is a barrier to assessing disability inclusion in the development and humanitarian fields. It suggests that the institutions' disability-inclusive policies and the strategy's accountability framework will address this gap (United Nations, 2019).

The UN has published two progress reports on the implementation of the Disability Inclusion Strategy: one for the 2019 program year (United Nations, 2020), and another for the 2020 program year (United Nations, 2021). The first report included results from 57 UN entities and seven pilot reports at the country level.[17] The second progress report included results for 66 UN entities and 130 country teams. It highlights some gaps, among them the need to strengthen capacities and technical expertise, as well as the general lack of data on persons with disabilities in national statistics.

The COVID-19 pandemic brought unexpected challenges to the progress on mainstreaming disability inclusion, particularly in the field of inclusive education, as schools in many countries were closed for long periods. Many entities and country teams have reported slowed progress, pointing to three main factors associated with the pandemic: the reallocation of funds and the reduction of funds available for inclusive education; the intense workload related to the COVID-19 response; and movement restrictions preventing staff from accessing offices.

2.4 World Bank Disability Inclusion and Accountability Framework

While UNICEF and UNHCR are part of the UN system and are required to follow the UN Disability Inclusion Strategy, the World Bank has a treaty-based relationship with the UN and does not have the same obligation. The World Bank cooperates with the UN on the 2030 Agenda, particularly through the funding of activities and data production. In 2018, the World Bank developed its own Disability Inclusion and Accountability Framework. Its main objective was to mainstream disability in World Bank activities. It is worth remembering that the World Bank is primarily a bank. It does not implement development projects itself but instead provides funds and supervision to countries implementing development programs. The World Bank monitors its results and tracks them internally according to indicators in the results frameworks used by

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[13] The four indicators are leadership: if the senior leadership champion disability inclusion; strategic planning: if explicitly referring to persons with disabilities in their strategic planning documents; a disability-specific policy/strategy; and institutional set-up, under which responsibility is assigned for technical guidance, coordination, and advocacy.

[14] The indicators for inclusiveness focus on strengthening the accessibility of physical premises, digital technologies, and goods and services, and deepening engagement with organizations of persons with disabilities. The indicators are consultation, accessibility, conferences and events, reasonable accommodation, and procurement.

[15] The indicators for programming focus on disability inclusion in programs and projects, evaluation, country program documents, and joint initiatives.

[16] The indicators for organizational culture focus on inclusion in employment, capacity development for staff, and communication.

[17] The scorecard for disability inclusion for the country teams had not been finalized at the time of the first report (UN 2020)

the projects. When reporting to donors, it negotiates local results frameworks according to the needs of each donor.[18] The World Bank reports to donors are tailor-made yet built on its own strategies and monitoring system.

The World Bank's primary mission is to end extreme poverty and promote shared prosperity. Persons with disabilities face multidimensional poverty more often than persons without disabilities (World Bank, 2018a). Therefore, the World Bank's goals cannot be reached unless the inequality and exclusion of persons with disabilities are addressed. Based on this understanding, the World Bank's framework for disability inclusion and accountability provides guidelines for disability inclusion in grant agreements for development funding. The specific terms are negotiated with governments benefiting from World Bank funds. The World Bank Disability Inclusion and Accountability Framework provides an internal road map for disability inclusion in the organization's policies, operations, and analytical work, and for supporting client governments in implementing disability-inclusive development programs (World Bank, 2018a).

The World Bank Disability Inclusion and Accountability strategy outlines six steps toward disability inclusion: (1) the twin-track approach of including persons with disabilities as beneficiaries in all World Bank projects, while also implementing specific projects to address the remaining gaps in disability inclusion; [19] (2) making sure all World Bank policies, guidelines, and activities are disability inclusive; (3) identifying focus areas for disability inclusion; (4) collecting data to document the circumstances of persons with disabilities; (5) building staff capacity; and (6) developing partnerships for implementing disability inclusion. Each of these steps or areas of commitment has a focal point where guidelines on how to detect and report on disability inclusion are developed (World Bank, 2018a). The Disability Inclusion and Accountability Framework is upheld by our informants as highly important to mainstream disability inclusion in the World Bank's work. In addition, focal points meet regularly to report on progress on each of the commitments.[20] Yet, according to one informant,

> It would be very difficult to present disaggregated data on how many persons with disabilities are reached through our projects. We have undertaken portfolio reviews on disability inclusion that focus primarily on the project level data.[21]

The lack of disaggregated data on disability inclusion makes it challenging to comprehensively document inclusion. However, the World Bank is working steadily with partner governments to promote disability inclusion. For example, by developing a guidebook for developing inclusive household survey questionnaires (Tiberti & Costa, 2020), or by developing a guidebook for digital universal access for when governments are aiming to modernize and digitalize their services (World Bank, 2021a). Likewise, for government services to be inclusive there is a need for trusted and accessible identification systems to avoid groups being left out of development initiatives (World Bank, 2020b).

The UK's Foreign, Commonwealth, and Development Office (FCDO, formerly the Department for International Development, DFID) launched its Inclusive Education Initiative (IEI) in 2019, which the World Bank is hosting and has further developed

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[18] Interview World Bank, November 2021.
[19] See the Introduction for an explanation of the 'twin-track approach'.
[20] Interview, World Bank, November 2021.
[21] E-mail correspondence with disability expert, February 2022.

(FCDO/IDA, 2021). The IEI was set up as a multi-donor trust fund and is supported by the Norwegian Agency for Development Cooperation (Norad) and the UK government's Foreign, Commonwealth, and Development Office (FCDO). The aim of the trust fund is to improve the educational participation and learning outcomes of children with disabilities. To achieve this, the IEI centers on funding to: (1) enhance stakeholder capacity and service delivery at the country level; (2) improve coordination, collaboration, and knowledge sharing; and (3) invest in innovative interventions to strengthen inclusive education (IEI, n.d.). Responding to its GDS18 commitments, specifically goal 1) 'ensuring that all WB-financed education programs and projects are disability-inclusive by 2025' (World Bank, 2018b, Commitment 1), the World Bank developed a guidebook to help potential applicants understand how to make education projects disability inclusive, and thus eligible for World Bank Investment Project Funding (World Bank, 2021b).

The World Bank's commitments made at the GDS18 include supporting developing countries to invest more in persons with disabilities and strengthening the ways that 'Global Practices' can engage with disability inclusion (DFID, 2019).[22]

2.5 UNICEF program performance management system

Nine years ago, UNICEF established a program results and management system, which functions for all stages, from the planning to execution to reporting against results. As described by UNICEF, the performance management system, inSight, has the capacity to provide staff with up-to-date and easily accessible financial and program management data, which supports performance measurement and day-to-day decision-making at all levels of the organization; it can provide managers with daily detailed information on the status of program implementation and the achievement of results; it offers timely and consistent information across all levels in the organization via a single point of entry; it links information on activities, results, and expenditure at program and country levels to policy areas, goals, and targets in UNICEF's strategic plan; it puts the agency in a position to produce a wide variety of reports based on detailed data, for example on its efforts regarding inclusive education and expenditure toward children with disability; allows the tracking of UNICEF's contribution to the Sustainable Development Goals (UN, 2015); and it allows donors to follow up allocations and agreements through the portal and to produce reports according to their own specific needs, interests, and policy requirements.[23]

A prerequisite for inSight is a set of codes known as the Program Information Database (PIDB) coding system, which are applied at the level of the outputs and activities, enabling the operationalization of UNICEF's Strategic Plan. UNICEF's disability program is twofold: it combines targeted interventions for children with disabilities and disability-inclusive mainstreaming programming. The PIDB coding system includes disability-related specific intervention codes (SICs) and a disability tag created to allow the detailed and accurate reporting of results and expenditures. UNICEF applies these codes in all its countries of operation and mainstreams disability inclusion in its programs across the world. Disability inclusion is central to cross-cutting programming in its 2022–25 Strategic Plan (United Nations/ECOSOC, 2021),[24] which has

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[22] 'Global Practices' refers to certain methods, techniques, mechanisms, and practices that have been tested and produced results at a global level and can serve as examples and templates.
[23] Information from interview disability experts at UNICEF headquarters
[24] The Strategic Plan says: 'UNICEF is elevating programming on disability rights within this Strategic Plan to advance disability rights in everything it does, including through support to the families,

a results framework with a total of 34 indicators to measure results for disability in-clusion.

UNICEF produces reports that take stock of results at the global, regional, and country levels, including its annual report with a data companion and scorecard; country, regional, and divisional annual reports;[25] and global annual results reports covering program results achieved by the contributions received from partners.[26] The country-office annual reports allow substantive, detailed, and extensive reporting on the various programs implemented, while the regional reports aggregate what has been achieved at a country level for a specific region. Country offices also have the option to add indicators to their country program and reports beyond those found in the strategic plan. Some examples of UNICEF statistics on disability inclusion are provided in Table 1.

Table 1 Examples of UNICEF data on disability inclusion.

Year	2018	2019	2020
Number of children with disabilities reached (1)	1.4 million	1.7 million	2.2 million
Number of disabled children reached with UNICEF-supported cash transfer programs (2)	414,701	699,939	826,356
Total number of children reached with UNICEF-supported cash transfer programs (2)	38.4 million	51.2 million	130.7 million
Share of children reached with UNICEF-supported cash transfer program who are disabled (4)	1.0 %	1.4 %	0.6 %
Percentage of UNICEF humanitarian responses systematically providing disability-inclusive programs and services (1, 3)	36 % (20 of 55 countries)	36 % (21 of 59 countries)	44 % (28 of 64 countries)
Number of children with disabilities provided with assistive devices and products (1)	Over 66,000	Over 138,000	Over 152,000
Number of children with disabilities reached with emergency kits (3)	-	-	74,991
Number of countries supported on inclusive education (1)	130	128	131

(1) Berman-Bieler & Takona (2021).
(2) UNICEF 2021, Fig .3.1.
(3) UNICEF 2021, Fig. 3.2.
(4) Our calculation.

In addition to such reports, UNICEF uploads its data to the OECD-DAC database an-nually, and inSight aligns with the OECD-DAC marker described above. This oppor-tunity is important for a donor like Norad, as it has chosen to use the OECD-DAC marker on disability for its development projects. Because inSight aligns with the

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parents, and caregivers of children with disabilities.' (p. 9). And it continues: 'UNICEF will main-stream disability inclusion in all its child protection work …' (p. 15).
[25] See, https://www.unicef.org/reports/country-regional-divisional-annual-reports.
[26] See, https://www.unicef.org/reports/global-annual-results-2020.

OECD-DAC marker, it allows Norad to generate output in accordance with its own reporting requirements.

Despite UNCEF's comprehensive program performance management system, there is limited information easily accessible on disability inclusion on UNICEF's web pages. Most of what we found is on the aggregate, global level. We reviewed country reports from Niger and Uganda and found little information regarding disability inclusion.[27] For Niger, it was reported that 4,150 children were reached through inclusive education in the capital and a few other regions in 2019, but the report did not specify the total number of children at school in Niger, nor the amount spent on inclusive education or what part of the total budget this represented (UNICEF, 2020a). UNICEF's 2020 annual report for Niger focused on the COVID-19 pandemic and has limited information on children with disability. One exception is a description of UNICEF's partnering with Handicap International[28] to support the inclusion of 5,158 children with disabilities in the education system (UNICEF, 2021b).

The 2020 annual report for Uganda focused on the COVID-19 pandemic and extended school closures in the country, which kept 15 million children out of school and which affected the poorest children the most, including children with disabilities. UNICEF Uganda supported 1,479 primary and secondary children with braille and audio material and reported that 43,000 parents were reached through radio talk shows on how to care for visually impaired children at home. UNICEF Uganda further held consultations with what they call 'special interest groups' and shared the findings from these consultations with the National Council for Disability at a high-level forum (UNICEF, 2020b).

The lack of numbers in Niger and Uganda might be considered a disappointment by impatient champions—organizations as well as individuals—of improved rights, life chances, and the living conditions of persons with disabilities. At the same time, UNICEF seems to have developed an impressive tool, which can provide much needed data that can be used to enhance its—and its partners'—performance regarding disability inclusion as well as data about its activities and achievements to inform donors and other interested parties. While all systems, including inSight, can be improved (technically), their success depends on their right use, e.g., human resources. We return to this aspect in Chapter 3.

Nevertheless, UNICEF's experience with inSight, including the many years of developing and enhancing the system, is highly valued by the UN family. As part of the UN reform, UNICEF experts supported what is called UN INFO, a UN data portal under development, which aims to monitor the UN's contribution to the Sustainable Development Goals, and which also calls for disability inclusion.[29] Furthermore, the agency's monitoring experts have helped other agencies in the design and development of *their own* monitoring and performance systems.

One may ask, as did we, why other UN agencies have not simply 'copied' or introduced slightly adapted versions of the UNICEF system? One answer may be that the various UN agencies have such distinct mandates and profiles that a replication of UNICEF's system would not fit other agencies, even if were significantly modified. A second answer may be that the various UN agencies use different technologies, operating systems, and platforms and that more coordinated efforts to develop such

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[27] When reviewing recent annual reports for UNHCR and the World Bank for Uganda and Niger, we did not find any information on persons with disabilities.

[28] The organization changed its name from Handicap International to Humanity & Inclusion in January 2018, see: https://humanity-inclusion.org.uk/en/our-new-brand.

[29] See, https://uninfo.org/.

systems, and adaptations of the UNICEF inSight system, therefore, would likely be considered too complicated and would entail a high risk of failure.

To sum up, UNICEF developed a comprehensive performance management system that allows the detailed monitoring of and reporting on the agency's work, including tracking the results of activities aimed at improving disability inclusion. As we return to below, it has yet to reach its full potential.

2.6 UNHCR efforts in tracking disability inclusion

The UNHCR recognizes that the under-identification of persons with disabilities is a significant challenge to monitoring inclusive planning and the implementation of access, protection, and assistance to persons with disabilities. The organization aims to strengthen the collection and use of reliable data disaggregated on disability, as well as to build capacity and develop learning and guidance kits (UNHCR, 2019a).

From July 2021, the UNHCR started to use the Washington Group Short Set of Questions for adults and the Child Functioning Module for children in its registration interviews to monitor the extent to which disabled persons are included in its protection and service activities.[30] The UNHCR also committed to the UN Disability Inclusion Strategy of 2019 and revised its 'Age, Gender, and Diversity' policy in 2018, with a particular focus on persons with disabilities and the disaggregation of data (UNHCR, 2018).[31] This policy is described as crucial to ensure that UNHCR services and programming are inclusive and accessible for all forcibly displaced persons (UNHCR, 2019a).

The UNHCR estimates that around 12 million persons with disabilities were displaced by the end of 2020 by applying the 15 percent global estimate of disability to the almost 80 million forcibly displaced persons in 2020 (UNHCR, 2020b). The 2020 Global Report (UNHCR, 2021a:192) and the Age, Gender, and Diversity Report (UNHCR, 2021b:20) give global numbers for disabled persons reached through UNHCR operations, stating that targeted services reached at least 55,672 adults with disabilities and 7,948 children with disabilities. These numbers suggest that through targeted interventions, UNHCR reached only 0.5 percent of the 12 million displaced persons with disabilities.[32] However, how many persons with disabilities that the agency reaches through mainstreaming programs is unknown.[33]

Furthermore, 51 operations reported an increased proportion of persons with disabilities included in services targeting particular needs. For example, 3,749 households with a disabled household member received direct cash-based and material assistance and 1,100 households benefited from improved water and sanitation facilities. Although not accessible in public reports, but available in internal reports shared with us for Niger in 2020, UNHCR had 302 refugees with disabilities accessing food distribution and cash assistance, and 11 refugee children with disabilities receiving targeted assistance in accessing education. For Uganda, 2,808 persons with disabilities were supported through the establishment of support groups.[34] We were informed that UNHCR intends to improve its reporting and will address this through additional measures such as mandatory disaggregation by sex, age and disability, use

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[30] Interview with UNHCR headquarter disability expert, November 2021.

[31] Interview with UNHCR headquarter disability expert, November 2021.

[32] Own calculation.

[33] Numbers and statistics are hard to find. For instance, we reviewed the 2020 'Data disaggregation of SDG indicators by forced displacement' report, and only found disability mentioned once, in a footnote on page 10 (UNHCR, 2020a).

[34] Email correspondence with headquarter disability expert, February 2022.

of the Washington Group Questions, use of a functionality marker on disability in-clusion, and a requirement to partners to disaggregate data as well.[35]

The UNHCR has built partnerships with various DPOs for many years, and benefits from consultations, capacity building, and other support that help improve disability inclusion in its work. However, our interviews also suggest that there are contexts where the DPOs have not been consulted, nor informed about the work of UNHCR. In 2020, the UNHCR and the International Disability Alliance (IDA) agreed formally to cooperate to enhance the equal protection, inclusion, and participation of forcibly displaced and stateless persons with disabilities (International Disability Alliance, n.d.).

In its operations, the UNHCR takes a participatory approach, making sure to in-clude persons with disabilities in community organizations and decision-making. It emphasizes equal access to information and takes steps to modify communication channels to ensure they can reach persons with disabilities. The organization is de-veloping capacity in the field of identifying persons with disabilities to monitor their access to protection and assistance (UNHCR, 2019a).

As mentioned above, the UNHCR intends to collect and aggregate data related to age, gender, and disability systematically in its forthcoming result-based manage-ment system to aid better monitoring and reporting on the access and inclusion of persons with disabilities. It has developed an e-learning program and a guide for working with persons with disabilities (UNHCR, 2019a). Finally, the UNHCR devel-oped an integration handbook for the resettlement of refugees with disability (UN-HCR, 2021).

2.7 Expenditure on disability inclusion

We asked—and attempted to answer—whether multilateral organizations have man-agement and monitoring systems in place to report on their activities and accom-plishments to improve the inclusion of persons with disabilities. We investigated if these reports indeed are produced and available to the public. We also examined if it is possible to determine the size of funds spent on disability inclusion for each of the three organizations, and how these total expenditures could be, or are, broken down and reported in detail, e.g., by country, type of activity, type of disability, gender, or age. In short, if it is possible to follow the money spent on disability inclusion.

In our interviews, we requested expenditure information on disability inclusion; we examined the web sites of the organizations and reviewed numerous reports, in-cluding those recommended by our informants. We did not have access to internal accounts or reports prepared for donors. Except for UNICEF, we found very little in-formation on expenditure on disability inclusion, and nothing on inclusive educa-tion. Even the figures published by UNICEF lack very detailed expenditure infor-mation. According to UNICEF, staff with access to the inSight system and proper training can produce the output they need in their daily work; for instance, to follow expenditures and assess progress and accomplishments at the program and country levels. Further, analysts at headquarters can benefit greatly from inSight, including by being able to extract expenditure data, such as when preparing various UNICEF reports for publication or for individual donors

Donors are, or will be, offered login credentials and training on how to extract data on disability inclusion (as well as expenditures, activities, and results on any other

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[35] Email correspondence with headquarter disability expert, February 2022.

themes) from inSight. Yet, such information is not readily available to the public domain. UNICEF offers some results at the aggregate level: the total global expenditure on disability inclusion in 2020 was USD 239.3 million (Berman-Bieler & Takona, 2021), which is a slight increase from the two previous years (Table 2). UNICEF's total expenditure the same year stood at USD 6,535 million (UNICEF, 2021, p. 6), which implies that 3.7 percent of its total expenditure was directed toward disability inclusion. As shown in Table 2, this share has been relatively stable in recent years.

Table 2 UNICEF expenditure on disability inclusion.

Year	Global expenditure on disability inclusion in USD millions (1)	Total expenditure in USD millions (2)	Share of total expenditure on disability inclusion (3)
2018	233.4 (123 countries)	5,946	3.9 %
2019	213.8 (142 countries)	6,259	3.4 %
2020	239.3 (144 countries)	6,535	3.7 %

(1) Berman-Bieler & Takona (2021).
(2) UNICEF annual reports for 2018 (2019, p. 8), 2019 (2020, p. 10), and 2020 (2021c, p. 6).
(3) Our calculation.

The overall 2019 UNHCR budgets that include *elements* of disability inclusion and persons with disabilities are: health, USD 503 million; education, USD 462 million; and persons with specific needs, USD 390 million. We found no UNHCR reference to development funding particularly tagged as disability inclusive (UNHCR, 2022; UNHCR, 2019a). Nor did we find any mention of UNHCR expenditure on disability inclusion in available reports. Still, some expenditure information has been made available to us.[36] For an output indicator on 'special services for persons of concern with disabilities', for example, the UNHCR spent nearly 640,000 USD in Uganda in 2017 and about 483,000 USD in Niger in 2020. These figures only capture what was reported under this dedicated indicator, not other actions that may be mainstreaming.

The systematic inclusion of persons with disabilities in World Bank operations is essential to achieve the World Bank's twin goal of ending extreme poverty and promoting shared prosperity. At GDS18, the World Bank committed to ensuring that 75 percent of its funds for social protection programs will be disability inclusive by 2025 (World Bank, 2018b, Commitment 8). Nevertheless, we did not find any documentation of specific expenditures tagged as disability inclusive.

Except for UNICEF, we did not find any published estimates of total expenditures on disability inclusion, figures on the number of persons reached by various programs and initiatives, nor accounts of the number of persons with disabilities who have benefited. This lack of public records on expenditures makes it difficult to follow the money, and for stakeholders to make well-informed choices on where to most efficiently allocate available funding to best contribute to meeting the rights to inclusion of persons with disabilities.

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[36] Email correspondence with UNHCR headquarter disability expert, February 2022.

3 Challenges and dilemmas

Disability-inclusive development requires a collective knowledge and awareness across institutional and operational levels. Strategies and systems should build on a synthesis of 'multiple knowledge' internalizing the various forms of indignities and disadvantages experienced by disabled persons in different contexts (Brown, 2010).

Tracking efforts often starts with the strategic plans for how disabled persons are intended to be included in operations and programs, and the development of systems for monitoring and following up such efforts. Yet, good strategies and systems tend to emerge from processes where organizations have incorporated knowledge and experiences from a variety of local contexts where the organizations operate. This exchange between institutional levels should continue during the implementation of the monitoring systems, as headquarters need open communications lines and the capability to respond and adapt to the experiences of the staff and stakeholders feeding the systems on the ground. When systems are not well rooted in local contexts, or well understood and 'owned' by local staff, there is likely to be poor data input in the monitoring systems, which are then likely to also yield poor or misguiding results outputs.

Knowing to what extent systems are understood and experienced as relevant will help inform data users on the quality of the data. Moreover, knowing what challenges a system represents to people in the field will suggest how data should be read and interpreted when organizations report on their strategic commitments and goals. The remaining question asks if the systems serve to provide reliable data on whether the money granted for disability inclusion is reaching disabled persons in ways that are meaningful to them. That is, does the work on strategies and monitoring systems pay off in the organizations' actual capacity to document that disabled persons' lives change in a positive direction?

In this chapter, we include some perspectives of country-office staff of the three organizations in Niger and Uganda, as well as views shared by informants in partner organization in the two countries. We first look at some general experiences, like the lack of good baseline data, and at the differences in tracking targeted and inclusion activities. Second, we look at specific experiences with the OECD-DAC marker, the Washington Group questionnaires, and the UNICEF performance management system. Third in the knowledge subsection, we look at one of the most recurrent concerns of our informants—that of training—and we discuss the ethical issues and some contextual factors that can affect tracking efforts. Among the latter, the topic of stigma was frequently raised, and we discuss this topic further as an issue of particular concern in identification, operation, and tracking efforts. Certain functional variations are perceived as more challenging that others, and in honoring Article 8 of the Charter for Change, we pay special attention to persons with cognitive and neurodevelopmental functional variations. We finally ask what characterizes the gap between good intentions and accountability.

3.1 Challenges with monitoring and tracking

In the assessment of how multilateral organizations track the inclusion of persons with disabilities, we identified challenges on three monitoring levels that can aid or impede the accountability of disability inclusion. The first is related to a lack of baseline data for persons with disabilities coupled with the challenges of estimating the prevalence of disabled persons. Currently, prevalence is often based on estimates, not actual data. Second, the twin-track approach to include persons with disabilities distinguishes between *targeted* and *mainstreamed* approaches. The approach chosen has implications for how easy it will be to monitor if and how many persons with disabilities are reached and benefit from the intervention. Third, we address the experiences of multilateral organizations with monitoring and tracking inclusion.

As discussed in previous chapters, no monitoring systems are currently universally applied, and all three multilateral organizations in the present study have different ways of monitoring their programs and activities. This is not necessarily preventing transparency and accountability to the donors but makes comparison between actors more challenging. Also, no matter how good a system is on the drawing board, its success depends on the users, the data fed into it, and the analysts preparing reports and outputs based on these data. In this chapter, we discuss the monitoring *practices* in the three organizations. We asked informants questions like: To what extent do the organizations know how many persons with disabilities they assist? Do they know if the funds are successfully spent? Do the organizations know if their projects reach their disability inclusion targets? And what are the possible barriers to the improved monitoring and tracking of disability inclusion? In addition, we draw on the literature to situate our findings in relation to other findings.

A shared understanding of what it means to track inclusion among staff at the implementation level is important for successful accountability and reporting to the donor communities. Sufficient and relevant communication between headquarters and local offices is an overall challenge for all organizations. A mutual process of synchronizing headquarters and local understandings of the use and purposes of the monitoring tools can improve the relevance of the tools, help implementation compliance with intentions, and inform analysts of any issues and limitations concerning the data emerging from the systems. Good tools for measuring disability inclusion will not produce good data if they are poorly suited to capturing information of local importance regarding disability inclusion, or if the staff on the ground do not know how to report data according to the expectations of those analyzing the data. Compromises between the importance of reporting on factors of local importance and the need for internationally comparable data are inevitable, but understanding the local information loss and the biases that result from such compromises will help inform data analysts in their reporting and interpretation.

Lack of baseline data

Multilateral organizations depend on staff and partners on the ground for collecting inclusion data according to intentions and plans. Local staff similarly depend on locally relevant tools and sufficient training to use these tools correctly. This mutually dependent relationship can produce a good monitoring system, but also one that can challenge the process. Local informants in the selected organizations shared that they mostly had insufficient knowledge of how to use the tools and indicators. Even where good tools were available, the lack of training was an obstacle to the collecting of good data on disability inclusion.

Both staff on the ground and at the headquarters level raised the need for more training and a better understanding of what should be monitored:

> To me, the main challenge is understanding what your baseline is. The other is to have a common understanding about what we are tracking. It is also understanding that results and impact can be different depending on circumstances, and to have the knowledge about what you are looking for.[37]

Without baseline data that adequately measures the conditions before the projects starts, it becomes difficult to measure the changes and impacts of a project.

Most informants at both the national and the headquarter levels of the organizations noted that the work toward improving the tracking of disability inclusion is a long-term project. A good process takes time to develop and to become internalized and requires ongoing qualified support from experts:

> So that capacity [of measuring inclusion] sometimes is lacking, and we have seen that the quality of data is usually increased when we have that kind of dedicated support across the organization [a data expert sent from the headquarter to support and qualify data entry locally]. We also have challenges when it comes to interpretation of the information. Sometimes, if somebody is not aware of what they are measuring, there can be potential for misinterpretation. This is especially critical since you know data is harvested across the organization. So, if you have somebody that really doesn't have their finger on that pulse, pulling something together, there is the potential for misinterpretation or pulling it in in a way that misrepresents the picture. So [it] is really about quality assurance and monitoring.[38]

Investment in the follow up and training of staff in the field demands an allocation of funding and taking a long-term perspective. This observation is in line with a recent report by Itcovitz and van Kesteren (2020), which strongly recommended broadening the understanding of inclusive education and strengthening disability data collection and usage. They argue that an increased understanding of effective change starts by having the right data. In our discussions, we found that local staff were not only insufficiently trained in how to use the monitoring tools but were also unfamiliar with the very strategies for disability inclusion of their own organization. A few respondents asked us to share such documents with them after we had finished the interview. That designated staff did not have this information underscores the communication challenges in the organizations and possibly also the time and capacity constraints that, in the absence of further incentives, do not encourage prioritizing investing time in learning the disability policy and practices of their own organization.

The twin-track approach: Inclusive versus targeted programs

This report presupposes that an increased access to data can increase the accountability and efficiency of disability inclusion. As the strategic focus increasingly reflects the shift from a medical to a social and human-rights-based approach to disability, accountability in programming must also change from simply counting the disabled recipients of handouts and training. Within the new paradigm of the more mainstreaming of disability inclusion, with its stronger focus on universal designs and the

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[37] Interview with a disability inclusion expert, November 2021.
[38] Interview with a disability inclusion expert, December 2021.

removal of barriers for disabled persons in all sectors, traditional counting and measuring approaches fall short. Mainstreaming approaches require more and different data to measure if disabled persons experience barriers as lowered, and exclusion mechanisms as weakened, and if they indeed participate alongside the thousands of non-disabled participants that may be targeted by mainstream policy and programs. One respondent noted:

> It is easier to track when we have targeted projects, because we know how many people we set out to address [...]. The complexity arises when you have a larger project that doesn't have specific [disabled] beneficiaries identified. This is a dilemma for development for many years – it is the same for gender. So, we have to be much more explicit in mainstream projects about how we are going to track disability inclusion.[39]

These challenges will remain, because there has been a shift away from direct service provision (mainly in the health sector) toward the institutional capacity development of duty bearers (mainly in the education sector); that is, away from targeting projects toward inclusive projects. Thus, a combination of mainstreaming and targeted programs is still the most common strategy for the organizations.

Another ongoing shift is toward the donor funding of large multilateral programs and global processes, with a reduced share of funds earmarked for the national-level empowerment of rights holders, local DPO capacity building, and civil society capacity development (Larsson & Nilsson, 2021).

There are good intentions behind the twin-track programming approach, as well as good intentions and commitment for tracking disability inclusion. The low numbers of persons with disabilities reported as targeted and reached will not necessarily mirror the actual number of people who have benefited from and experienced positive impacts from mainstream programming.[40] However, the low numbers found for disability-inclusive activities in reports may suggest that the available tracking systems are yet not capable of capturing and communicating such impacts. As of today, the tracking of disability inclusion still faces too many challenges to be labeled successful and transparent to the donor communities. One informant stressed the need to develop additional forms of feedback mechanisms, such as data collected by qualitative methods and through dialogue, to better inform the donor community of the impact of their funding.[41] Mainstreaming such alternative methods for tracking impacts could be the next big challenge on the accountability agenda.

3.2 Experiences with monitoring and tracking

The challenges of quantifying the number of people reached and the changes obtained by interventions have implications for how donor investments are accounted for. In the next paragraphs, we therefore discuss some obstacles to successful monitoring as experienced by the informants.

Experiences of using the OECD-DAC marker

Norway started using the OECD-DAC marker for disability inclusion for its development aid from 2018, despite it not being mandatory for non-EU members. In this

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[39] Interview with a disability inclusion expert, November 2021.
[40] Interview with a disability inclusion expert, December 2021.
[41] Interview with a disability inclusion expert, December 2021.

section, we draw on information from a recent evaluation of Norway's effort to promote disability inclusion through aid funding in the decade from 2010 to 2019. The experience helps exemplify how challenging the feedback mechanisms can be for monitoring the inclusion of persons with disabilities.

Larsson and Nilsson (2021) calculated disbursements to disability as a share of the total Norwegian aid. In 2019, the targeted disbursements nearly doubled from around 0.34 percent to 0.63 percent of the aid budget. The disbursements to inclusive initiatives, in the sense that disabled persons had been included and benefited from a project alongside non-disabled persons, increased between 2013 and 2015 from around 0.7 percent to 2.8 percent of the aid budget, and has since remained at the same level (Larsson & Nilsson, 2021:25). In other words, for 97 percent of the Norwegian development assistance, one cannot document that disabled persons were included.

Walton (2020) used a keyword approach to identify international aid projects intended for disability inclusion from some key donors reporting on the OECD-DAC disability marker. The study compared the keyword approach to the first report on the OECD-DAC disability marker in 2020 (reporting from 2018). It showed that the addition of this marker represents a critical advancement in ensuring better data on disability inclusion in development, despite its weakness in terms of being voluntarily applied by donors and the lack of independent quality assurance on whether the project is disability inclusive or not.

The key findings from Walton's analysis are in line with the Norad evaluation report, which found that aid projects including persons with disabilities made up less than 2 percent of all international aid between 2014 and 2018. When calculating funding, disability inclusion totaled USD 3.2 billion between 2014 and 2018, representing less than 0.5 percent of all international aid, equivalent to USD 1 per person with disabilities in developing economies (Walton, 2020).

As the OECD-DAC marker only addresses the intentions of disability inclusion in plans, it must be combined with the reporting toward results frameworks to be able to say anything about the actual impact and how activities benefited any persons with disabilities; that is, the intentions in the plans must be supplemented with information on the money spent and the results achieved and included in the reporting. The marker alone does not produce such accountability.

One informant further discussed how the marker could be vulnerable to exploitation. For example, if disability inclusion is a criterion for access to funds, an applicant could just tick this box, without any real disability inclusion substance in the project. Such challenges put further demands on a donor's evaluation of plans and proposals.[42] This weakness might be part of the reason for the multilateral organizations' skepticism toward the marker as a good and comprehensive tool for tracking disability inclusion. There is thus a need to ask what it takes to obtain disability inclusion. Adding ramps to school buildings will not change access for other disabled children than wheelchair users, and even this group may not be able to access the schools unless the toilet facilities are also improved. So, counting ramps alone may not imply actual inclusion.

Experiences with the Washington Group questions

The Washington Group questions, presented in Chapter 2, identify persons with disabilities in censuses and national household surveys and can be used to assess the prevalence of persons with disabilities for more limited populations as well. The

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[42] Interview with a disability expert, December 2021.

World Bank supported the development of the Washington Group questions and is now aiming to mainstream them into all censuses and household surveys it funds. An informant said that the biggest challenge to tracking inclusion is to have a common understanding of the numbers of persons with disabilities and then to identify to what extent this group is included in activities, society, and all aspects of life. When used in standard national surveys, the Washington Group questions can facilitate the first, but not the latter. The Washington Group questions can measure the prevalence of disability in a population, but generally, the questions cannot measure inclusion.

There are other challenges with the Washington Group questions. Because the prevalence of persons with disabilities is relatively low, large survey samples are needed produce reliable data on the prevalence of disabilities in a particular age cohort, like in school-aged children. Second, if there is a need to find information about one particular functional variation, like in school-aged children with a visual impairment, the sample needs to be even bigger because each group is relatively small. Third, in household surveys, the enumerator would usually only gather information from one person in the household, often the household head. This person will not always provide accurate information on how well one among the potentially many household children see or walk without problems, or how well they can remember. Finally, some of the questions may be sensitive in local contexts and may lead respondents to evaluate and report inaccurate on the levels of functioning.

The Key Informant Method, developed by the International Center for Evidence in Disability under the London School of Hygiene and Tropical Medicine, aims to reduce some of the challenges listed here by using the Washington Group short set of questions and the Child Functioning Module in a two-step operation, where local key informants from all survey clusters are first trained to recognize and list children with disabilities before the entry of survey teams. The enumerators then use the Child Functioning Module for screening the children listed (Banks et al., 2021). The Key Informant Method is particularly suitable for identifying larger numbers of disabled persons within a limited geographical area, like a refugee camp. When used in a target area, the Washington Group short set of questions and the Child Functioning Module can be used to address prevalence, but also to help assess to what extent disabled persons are benefiting from the programs they are eligible for, either because they are in the specific target group for an activity, or because the activity is meant to be inclusive.

Disability-inclusive development aims to identify exclusion mechanisms and lift the barriers to inclusion for disabled persons. The more recent Washington Group module on inclusive education was designed to help in this process.

UNICEF has worked relentlessly in favor of the use of the Washington Group short set of questions and the Child Functioning Module in the countries where they work and, consequently, the number of countries using the Child Functioning Module is slowly increasing. Nineteen (out of 190) UNICEF-supported countries used the Washington Group Questions on Child Functioning in 2019 (FCDO/IDA, 2021).[43] The improved data on disability in children have made it possible for UNICEF to report in greater detail on the prevalence of various aspects of disability in children, and how disability is associated with other variables, such as nutrition, education, and poverty (UNICEF, 2021a).

UNHCR have used a module on disability in its registering system since early 2000, as part of its codes to identify vulnerable persons eligible for additional support.

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[43] Surveys are available at https://mics.unicef.org/surveys.

There are 71 codes, of which 11 are more frequently used, with 'disability' as one of them. Yet, these codes produce very low estimates on persons with disabilities among refugees. The codes used several impairment categories followed by a short description. An internal review revealed that registration officers relied on their perceptions to identify persons with disabilities and registered only what they could see. UNHCR then approached the Washington Group to discuss how its questions could be used in humanitarian action. From July 2021, UNHCR has replaced its earlier method to identify persons with disabilities and started to use the Washington Group questions in the registration interviews to map persons with disabilities among the refugees. It is now using both the Short Set of Questions and the Child Functioning Module in this process.[44]

Experiences with inSight

Disability inclusion is part of UNICEF's Strategic Plan, which includes several indicators with a disability tag. By introducing the Child Functioning Module in household surveys in cooperation countries, UNICEF has estimated that the number of children with disabilities stands at around 240 million (UNICEF, 2021; UNICEF 2021a). For 2020, UNICEF reports that it had reached 2.2 million children with disabilities through various programs and activities, i.e., less than one percent of all children with disabilities. This finding is in accordance with the findings of Walton (2020) and Larsen & Nilsson, (2021) discussed above. Thus, according to the tracking systems currently available, few children with disabilities are documented to be included in development and humanitarian projects.

Although a common or comparative tracking system across all multilateral organizations could be a gold standard for the documentation of findings, this faces several challenges because of the different roles of the multilateral organizations and the very different contexts in which they operate. Each organization has a different task, mandate, and program implementation. People across the organizations operationalize disability inclusion differently, influenced by their respective field of operation. For instance, a road, a school, and legal reform require different considerations on how to best involve disabled persons affected by the intervention. This might not be feasible, cost effective, or even meaningful to demand, as inclusion in education and in a road-construction program can mean very different things. This could be a worthwhile subject for further analysis in future research.

At the more technical level, UNICEF experts experienced that one of the challenges of operating the system was due to local staff having insufficient competence of the strategic project plans and planned activities. This can make it difficult for them to enter appropriate codes into the system. One of the informants in a country office asked:

> Is it sufficient to say we had a conversation with disabled people and then we can tick the box, or are we ensuring that it remains a systemic part of the work we are doing? It is easier to track when we have targeted projects, because we know how many people we set out to address [...] The complexity arises when you have a larger project that doesn't have specific beneficiaries identified.[45]

Informants indicated that to complete their duty toward the documentation, they often just enter something because the system requires it. UNICEF is aware of these

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[44] Interviews with disability inclusion experts. November and December 2021.
[45] Interview with a disability inclusion expert, November 2021.

challenges in the field, and aims to mitigate this in three ways: First, to put more emphasis on training in the use of the monitoring system in its next strategic plan (2022–2025); second, to assign focal points to assist staff in using the monitoring system correctly; third, to develop 'artificial intelligence' that can recommend the right choices to be entered into the system, based on project information and results.[46]

3.3 Knowledge on monitoring and tracking

The adequacy of the tools and the knowledge about how to use the tools are interrelated. Good tools alone are not sufficient if staff do not enter the intended information into the monitoring systems. In this section, we continue to describe some of the practical challenges experienced by the informants. Many of the informants described working under challenging conditions with heavy workloads that can easily deflect attention away from the monitoring and reporting tasks. One of the informants expressed despair over the vast number of challenges confronting those who interact with disabled persons in poor contexts and said:

> [W]hen we are doing this monitoring, there is a big challenge. The first is, there is not a lot of capacity in the schools, it is a lot of need to improve the learning environment of these schools. It is old schools, not too much equipment [...] the main challenge is the lack of resources to improve the school and the learning environment for this specific group. Those who are blind need a specific material for learning. Sometimes it is a lack of this. And some children want to learn more, but there is a lack of resources for this.[47]

Being confronted with such dire situations, local staff often feel compelled to prioritize helping the target group to meet their basic needs instead of spending time on the monitoring of inclusion. A headquarters informant declined to guide the researchers toward country level staff, arguing that they were already overwhelmed by requests from external interests, and at least until they finished the end-of-year reporting, this informant felt they could not put further workload on local staff. More knowledge is clearly needed. Nevertheless, meeting increased demands for documentation requires a system that is simple and accessible enough to not prevent staff from attending to other important duties.

Need for training

One of the main conclusions in the 2021 progress report on the UN Disability Strategy is that there is an unmet need for more knowledge about disability inclusion (United Nations, 2020b). This knowledge gap was a recurrent theme in our interviews with informants at both headquarters and at the local offices. One of the local informants said:

> Right, so I think we need better understanding of what disability is and what is meant by inclusion [... then] I think that the focus is getting more evident and strengthened. And when you get more insights, the sector also becomes more obliged to do things in a certain way. When we have roundtable discussions, we see how different the perspectives are on what disability and inclusion

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[46] Interview with UNICEF headquarter staff, December 2021.
[47] Interview with local field staff, December 2021.

is. You realize there is a knowledge gap. And when you can see that at sector level, what can you expect down there? And at school level, the system is giving teachers a very basic knowledge on inclusion. So, they will not know how to handle, or even to identify if a child has a challenge, sometimes not even the parents themselves [know].[48]

The lack of understanding of what inclusion entails, as described in this quote, will inevitably impact on how the inclusion of disabled persons in programs and projects is measured and reported on. It has further consequences for the quality of data collected and can lead to a high risk of a misinterpretation of the data taken out of the monitoring systems by analysts. UNICEF experts were concerned that such challenges were weakening their monitoring system. They suggest this should be mitigated through more training and guidance, as well as by dispatching support staff to improve the data quality.[49]

Despite systemic weaknesses, staff expressed that they try their best to work for disability inclusion, within the knowledge and time constraints present. Beyond what is captured by the monitoring systems, substantial disability-inclusive efforts appear to be carried out on the ground by UNICEF, UNHCR, and World Bank staff as well as by social workers, teachers, engineers, and other professionals affiliated with their partner organizations and institutions. When efforts happen outside and beyond easily accessible reporting frameworks, underreporting results. Many of these initiatives are interacting with local knowledge, in exchanges and consultations, in ways that help facilitate more practical operations to become implementable, in line with their intentions of including persons with disabilities. The findings of how local staff also engage in difficult situations by spending their own money on imminent needs is often under-communicated. This type of local involvement in the gray zone between work and private commitment is done at the discretion of local staff; and the direct or indirect effects of this involvement might be influenced by their values, knowledge, and spontaneous interpretation of the situation at hand. For example, staff with insufficient knowledge on disability inclusion may inadvertently promote the participation of persons with certain functional variations over others. When knowledge is constrained and the space for discretionary power is large, groups perceived as more easily 'includable', e.g., through the construction of a ramp, may be promoted over what could be perceived as more 'challenging' groups, often persons with cognitive and neurodevelopmental disabilities. The success stories, as well as failures, resulting from such processes are difficult to account for, and may not reach the central organization and donors, nor appear in reports.

Our local informants also addressed the challenge of having to relate to different tracking systems, including systems within the implementing organizations and others between the implementing organizations and the governments they work with. Not all governments address disability inclusion in their systems, further complicating reporting on efforts in this area. The number of actors engaging with disability inclusion in a country can be high, and each government must meet the challenge of relating to a complex mix of actors engaging in different areas of disability inclusion, and with groups with different functional variations, thus requiring a variety of indicators. If a government and the implementing organizations do not share the same understanding of disability and disability inclusion, or do not share priorities within the field, implementation and monitoring become equally difficult.

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[48] Interview with local field staff, December 2021.
[49] Interview with a disability inclusion expert, December 2021.

In competence building efforts, staff expressed a lack of understanding for how dire the situations are across many countries. The field staff interviewed mentioned limited access to digital technology, a lack of technical knowledge, and a lack of shared understandings and definitions. Different staff highlighted widely different concerns, perhaps reflecting their different professional backgrounds and different practical needs. One addressed the understanding of the disability concept from a more legal perspective, understood in terms of a person's eligibility status to public welfare services and support programs, and said:

> The Washington questions are identifying persons that are at risk of facing restrictions in [/exclusion from] participation, and therefor may have a disability. It is not a disability assessment, which is usually legally defined at the national level. It is no globally agreed method on disability assessment. They are conducted nationally and there are different processes in every country.[50]

This quote brings up an important issue: the legal aspect of disability. Such legal classifications are often more closely related to the classical medical definition of impairment and while instrumentally useful, they belong to a different paradigm than the value-based definitions referred to in most charters and conventions.

The impression from our interviews was that local field staff are eager to learn more about disability and inclusion. Some said they had agreed to the interview primarily to get an opportunity to learn, rather than to share their experience (nevertheless, they communicated many interesting observations to us). At the end of the interview, some asked us to share key documents on disability inclusion, including material from their own organization. We interpret this as an expression of interest for, and commitment to, improving their work on disability inclusion, the need for capacity building to achieve that, and the interest in improving the tracking of results.

Given time and other capacity constraints, organizational incentives may be needed to motivate field staff to spend the time needed on developing better skills in disability inclusion tracking. However, busy fieldworkers may perceive such tasks as yet an additional task on top of all the other obligations their job-description entails. One of the informants explained this as a need to 'revoke the capacity of our own staff and the district staff of our partners to understand inclusion'.[51]

Ethical dilemmas and contextual factors

Working on disability and inclusion can involve several ethical dilemmas, and such dilemmas are for practical reasons more often experienced when confronted with real-life situations in the field. We refer to the two unresolved dilemmas in the inclusive education debate as: first, where to draw the line for who cannot be included in a project, and second, how to prioritize between participants within the ever-present financial constraints. Both these dilemmas were exemplified in a story from one of the field officers we interviewed:

> Some years back [...] there was a little child that had cerebral palsy. And as I was going to [the] village, I was already talking with his grandmother. He was living with [his] grandmother. Then I slowly understood that this child was supposed to die. He was taken away from his mother and given to his

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[50] Interview with a disability inclusion expert, December 2021.
[51] Interview, headquarters staff, November 2021.

grandmother, and he was supposed to die, and he was refusing to die. So I was supporting him personally. You know I was bringing some food when I was coming to [the] village. The father who was working in [a neighboring country] called me one day and said thank you, Sir, for what you have been doing. I have heard about it, but I need to explain to you we cannot support this child because he is taking away all the resources from a whole family. I am the only one gaining some resources; I cannot put all those resources only on him, and leave his brothers and sisters, and also my parents. All these things you have to understand in the context surrounding those children.[52]

Ethical dilemmas lead to practical priorities and solutions that reflect the available resources, and these can often conflict with the normative framework provided by the CRPD, the organizational strategy plans, and the value statements from the donor communities. When the tough choices are left to the discretionary power of local staff, it can create conflicts with the expectations expressed in monitoring tools. If real-life priority requirements remain unresolved, the ethical dilemmas are passed on to the local staff and practitioners. The question remains how to be open to and invite the honest reporting of the choices being made, and the rationale these choices were rooted in. A monitoring and tracking system should not avoid documenting how norms are negotiated against social and financial constraints in real-life situations. It should, on the contrary, aim to document and learn from them.

Challenges vary across contexts. Whereas the country staff interviews in this study were all conducted with staff working in Africa, a study from the Philippines found attitudes toward inclusive education to be generally positive (Gallo-Toong et al., 2020), while studies from Nigeria have found different attitudes toward inclusive classrooms between urban and rural areas (Tomori, 2020; Fakolade et al., 2017). The local variations often underscore how both programming and monitoring must be informed also from the local contexts they take place within. Detailed local knowledge is key to developing efficient monitoring programs, and the most adequate local knowledge about disability is usually found within the organizations of disabled persons in each locality.

3.4 Stigma of physical, cognitive, and neurodevelopmental disability

Stigma related to disability was a recurrent theme in many of our interviews, particularly at the local level in both Niger and Uganda. Stigma influences identification for accountability purposes in several ways. It represents a social and physical mark, has a cause and a purpose, and is socially reproduced through processes of exclusion. Stigma is at times deliberately produced and assigned. It represents a political tool for elites in different societies to socially legitimize the discrimination, ill-treatment, and abandonment of responsibility for certain groups of individuals (Tyler, 2021). In modern welfare states, the increasing casting of persons on disability benefits as 'welfare cheats'; has marked a transition from traditional rights-based welfare policies into liberalist attempts to cut down on social expenditures. The disability stigma relates to dependency, with visual bodily impairment marking the individual as a burden. In countries with few public welfare arrangements, disabled persons remain the responsibility of their families, where social stigma helps legitimize practices such as the ethical dilemma with the boy who was left to die with his grandmother in the

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[52] Interview with local field staff, December 2021.

previous section. The notion of disability as a burden is not uncommonly rationalized within spiritual paradigms, such as a divine punishment, a test of faith, or as a type of hardship that may produce virtues, such as humbleness and modesty. The way disability is perceived in a community, or by implementing actors, can have importance for the identification, monitoring, and tracking disability inclusion.

The role of stigma in tracking inclusion

For accountability, and especially identification purposes, stigma and processes of stigmatization can be both helpful and a challenge. Visible disability can be easily detectable, such as difficulties walking or seeing. Efforts to conceal less visible disabilities can be harder to track as they can go unnoticed in certain public contexts, be misunderstood for bad behavior, or may be hidden away to avoid bullying and aggression. The challenges with identification can have implications for the tracking even of persons who are included in interventions, as some may go under the radar and remain unaccounted for in reporting systems. Among the latter we typically find some neurodevelopmental disabilities, and some children with hearing impairments. Local variations in the expressions and consequences of being stigmatized affect how many and which functional groups are at risk of becoming unaccounted for.

Stigma literally means a mark on a body and is socially interpreted as a sign of inferiority. Disability and stigma remain an under-researched topic in many development settings, but both existing stigma and the changes in stigma that result from social incentives are relevant to identification issues and tracking efforts. While stigma in places where people fluctuate in and out of critical poverty can even see a person left to die under constraint, there are also many examples of social incentives that counteract such practices. In some religions, the disabled may be the prioritized recipients of charity obligations, while in other places, beggars with disabilities may simply be chosen over beggars with no apparent reason to not work. In welfare sates with disability grants, the non-disabled may falsely claim to be disabled to access the grant. For identification and inclusion purposes, both underreporting and overreporting may occur from these types of processes. A literature review by Rohwerder (2018) suggests that the evidence base of stigma interventions is weak, and that despite several reported interventions and programs implemented to reduce stigma there is still limited evidence of the actual functionality of these programs.

Aiming to avoid stigma, while simultaneously dodging issues related to variations of local disability definitions, the Washington Group questions address functioning rather than disability. Years of research and experience led to the formulation of questions that are easy to answer and serve to identify the likelihood of a disability without using the word 'disabled'. Despite such good intentions though, it can be difficult to avoid the endemic challenge of stigma in the field. One of our informants commented: '[we] are not trying to fool anybody here, so you can ask Washington Group questions, and somebody could say to the enumerator: are you asking if I am disabled?'[53]

A double challenge relates to the identification and inclusion of persons with cognitive and neurodevelopmental disabilities. First, their functional variation may be more difficult to recognize and correctly identify; and second, most disability initiatives target persons with known effective interventions, e.g., ramps are constructed so that wheelchair users can enter, and teachers are educated in sign or braille. Very few well-documented, easily acquired, low-cost programs currently exist for the

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[53] Interview with a disability inclusion expert, December 2021.

successful inclusion of persons with cognitive and neurodevelopmental disabilities. Therefore, programmers tend not to look for them. Adding to this is that they are rarely themselves organized, and they are often underrepresented in the national DPOs, leaving them with few advocates to push the agenda for their equal inclusion rights. Training among teachers in developing countries on how to recognize and include children with these types of disabilities is generally lacking. Even when properly trained to identify and include children with various disabilities, this group may still be hidden and kept away from school due to the attitudes among parents:

> Disability is being seen as a punishment. It is something that is shameful. So, for parents, if your child is born — either it is blind, he cannot move around, or [has] cerebral palsy, for example. This is perceived as a kind of punishment. You must have done wrong in the past for God to punish you and give you such a child. So, work with their parents, that [is] our first support systems for their children, the shame that is attached to it. It also comes with an added challenge for the parents because those children with specific needs, need more resources in order to properly support them. And sometimes those resources are lacking. So, you have shame.[54]

Frameworks for universal access to schools tend to be limited to more visible accommodations for visible impairments, such as constructing ramps for wheelchairs and distributing braille books to children with visual impairments. Such interventions are also easy to track by counting. Whereas a program may tick the box for disability inclusion if the schools constructed are equipped with ramps, the real indication of inclusivity would be to see if children with wheelchairs attend the school and learn there: A ramp alone is a poor indication of inclusion if the road to school is muddy and thus inaccessible throughout the rainy months. Including children with cognitive and neurodevelopmental functional variations in a classroom may require accommodation for different learning styles, and success may depend on individual adaptation through a process of trial and failure. In countries with a child/teacher ratio approaching 50:1, this is clearly challenging when the organizations are not yet able to offer well-defined models that can be thought through, staffed, and funded. When not identified, children with cognitive and neurodevelopmental disabilities will most likely drop out of school or face expulsion due to what may appear to be behavioral issues. Alternatively, stigma may see such children labeled with cruel terms such as 'idiot', 'dummy', 'fool', 'crazy', 'savage', further limiting their inclusion. Failing to identify and promote the rights of such stigmatized groups can easily become an excuse for the non-inclusion of a group with functional variations that we do not know how to accommodate in interventions in the first place. Informants frequently supported this notion that disability inclusion is *more challenging* for children with so-called invisible disabilities.

Stigma, disability, and the brutality of poverty

The challenges of tracking the inclusion of persons with cognitive and neurodevelopmental disabilities are complex. While some will be hidden away by their families due to shame or to protect them from bullying and aggression from the outside community, others may be primarily perceived as dumb, weird, or purposefully behaving badly. The practice of blaming the disabled person for not behaving like others may be seen alone or together with narratives of shame and divine punishment, which are

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[54] Interview with local field staff, December 2021.

endemic in many development contexts. The stories influence not only the families involved but also the attitudes that are communicated in the disabled persons' local communities. Negative cultural and religious beliefs about the causes of disability can be associated with issues such as an ancestral curse, the actions of the parents (the mother in particular, especially during pregnancy), the actions of the disabled person, and supranational demons and spirits, as well as witchcraft and God's punishment (Rohwerder, 2018).

This narrative of shame and burden might be mitigated if the economic burden attached to having a disabled family member was decreased. In a discussion about the role of stigma in a context where disability was one factor, and which could lead to increased access to financial aid, one of the local staff responded:

> If you come into a community and you say we are thinking about supporting households who have a child with specific needs. Then yes, these people [with disabilities] are going to double [...] So sometimes it becomes very complicated. Yes, the stigma is there, but not so much that even if you provide aid, people will be hiding their children? No. It comes to a level whereby in order to get honest answers, sometimes it is even better to not say we are coming to support to help, because then you are going to have very surprising figures coming up.[55]

The processes of stigmatization may be explained as the products of traditional superstitious beliefs, but often also seem to have a practical rationale driven by available opportunities and limitations. Stigmatizing, othering, and expelling a non-productive family member in a context of critical constraint is a rational choice left to many facing the brutal realities of endemic poverty. When the food is scarce, the productive family members eat first, because if they die, everybody dies. Yet, if new resources are made available due to the presence of a disabled family member, this might change the coping strategies of a household and alter the processes of exclusion and give less value to stigmatization. Not only individuals, but entire families risk being stigmatized and excluded. A representative of a DPO told us:

> An association decided to give a family of disabled people an amount of soap. The intention was that they could sell the soap and make an income. But the people in the village came to the house and they all asked to be given some soap, so now all the soap was gone. But that was not a bad thing. Because now people in the village owe something to this family. And they know, now, that this can happen again, that people give things to this family because they are disabled. So, they will no longer exclude and disassociate from this family.[56]

This suggests that economic incentives can be efficient in the fight against stigma and exclusion, whereas the more traditional awareness campaigns, those that try fighting the so-called harmful traditional beliefs, may just not have taken seriously that behind many such beliefs lie good reasons.

The practice of hiding disabled family members influences the monitoring and tracking of inclusion simply because a person cannot be included if they are not acknowledged in the first place. This was exemplified by one of the informants:

> There are more stigmas attached to children with learning disabilities than children with physical disabilities. Just to give you an idea. We were conducting

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[55] Interview with local field staff, December 2021.
[56] Interview with a DPO leader, January 2022.

a barriers study [...]. When we went to villages and asked the parents about children in the households. We found out that a good chunk of the parents was actually not listing children with learning disabilities or mental disability among their children. So, when we ask them, do you have such a child? They will say no. Then you remind them, because sometimes you see a child sitting alone under a tree, and we ask about him. They say, oh yes, you are right, he is there.[57]

Thus, this is calling for interventions that can provide tools to probe for the inclusion of elusive populations. There are some existing techniques in survey methodologies that can enquire about gaps between listed pregnancies and the children accounted for by the parents that may be transferable to this type of context. If households would be tracked by the number of children born, this might provide access to disabled children who would otherwise be left out. Though, situations like the fieldworker cited above presented might appear when social workers use more qualitative approaches in a village setting, particularly for sensitive topics attached with stigma.

Good intentions versus the accountability of inclusion

Several stakeholders addressed the lack of knowledge about different learning styles among teachers as a prevalent challenge, multiplying the difficulties among persons with cognitive and neurodevelopmental disabilities. Coupled with cultural beliefs and the lack of knowledge, these issues make cognitively and neurodevelopmentally disabled persons the most vulnerable among the vulnerable. One of the informants on the ground elaborated on this challenge by explaining how:

... it has been one of the most challenging components of our activities with inclusive education. That is the lack of teachers that can properly support children with learning disabilities. If you put them into inclusive classes, which is a good thing for them [and] for integration and awareness among other children. The problem is teachers perceive[ing] those children as slowing down the whole class. And we have been having much more challenges talking with the teachers. You might find teachers that are willing to work with children with locomotion disabilities, will be very much reluctant to work with students with learning disabilities. That is because they need extra attention and extra care. And those teachers are already stressed. They are not having, as you can imagine, easy conditions. So, it's complicated. There is a special stigma that is attached to them [...] and if it's a girl, it's another story. And we don't have this kind of policies of strategy and distinction for learning disability.[58]

Inclusion is difficult in this context and so is the ability to monitor and track.

The lack of tracking of inclusion does not mean that there is no inclusion. The informants demonstrated good intentions to implement and mainstream long-term approaches to challenge and influence the social norms they identify as obstacles to inclusion. Werner and Scior (2016) provided an overview of interventions aimed at reducing stigma among persons with intellectual disability and reflected on how the interventions focused mainly on raising awareness rather than actively changing behavior. The same authors wrote that the evidence they found on the existing

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[57] Interview with local field staff, December 2021.
[58] Interview with local field staff, December 2021.

interventions was rather thin, and that there is a demand for both further research and interventions. Our informants suggested a more practical approach could be to focus on economic incentives to empower families with a disabled household member, and in that way, they could indirectly reduce stigma.

Our informants in Niger and Uganda confirmed an awareness of the challenges, as well as offered some ideas of how to tackle stigma in their interventions:

> There is a lot of misunderstanding, because the parents have never been to school, they may live far from [civilization], they do not know anything about the basics. Sometimes they do not know to read and write. So, the first challenge is to convince them that children with disability can also do things that normal children can do. To do this sensibilization is not one-day work, this is permanent work we have to do. It takes time to change their attitude. There is also a cultural constraint. Some people may say he has a disability because of this or that, they use to have this kind of causes to disability, and we say no, it has natural causes. You should not be victimized because they are like this. So, we convince some, because it is no need to stigmatize these children.'[59]

The leader of a DPO, himself living with a visual impairment, illustrated the power of example in his country, where he had traveled from place to place and given speeches, and now has a special slot on national TV. He is convinced that for disabled persons and their families in the districts to see educated, eloquent disabled persons like him, taking, being listened to, opened their eyes, especially to the potential in their own disabled children. Demonstrating the possibilities and sharing knowledge about the ability and potential of persons with disabilities are important, and, accompanied by the enforcement of anti-discrimination legislation, can help set new normative standards. Yet there is little evidence that moralist-style anti-stigma 'sensitization' campaigns will work unless the causes of stigma are also addressed and supported by economic incentives and law enforcement.

Changing the attitudes toward and the roles of disabled persons is still a process that has just begun, but may be moving in a positive direction. One informant said:

> It is a very long process because we are talking about behavior change. We are talking about adaptation. We are talking about inclusion, so it is very difficult. But thanks to flexible donors […] we can start and try new things and even have the opportunity, I would call it opportunity to fail - and say that we tried this, and it didn't work out.[60]

People at the top as well as at the ground level reported an appreciation of the ability to do long-term work with their disability populations. They described interventions that were not straightforward, and some programs that would probably even fail in their attempts at new and innovative ways to include children with disabilities in a setting challenged by cultural stigma, lack of priority from the government, and low budgets dedicated to reducing stigma. Still, their dedication was strong.

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[59] Interview with local field staff, December 2021
[60] Interview with a DPO leader, January 2022

4 Conclusion

Efforts to track disability inclusion have progressed since the first Global Disability Summit in London in 2018 (GDS18). New polices and frameworks have been followed up by the continued development of management and monitoring systems, which also allows tracking efforts to improve the rights, opportunities, and conditions of persons with disabilities. Key actors working with and for persons with disabilities have responded to calls for such changes. There is now a need to ensure that these systems are refined and exploited in ways that maximize transparency on how funds intended to benefit disabled persons are spent. There is a need for enhanced training and capacity strengthening for the correct and systematic entry of data into systems, for extracting data from such systems, and for understanding and analyzing that data, which must be prioritized to benefit from the investments made in tracking systems. For that, staff time must be clearly allocated toward such efforts across the organizations.

Staff from the three multilateral organizations who helped inform this study expressed a strong commitment to disability inclusion. They also shared a common motivation for improving the performance of their management and monitoring systems, and for better documenting how funding for disability inclusion is used. However, several challenges remain. The tracking of efforts so far suggests that only a marginal share of development funds is today tagged or in other ways registered as disability inclusive. Our investigation indicated that only limited information exists on whether funding intended for disabled persons and inclusive programming is spent in line with intentions. In that way, there appears to be a gap between the good intentions expressed by the organizations' headquarters and the reality on the ground.

A remaining challenge for all organizations is to document what funding has led to increased participation, and for how many, who, and with what benefits for those included in the programs. What can be extorted from existing systems today is not sufficiently informative to help stakeholders to make well-informed choices on where to most efficiently allocate the available funding to meet the rights to inclusion of persons with disabilities. Systems and practice need strengthening for all the good intentions to translate into results.

One finding is that local offices are overwhelmed with their workload, including what appears to be a steadily increasing amount of administrative and reporting responsibilities. One consequence can be inaccurate documentation on the ground, which can influence the quality of the aggregated data for disability inclusion.

This report also suggests that staff are insufficiently trained on how to identify and document disability inclusion. In addition, local knowledge appears to have been underexplored in the development and implementation of programs for and monitoring of disability inclusion. The perhaps starkest expression of this was that amidst all the good intentions of inclusion, the feedback from a national DPO, which reported rarely being consulted by the multilateral organizations. When asked if the organization had been given an opportunity to use its right to influence decision-making processes concerning issues relating to persons with disabilities (CRPD Article 4), the

DPO leader told us that they had only once been invited to meet with UNICEF. On that occasion, they were *informed* about the organization's activities and plans, and the representative added: 'For the last two organizations, we are not informed at all of their activities in [our country]. So, you can imagine that, for your other questions, we really don't have an answer.'[61]

Local staff of multilateral organizations may find themselves trapped between headquarter guidelines and local communities, given little time and room to involve local DPOs and explore local variabilities in the conditions targeted and monitored. It can be a takeaway from this report that while disability inclusion is the primary goal, practicing the same in planning, implementing, monitoring programs and projects often appears to struggle with this ambition. By signing the Charter for Change at the Global Disability Summit in 2018, all the multinational organizations interviewed in this report committed to: 'Promote the leadership and diverse representation of all persons with disabilities to be front and center of change; as leaders, partners and advocates.' This includes the active involvement and close consultation of persons with disabilities of all ages. Walking that talk takes further commitment.

Our interviews highlighted some basic weaknesses even in the understanding of disability and what disability inclusion entails among the organizations' staff on the ground. Also, national statistics lack good baseline data on the aspects of life that are important to disabled persons, like education, employment, income, and exposure to violence. Often prevalence numbers are missing altogether. Adequate tools remain scarce to track the development in efforts to fight persistent exclusion mechanisms, those that keep disabled persons deprived and marginalized, through policy and action.

Good accountability mechanisms help development actors keep their eyes on the ball in their everyday activities and encounters. To further improve on developing meaningful tracking of funding and commitments intended to promote the inclusion of persons with disabilities, clearly the involvement of the organizations of disabled persons must be—to use a much-repeated concept in this report—*mainstreamed* at an entirely different level than they are today.

Succeeding on the disability agenda will depend on the organizations' ability and willingness to regain the momentum after the COVID-19 pandemic, which for the past two years has attracted staff and time away from other program areas.

We were pleased to learn that UNICEF has both the training of staff and the establishment of local focal points as key action points in its new strategic plan and are hopeful these steps will improve the use and hence output quality of their management and monitoring system, inSight. UNICEF has developed a comprehensive approach to monitoring and tracking disability inclusion. It might not be necessary for all organizations to develop similar tracking tools, but other multilateral organizations should take inspiration from this effort. The important thing is to develop tools that can help guide and improve performance on the types of disability inclusion that matter to disabled persons, and the ability to demonstrate their efforts and achievements to donors through reliable data.

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[61] Interview with a DPO leader, January 2022.

Recommendations

- Disability inclusion is a normative standard and indicates the direction for all future action from the multilateral organizations included in the present study. The organizations need to document that they are moving in that direction.
- What is not counted and measured is less likely to be done. The multilateral organizations should be held accountable for their concrete commitments made to the disability agenda. The tools to monitor and track such efforts should be tailored to reveal successes as well as failures.
- Successes, shortcomings, and failures to meet commitments should be regularly reported on in a way that places monitoring of the type of outcomes that matter to disabled persons center stage.
- The non-involvement, rare, or random involvement of DPOs in the planning and monitoring of investments in the disability agenda is in breach of the commitments made by the multilateral organizations, and must end. DPOs must, in ways that are meaningful to them, be invited to influence and even guide the national activities on disability inclusion and ensure that tracking helps document improvements in the areas that are most important to them.
- External social audits of the data entered large monitoring systems should be considered commissioned to ensure the reliability and accuracy of the data entered, and to help guide and motivate improvements. National DPOs should be involved in such audits.
- The multilateral organizations should consider increasing their systems' flexibility to better accommodate meaningful reporting from a variation of different local realties, influenced by the priorities of the local DPOs.
- Improved bottom-up information flows should help inform the staff responsible for data analysis.
- Staff overall need more training on their own organization's strategies on disability inclusion and monitoring.
- Training and better system management involve funding national offices and the willingness to place disability issues higher on the priority list, vis-à-vis other tasks and the obligations of staff.
- On the technical side, there still seems to be some way to go before good monitoring systems can address the most important questions: What programs succeed in meaningful inclusion, what programs do not, and how far are we from including people with disability in all mainstream programs?
- Disabled persons differ, and certain groups tend to fall behind. To comply with Article 8 in the Charter for Change, i.e., to put those furthest behind first, there must be an enhanced focus on monitoring and documenting the improved inclusion of persons with intellectual and neurodevelopmental impairments, who are systematically neglected even in disability-inclusive programming. In accordance with Article 8, a particular responsibility therefore rests on ensuring the identification of and needs assessment for persons with these types of functional variations, followed by the identification of and monitoring of indicators of importance to these groups.
- To help regain the momentum of the disability agenda after the COVID-19 pandemic.

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Tracking disability inclusion in multilateral organizations

This report investigates the developments and efforts to monitor inclusion of persons with disabilities in the programs and activities of UNHCR, UNICEF, and the World Bank in the years between the first and second Global Disability Summits (2018 and 2022). The report draws primarily on information from, and the experiences shared by, the staff of these three multilateral organizations. It asks if and how recent polices, guidelines, and accountability frameworks have led to improvement in the monitoring of disability inclusion. It describes some central tools used to track and monitor disability inclusion in development and humanitarian programs, including the Washington Group questionnaire modules, the OECD-DAC marker for disability inclusion, different strategies and accountability frameworks, and UNICEF's Program Performance Management System. The report discusses the three organizations' experiences with these tools, both at headquarter level and at local offices in Niger and Uganda.

Although this report finds certain progress regarding the monitoring of disability inclusion since the first Global Disability Summit, particularly on strategies and commitments, the findings discuss how the step from ambitions to documentation of successful disability inclusion continues to be limited. UNICEF was only able to track that 1 percent of estimated 240 million children with disabilities was included in its programs in 2020. UNHCR, limited to track its targeted efforts, could document that 0.5 percent of the estimated 12 million refugees with disabilities were included in its service and protection efforts. While the World Bank did not provide numbers documenting disability inclusion. The report discusses challenges of implementing good-quality management and monitoring systems and some of the reasons behind the low numbers documented.