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Advancing Disability-Inclusive Humanitarian Programming and Coordination in South Sudan

Institute for International Law of Peace and Armed Conflict (IFHV)
Ruhr University Bochum (RUB)

Leave No One Behind! Mainstreaming Disability in Global and Local Humanitarian Action in line with the *IASC Guidelines* on Inclusion – Phase 3

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Strategic Agenda

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Description: In 2023, despite immense challenges, a Trachoma Mass Drug Administration (MDA) campaign reached communities in Rubkona and Guit counties, Unity State, South Sudan. With floods persisting for a fourth consecutive year, many roads were impassable, forcing teams to rely on boats in some areas to distribute medication and access remote settlements.

This publication has been produced within the framework of the ‘Leave No One Behind! Mainstreaming Disability in Global and Local Humanitarian Action in line with the IASC Guidelines on Inclusion – Phase 3’ project, which is implemented jointly with Humanity & Inclusion (HI), Christian Blind Mission (CBM) and the Institute for International Law of Peace and Armed Conflict (IFHV) at Ruhr University Bochum. The project seeks to help international and local humanitarian actors implement the Inter-Agency Standing Committee’s (IASC) Guidelines on Inclusion by developing tools and capacities, providing localized technical support and increasing the evidence base through applied research and documentation of good practices. The project is implemented on a global level and in six countries of East and West Africa: Somalia and Somaliland, South Sudan, Uganda, Cameroon, Niger and Nigeria. The German Federal Foreign Office funds this project.

To safeguard academic standards, the authors of this paper, Abu Faisal Md. Khaled and Dennis Dijkzeul, have carried out this study independently. They are solely responsible for the contents of this report.

Acronyms

AAP	Accountability to affected population
AoR	Area of responsibility
CBM	Christian Blind Mission
CBPF	Country-based Pooled Funds
CEPO	Community Empowerment for Progress Organization
CERF	Central Emergency Response Fund
CRPD	Convention on the Rights of Persons with Disabilities
DITT	Disability-Inclusion Task Team
DRG	Disability Reference Group
FGD	Focus group discussion
GAM	Gender with Age Marker
GBV	Gender-based violence
GITT	Gender Inclusion Task Team
GPAA	Greater Pibor Administrative Area
HCT	Humanitarian Country Team
HI	Humanity & Inclusion (formerly known as Handicap International)
HNRP	Humanitarian Needs and Response Plan
HPC	Humanitarian Program Cycle
IASC	Inter-Agency Standing Committee
ICCG	Inter-Cluster Coordination Group
IDP	Internally displaced person
INGO	International non-governmental organization
IOM	International Organization for Migration
IPC	Integrated Food Security Phase Classification
KII	Key informant interviews
LFTW	Light for the World
LNOB	Leave no one behind
MHPSS	Mental Health and Psychosocial Support
MoU	Memorandum of understanding
NDIP	National Disability and Inclusion Policy
NGO	Non-governmental organization
NNGO	National non-governmental organization
NRC	Norwegian Refugee Council
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
OPD	Organization of persons with disabilities
OVCI	Organismo di Volontariato per la Cooperazione Internazionale (Voluntary Organization for International Cooperation)
SSAVI	South Sudan Association of the Visually Impaired

SSHF	South Sudan Humanitarian Fund
SSUPD	South Sudan Union of Persons with Disabilities
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
UNMISS	United Nations Mission in South Sudan
WASH	Water, sanitation and hygiene
WFP	World Food Programme
WG-SS	Washington Group Short Set of Questions
WHO	World Health Organization

Map of South Sudan

Note. From United Nations. (2011). Map No. 4450 Rev. 1.1. **https://www.un.org/geospatial/sites/www.un.org.geospatial/files/files/documents/2020/Apr/south_sudan_4450_r1.1_oct11_125.pdf**

Executive Summary

Disability inclusion in humanitarian action in South Sudan has made strides, but challenges remain in integrating it systematically into protection programming and coordination. This report examines how the *Inter-Agency Standing Committee (IASC) Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action* have been implemented, focusing on four 'must-do' actions. It identifies gaps and opportunities for improving disability inclusion in protection programming and coordination, and addresses the central research question: *How and to what extent have humanitarian organizations anchored disability inclusion in key protection programming and coordination, as recommended in the IASC Guidelines, and where do gaps remain?*

The *IASC Guidelines* provide a structured approach to advancing disability inclusion in humanitarian action through its four 'must-do' actions: promoting meaningful participation, removing barriers, building empowerment and capacity support, and monitoring inclusion using disaggregated data. These actions ensure that persons with disabilities are not just beneficiaries of humanitarian action but also active participants in shaping the activities that affect them.

Persons with disabilities in South Sudan face intersecting vulnerabilities, with limited access to humanitarian protection services, livelihood support and emergency assistance. In rural areas such as Pibor, delivering humanitarian protection services to the affected population – including persons with disabilities – is even more challenging. While the government's 2023 ratification of the Convention on the Rights of Persons with Disabilities (CRPD) marked progress, implementation challenges persist, and disability remains underrepresented in national policies, humanitarian programming and coordination.

Organizations of persons with disabilities (OPDs) play a crucial role in advocating for disability rights and inclusion, but their engagement in protection programming and coordination is limited. Although some OPDs actively participate in advocacy, many lack the technical capacity and funding to contribute meaningfully to protection programming and coordination. Despite growing efforts to promote meaningful participation, OPDs often perceive their engagement in the Humanitarian Program Cycle (HPC) as tokenistic rather than meaningful. Capacity-building efforts tend to be project-based and lack long-term investment.

Familiarity with the *IASC Guidelines* and its four 'must-do' actions varies among humanitarian actors. United Nations organizations and international humanitarian organizations, despite varying guidelines, generally recognize the importance of the four 'must-do' actions, and they integrate disability considerations into their protection programming and humanitarian coordination. Disability-focused international non-governmental organizations (INGOs) such as Humanity & Inclusion (HI), Christian Blind Mission (CBM), Light for the World (LFTW) and Volunteer Organization for International Cooperation (OVCI) play a key role in promoting the *IASC Guidelines*. However, at the local level, humanitarian workers and local non-governmental organizations (NGOs) are generally less familiar with these guidelines. This limited awareness impacts disability-inclusive protection programming and humanitarian coordination.

Although the Washington Group Short Set of Questions on Disability (WG-SS) has been integrated into some needs assessments and cluster tools, a gap remains in collecting and using comprehensive disability-disaggregated data. Although disability-related data is included in the Humanitarian Needs and Response Plan (HNRP) and rapid needs assessments, the lack of detailed disaggregation remains a major barrier to effective disability-inclusive protection programming.

The protection cluster is central to inclusive protection programming and coordination, but challenges remain in delivering adequate protection services for persons with disabilities. OPDs lack consistent representation in the protection cluster, limiting their ability to influence inter-agency protection programming and coordination. Disability-focused INGOs, while active in protection efforts, often serve as indirect advocates for disability inclusion; but they cannot replace the need for direct OPD representation. At the local level, coordination mechanisms vary in how they engage OPDs and informal groups of persons with disabilities. As a result, disability inclusion is often inadequately addressed in protection programming.

The Inter-Cluster Coordination Group (ICCG) has made efforts to mainstream disability as a cross-sectoral issue. However, the absence of disability-focused NGOs or OPDs in the ICCG limits the availability of technical expertise on disability in inter-cluster coordination. The Gender Inclusion Task Team (GITT) is actively working to integrate disability-inclusive approaches into humanitarian programming. However, its expertise is largely gender-focused, limiting its ability to support disability inclusion. The Technical Support Mechanism on Disability Inclusion under GITT strengthens and localizes technical resources, thereby supporting the implementation of the *IASC Guidelines*.

At the highest level of in-country humanitarian coordination, the Humanitarian Country Team (HCT) faces challenges in harmonizing disability inclusion across United Nations organizations. Partly based on the United Nations Disability Inclusion Strategy (UNDIS), organizations such as United Nations Children's Fund (UNICEF), International Organization for Migration (IOM) and United Nations High Commissioner for Refugees (UNHCR) also have developed their own disability-inclusion guidelines. However, there is no overarching strategy to ensure alignment with the *IASC Guidelines*. This compromises consistency in disability-inclusive programming and limits mainstreaming efforts across the humanitarian response. Addressing these gaps requires dedicated disability-inclusion expertise within United Nations organizations and stronger coordination among GITT, ICCG and HCT to embed disability considerations across the humanitarian system in South Sudan.

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Description: A seven-year-old from Juba, South Sudan, developed contractures in his hands after a candle accident at home. Due to the disability, he now uses his left hand to write (year unknown).

1. Introduction

1.1 Background

During humanitarian crises, persons with disabilities face challenges rooted in environmental, institutional and attitudinal barriers (Lough et al., 2022). The 'Leave no one behind!' (LNOB) project has supported the mainstreaming of disability inclusion in humanitarian action since 2016. Now in its third phase, the project focuses on disseminating and operationalizing the 2019 *IASC Guidelines* at both global and local levels. Funded by the German Federal Foreign Office and implemented by HI, CBM, and the Institute for International Law of Peace and Armed Conflict (IFHV), the project aims to promote and support efforts to embed disability-inclusion in protection[1] programming and related coordination mechanisms.

1 Protection is concerned with the safety, dignity and rights of people affected by disaster or armed conflict. The IASC defines protection as, "[…] all activities aimed at obtaining full respect for the rights of the individual in accordance with the letter and the spirit of the relevant bodies of law (i.e., international human rights law, international humanitarian law, international refugee law)." Protection includes all actions undertaken by humanitarian and human rights actors to ensure that the rights of affected individuals and the obligations of duty bearers under international law are clearly understood, respected, safeguarded and fulfilled without discrimination (Sphere Association, 2018, p. 36).

Against this backdrop, the report explores the following central research question: How and to what extent have humanitarian organizations anchored disability inclusion in key protection programming and coordination, as recommended in the *IASC Guidelines*, and where do gaps remain? It examines how organizations have implemented disability inclusion in humanitarian protection programming[2] and coordination by applying the *IASC Guidelines* and its four 'must-do' actions: promoting meaningful participation, removing barriers, building empowerment and capacity support, and monitoring inclusion using disaggregated data. It also assesses how key coordination bodies – the protection cluster, GITT, ICCG and HCT – work to strengthen disability-inclusive coordination mechanisms across humanitarian responses.

1.2 Disability Inclusion and the *IASC Guidelines*

The evolution of disability inclusion in humanitarian action reflects gradual progress in international policy formulation. The adoption of the CRPD in 2006 established a human rights-based framework for persons with disabilities (Harpur, 2012). However, implementation faces several operational challenges, including limited resources, inadequate stakeholder coordination, insufficient capacity-building opportunities and low participation by persons with disabilities. The World Humanitarian Summit 2016 catalyzed renewed attention to disability inclusion, notably through the *Charter on Inclusion of Persons with Disabilities in Humanitarian Action* (Lough et al., 2022). These efforts culminated in the 2019 launch of the *IASC Guidelines*.

The *IASC Guidelines* offer a methodical approach to operationalizing disability inclusion through sector-specific, actionable recommendations and the four 'must-do' actions . These help systematically integrate disability considerations into humanitarian programming and coordination. The *IASC Guidelines* emphasize the importance of engaging persons with disabilities and OPDs in decision-making processes, ensuring their perspectives inform program design, implementation and evaluation. However, implementing the *IASC Guidelines* in South Sudan presents significant challenges that warrant careful analysis.

1.3 Humanitarian Situation in South Sudan

Since gaining independence in July 2011, South Sudan has faced severe challenges, including ongoing conflicts, economic hardship and inadequate infrastructure. Fourteen years post-independence and seven years after the revitalized peace agreement, the country remains in a critical humanitarian crisis, ranking last in human development according to the 2023–2024 Human Development Report (United Nations Development Programme [UNDP], 2024).

2 This includes mainstreaming protection, which aims to enhance the protective impact of programming for all individuals, including persons with disabilities. Specialized or stand-alone programs are designed to prevent and address specific protection concerns – such as violence, exploitation, deliberate deprivation or discrimination – while supporting affected populations in exercising their rights. This report emphasizes both the importance of integrating disability considerations into protection mainstreaming and the necessity of stand-alone protection programming.

South Sudan has experienced several periods of intense conflict – most notably in 2013 and 2016 – that have significantly worsened ongoing humanitarian crises. An estimated 9.3 million people (69 percent of the population) are expected to need assistance in 2025 (United Nations Office for the Coordination of Humanitarian Affairs [OCHA], 2024a). This reflects a convergence of factors: longstanding vulnerabilities such as high malnutrition rates, the arrival of over 900,000 individuals fleeing the Sudan crisis by mid-December 2024, extreme weather events, economic instability and limited access to government services.

Ongoing violence and displacement also hinder humanitarian operations. In the first three months of 2023, the United Nations Mission in South Sudan (UNMISS) documented 920 incidents of violence against civilians, resulting in 405 deaths, 235 injuries, 266 abductions and 14 cases of conflict-related sexual violence (Human Rights Watch, 2024). Aid workers also face grave risks; by August 2023, 22 were killed, highlighting South Sudan as one of the most challenging environments for humanitarian efforts (Human Rights Watch, 2024). In addition, severe flooding affected over 710,000 people as of August 2024, worsening conditions for persons with disabilities[3] (Protection Cluster South Sudan, 2023).

Beyond the immediate threat of injury from violence, landmines and unexploded ordnance, ongoing conflict restricts access to food, shelter and health care, worsening existing marginalization (Global Protection Cluster, 2023). In a context where persons with disabilities already face systemic barriers, conflict and displacement can further compromise their safety and well-being (UNHCR, 2023).

Looking ahead, the international community's role remains crucial in helping to address South Sudan's ongoing humanitarian crisis. In May 2023, the United Nations Security Council renewed sanctions – including targeted measures and an arms embargo – until May 31, 2024, aiming to promote compliance with peace agreements and protect civilians (Human Rights Watch, 2024). However, the effectiveness of these sanctions is contested; some regional actors advocate lifting the embargo to accelerate the implementation of the peace agreement. As South Sudan prepares for general elections in December 2026, it faces major challenges in meeting the legislative and institutional reforms mandated by the peace deal. The success of these reforms and the peaceful conduct of the elections will be critical to shaping the country's future – influencing the course of its humanitarian crises and determining its prospects for stability, as well as disability inclusion.

3 A key principle in protection programming is recognizing that certain groups face heightened exposure to risks. For instance, persons with disabilities often confront additional barriers within their communities and in accessing humanitarian aid or information. However, it is critical to avoid labeling individuals or groups as 'vulnerable,' as doing so can perpetuate stereotypes and overlook the agency, capabilities and diverse experiences of people within these groups. Instead, protection actors aim to identify and reduce the specific barriers, risks and threats that different communities and individuals experience.

1.4 Pibor

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Description: Persons with disabilities marched to create awareness during the International Day of Persons with Disabilities in Pibor (2022).

Pibor County, located in the Greater Pibor Administrative Area (GPAA), is facing a severe humanitarian crisis characterized by extreme food insecurity, ongoing conflict and widespread displacement. Climate-related challenges and limited access to crucial services exacerbate this crisis.

Food insecurity in Pibor stems from a combination of ongoing local conflict, disrupted humanitarian aid, unpredictable weather and high food prices – challenges magnified by the closure of key supply routes into eastern Pibor. As a result, during the April–July 2024 lean season, food insecurity in Pibor remained severe; an estimated 11,000 people faced Phase 5 ("catastrophe") of the Integrated Food Security Phase Classification (IPC), the highest level of acute food insecurity (IPC, 2023). The majority of the population is classified in "crisis" (IPC Phase 3) or "emergency" (IPC Phase 4), reflecting widespread and urgent needs. Many rely on wild vegetables and desert dates for survival (Oxfam International, 2024), and at least 12 people reportedly died of starvation in the GPAA region in July 2024. The health and nutrition crises are equally dire: data from May–June 2024 shows global acute malnutrition rates of 25.4 percent and severe acute malnutrition rates of 7.5 percent – both exceeding World Health Organization (WHO) emergency thresholds (REACH Initiative, 2024).

Meanwhile, by July 2024, six consecutive years of flooding left an estimated 300,000 people affected, compounding existing vulnerabilities and deepening the humanitarian crisis (Oxfam International, 2024; OCHA, 2024b). Manenji Mangundu, the Oxfam South Sudan Country Director, calls the situation "heart-wrenching," with thousands – including persons with disabilities – facing hunger and malnutrition. Extreme weather events continue to make an already dire situation even worse. Persons with disabilities in Pibor face heightened challenges during these crises, as mobility constraints, stigma and social isolation further limit their access to food and protection services.

This places additional responsibility on protection actors to adapt their interventions and ensure that specialized support reaches those most vulnerable, including persons with disabilities.

The humanitarian crisis is exacerbated by inter-ethnic clashes between the Murle – the largest ethnic group in Pibor County – and neighboring communities such as the Dinka Bor and Lou Nuer. These clashes have evolved from resource-driven to identity-driven conflicts, with clear demonstrations of ethnic hatred on both sides (Accord, 2013). The Murle – historically stereotyped as "backward," "hostile" and "aggressive" – have been subject to marginalization, which has contributed to the escalation of conflicts (Felix da Costa, 2023). These inter-ethnic dynamics are multifaceted and deeply rooted. The Murle society is structured around age-sets (*buul*), red chiefs (*alan ci merik*) and clans, which shape both identity and social interactions. While these institutions traditionally serve as mechanisms for conflict management, they have also been linked to violent conflict, particularly when exploited by political or military elites (Felix da Costa, 2018). The ongoing inter-ethnic tensions also increase risks for persons with disabilities, particularly women, who face multiple vulnerabilities. In conclusion, the crisis in Pibor County is severe, with food insecurity, conflicts and displacement creating a complex situation that disproportionately affects persons with disabilities.

1.5 Outline of the Report

The introduction outlined the background of disability inclusion, the *IASC Guidelines* and the humanitarian situation in South Sudan with a particular focus on Juba and Pibor. The subsequent chapter details the research methodology. Next, the report explores key actors in protection programming: persons with disabilities, OPDs, national government bodies, local NGOs, disability-focused NGOs and United Nations organizations. It then analyzes the humanitarian coordination mechanisms – examining the roles of the protection cluster, ICCG and HCT – and how disability inclusion is integrated into their efforts. The report concludes by offering actionable recommendations for stakeholders and identifying priorities for future research on disability-inclusive protection programming and coordination in South Sudan.

2. Methodology

This research adopts a qualitative design to assess the extent of disability inclusion in protection-related humanitarian programming and coordination. The study's dual focus on programming and coordination facilitates a deeper understanding of protection challenges faced by local NGOs, INGOs, United Nations organizations and coordination bodies working in South Sudan.

2.1 Research Focus and Design

The study examined the approaches of local NGOs, INGOs and United Nations organizations in delivering protection to persons with disabilities. Additionally, it focused on coordination mechanisms within key humanitarian bodies such as the protection cluster, GITT, ICCG and HCT.

2.2 Data Collection Methods

The data collection relied on qualitative methods, drawing from various sources to ensure a comprehensive and nuanced understanding of inclusive protection programming and coordination in South Sudan. These methods included the following:

- **Key informant interviews (KIIs):** KIIs were conducted both in Juba and Pibor, and in Pibor's surrounding areas – Lekuangole and Gumuruk Payams. Participants included persons with disabilities; representatives from OPDs, INGOs, national non-governmental organizations (NNGOs), United Nations organizations, GITT and ICCG members; the protection cluster; and other relevant clusters involved in humanitarian action.
- **Focus group discussions (FGDs):** FGDs were held with various stakeholders, including persons with disabilities and OPD members. These discussions were critical for gathering rich qualitative data, offering insights into the experiences of persons with disabilities. FGDs also captured beneficiaries' perceptions of inclusion, providing a deeper understanding of how disability is addressed in protection-related activities and whether these efforts meet affected persons' needs.
- **Participant observation:** Participant observation took place during meetings, training sessions and field visits, enabling observation of protection programming and coordination efforts in practice, as well as the implementation of the *IASC Guidelines* and its four 'must-do' actions.
- **Literature review:** Relevant literature, including academic studies and reports from humanitarian organizations, was reviewed. Documents analyzed comprised protection-related proposals, evaluations, policies, meeting minutes and coordination strategies.

The data for this study was collected through 30 KIIs, six FGDs, four observation tours, and three observation events, alongside numerous informal conversations with staff from local and international humanitarian organizations, persons with disabilities and OPD representatives.

2.3 Semi-Structured Questionnaires

The development of the semi-structured questionnaires was guided by the terms of reference in consultation with colleagues from HI, CBM and field-based partners. These questionnaires were used for both FGDs and KIIs. The questionnaires primarily featured open-ended questions, encouraging respondents to provide detailed and nuanced responses.

2.4 Data Analysis

The data analysis focuses on three key themes: disability inclusion, protection programming and coordination. First, it examines how – and to what extent – humanitarian organizations integrate disability inclusion within protection programming. Second, it explores the extent to which disability inclusion is integrated into different coordination mechanisms, emphasizing both the challenges in ensuring adequate representation and the opportunities for improved collaboration across humanitarian coordination efforts.

Triangulation was applied throughout the analysis, drawing on findings from the literature review, KIIs, FGDs and observational data. This methodological approach ensured the reliability and comprehensiveness of the analysis by enabling cross-validation across multiple data sources.

2.5 Time Schedule

The field research spanned a total of five weeks, from 21 March to 29 April 2024, with data collection taking place in both Juba and Pibor. HI staff played a crucial role in the logistical preparation, transportation, meeting coordination and stakeholder engagement. Their involvement ensured that the researcher was able to efficiently connect with relevant actors involved in disability-inclusion efforts.

2.6 Limitations of this Research

The study faced several limitations:

- **Limited number of interviews and events:** The short research timeframe made it challenging to interview some of the relevant stakeholders involved in disability inclusion. Similarly, it was not possible to attend any coordination meetings in Juba due to scheduling conflicts and limited accessibility.
- **Geographic and logistical constraints:** The research was concentrated in Juba and Pibor, meaning other regions were excluded. Additionally, the remote locations in Pibor County posed logistical challenges; it was not possible to visit many of the remote villages due to their inaccessibility. Extreme weather conditions and security concerns also hindered access.

- **Limited access to high-level United Nations officials:** In Juba, many high-level United Nations officials working in the protection cluster had demanding work schedules, making it difficult to arrange interviews with them. As a result, some perspectives from this group may be underrepresented.
- **Restricted access to internal documents:** Accessing internal documents from international organizations and OPDs was challenging due to bureaucratic procedures and the need for official authorization. Consequently, some relevant documents were not available for review, limiting the comprehensiveness of the data on protection programming and coordination.

3. Actors in Protection Programming in South Sudan

This chapter explores disability-inclusive protection programming and highlights key actors and their roles. It begins with an overview of persons with disabilities and their protection needs. Next, it examines how and to what extent OPDs contribute to protection programming through advocacy, representation and active participation. The chapter then examines the national government's role, followed by an assessment of how local NGOs and disability-focused INGOs implement the four 'must-do' actions to foster protection programming. Finally, it discusses how United Nations organizations integrate and apply disability-inclusive protection programming.

3.1 Persons with Disabilities

In February 2024, South Sudan ratified the CRPD, marking a major step toward recognizing and protecting the rights of persons with disabilities. However, its practical implementation faces numerous obstacles, including inadequate funding, unreliable data and persistent societal stigma. The 2008/2009 Population and Housing Census reported a 5.1 percent disability prevalence, but recent estimates suggest that approximately 1.2 million people (16 percent of the population) are now estimated to have disabilities (WHO, 2022). In parts of South Sudan, disability prevalence is even higher. An IOM survey in Aweil South County found that nearly one in four people (23.7 percent, or 347 individuals) has a disability (IOM, 2023). However, HNRP estimates that persons with disabilities make up about 15 percent of those needing humanitarian aid, even though years of violence and conflict in South Sudan may have elevated disability rates above this level (OCHA, 2024c).

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Description: Beneficiaries of trachomatous trichiasis (TT) surgery sit on benches as they wait to be attended by surgeons and nurses at Bentiu State Hospital, South Sudan (2021).

Persons with disabilities face many barriers that limit their meaningful participation in humanitarian protection programming and service delivery. An IOM survey from Northern Bahr el Ghazal State found that nearly half (44.7 percent) of persons with disabilities had never been involved in community service decision-making – with only 8.2 percent consistently engaged – highlighting major gaps in sustained participation (IOM, 2023). Most infrastructure remains inaccessible, with most government buildings, schools, health care facilities and local service-delivery points lacking the necessary accommodations. Limited access to information and transportation – especially in remote areas like Pibor – further isolates persons with disabilities and limits their access to protection services. For example, another IOM survey found that 69 percent of persons with disabilities cannot access humanitarian services, primarily due to physical distance (74.1 percent), inaccessible infrastructure (59.1 percent), economic resources (47.7 percent) and lack of information (44 percent) (IOM, 2022a). Many persons with disabilities require assistive devices such as wheelchairs or hearing aids, which are often unavailable or prohibitively expensive. In an FGD, persons with disabilities expressed their concerns:

> A year ago, we received wheelchairs, walking sticks, and other mobility aids to help us lead independent lives. Today, however, these devices are in need of repair, and the service providers have informed us that there is no funding available for the necessary maintenance. This situation has left us once again reliant on others for mobility.

This account emphasizes the impact that humanitarian program cycles can have on persons with disabilities. While these initiatives initially provide vital support, the absence of structured referral systems and maintenance often makes their benefits short-lived. Notably, there is no facility in the Pibor region dedicated to repairing mobility devices. Given the ongoing humanitarian crisis in Pibor, consistent financial support is needed to maintain the functionality of assistive devices.

Awareness of rights under the CRPD framework and *IASC Guidelines* varies among persons with disabilities, often correlating with education levels and urban-rural divides. While persons with disabilities in Juba with access to education tend to be more familiar with these rights and frameworks, those living in rural or less accessible regions, such as Pibor, often lack awareness. This disparity is exacerbated by low literacy rates, lack of accessible formats and limited resources for OPDs, which hinder effective advocacy and dissemination of these guidelines.

As indicated, protection risks in Pibor are heightened by extreme weather conditions, remoteness and ongoing conflict. The area experienced large-scale violence in 2020 and 2022–2023, which eroded pastoral livelihoods and destroyed critical infrastructure (REACH Initiative, 2024). Moreover, access to essential services such as health care is severely limited; in 2022, for example, only 14 of 26 health facilities were operational, placing Pibor among the ten counties with the lowest primary health care unit-to-person ratios in South Sudan (Global Protection Cluster, 2023). As a result, injuries and diseases are often left untreated, which can lead to new or worsened disabilities over time. Furthermore, the lack of disability-specific data in Pibor hampers protection programming and service delivery.

3.2 Organizations of Persons with Disabilities

OPDs have made meaningful progress in advocacy and awareness-raising. While many focus on specific disabilities, the establishment of South Sudan Union of Persons with Disabilities (SSUPD) has brought them together and strengthened their collective representation. With support from disability-focused INGOs, SSUPD regularly brings together OPDs for awareness campaigns, advocacy initiatives and capacity-building sessions. In Juba, OPDs benefit from better access to resources and advocacy opportunities. In contrast, in remote areas like Pibor, OPDs remain largely informal – with limited resources, fewer advocacy chances and minimal involvement in humanitarian programming. OPD representatives in Pibor have noted that financial constraints prevent them from obtaining official government registration, further limiting their participation. The concentration of OPDs in Juba has yielded mixed results. It has enabled broader engagement and partnerships, but has also left OPDs and informal groups outside the capital – such as in Pibor – with limited representation and fewer opportunities for advocacy and partnership because fewer actors are present in Pibor, and engagement at the Juba level is too resource-intensive for these OPDs.

Table 1: OPDs at the national and county levels

S/n	Name of OPD	Location
1	South Sudan Union of Persons with Disabilities (SSUPD)	Juba
2	Union of the Physically Disabled (UPD)	Juba
3	South Sudan Association of the Visually Impaired (SSAVI)	Juba
4	South Sudan National Association of the Deaf (SSNAD)	Juba
5	South Sudan Women with Disabilities Network (SSWDN)	Juba
6	South Sudan Wheelchair Basketball Association (SSWCBA)	Juba
7	Union of Visually Impaired (UVI)	Juba
8	Equatoria State Association of the Deaf and Dumb (ESADD)	Juba
9	Association of People Affected by Leprosy (APAL)	Juba
10	South Sudan National Deaf Children & Youth (SSNDCY)	Juba
11	South Sudan Association of Physically Impaired (SSAPI)	Juba
12	Disabled Action Group (DAG)	Yei Town
13	Community Disability Committee (CDC)	Rubkona County, PoC
14	Union of Persons with Disabilities (UPD)	Rubkona, Bentiu State
15	Disabled Union Aweil East	Aweil East
16	South Sudan People with Physical Disability (SSPD)	Wau, PoC

S/n	Name of OPD	Location
17	Torit Young Voices	Torit
18	SSAVI Torit branch	Torit
19	UPD – Eastern Equatoria State	Torit
20	UPD – Western Equatoria State Yambio	Yambio
21	Jonglei Disabilities Organization	Bor
22	Community Disabled Club	Bor
23	Warrap Disabled Association Group (WADAG)	Gogrial East
24	Greater Pibor UPD (GPUPD)	Pibor
25	Disabled People Group	Mundri West
26	People with Disability Mundri County (PWDMC)	Mundri East

Not all OPDs engage in humanitarian action, and among those that do, their role in humanitarian protection programming is often minimal. Even when consulted, their influence on program design, implementation and evaluation is limited, and they do not attend protection cluster meetings. Moreover, many OPDs – especially those outside Juba – are unfamiliar with key frameworks such as the CRPD, the Sendai Framework for Disaster Risk Reduction and the *IASC Guidelines*. Technical expertise and familiarity with key guidelines are largely confined to a small group of OPD leaders in Juba, leaving others with limited capacity for effective humanitarian advocacy. There is also insufficient awareness among OPDs of the global Disability Reference Group's (DRG's) online modules on introducing disability inclusion in humanitarian action. Even in Juba, among 11 participants representing different OPDs, only 4 were familiar with the *IASC Guidelines* – a shortfall attributed to language barriers and the lack of translations in Arabic or other local languages. Limited funding and high operating costs further restrict their capacity to build organizational capacity.

The principle of 'Nothing About Us Without Us' is often compromised in practice. Coordination bodies often perceive international organizations like HI as the primary representatives of persons with disabilities and OPDs. However, while HI is a disability-focused humanitarian organization, it does not claim to represent persons with disabilities or OPDs. As one OPD representative expressed in a KII:

> Rather than engaging directly with OPDs, United Nations agencies and donors opt to work through disability-focused intermediaries – a practice that falls short of genuine inclusion. Donors must also recognize this shortfall. Our goal should be to empower OPDs by partnering with them directly and ensuring they actively participate in every aspect of a project.

These practices limit the role of local OPDs, particularly when coordination mechanisms rely on well-established INGOs as the go-to experts on disability inclusion (Funke, 2023). However, the increased involvement of OPDs in co-leading technical support mechanisms and capacity development efforts since 2023 has helped foster some cooperation between coordination bodies and OPDs.

OPDs have voiced concerns about their marginal role in HPC, increasingly viewing their involvement as merely symbolic. They are often invited to project inaugurations to present an image of inclusivity rather than to participate in meaningful decision-making. Furthermore, many OPDs criticize training sessions – mostly on capacity-building – as repetitive, seeing them as 'tick-box exercises' that deliver few tangible benefits in terms of capacity-building or empowerment.

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Description: Technical Support members (inclusion focal points) posed for group photos during Training of Trainers (ToT) at Juba Regency Hotel, South Sudan (2024).

Perceptions on OPDs' capacity vary. While INGOs and United Nations organizations assert that OPDs lack the capacity to implement projects independently, SSUPD argues the opposite. For example, the African Disability Forum is executing a five-year 'We Are Able!' project through SSUPD, demonstrating its independent project-implementation ability. Likewise, SSAVI has established strong partnerships with various local and international actors, asserting its capabilities while also expressing frustration that some INGOs and United Nations organizations continue to underestimate the true potential of OPDs. In a KII, one SSUPD leader stated:

> Our union's capacity is rooted in our policies and systems; if given the necessary funds, we can recruit and deploy a team of experts, even if we do not always have those roles filled.

In addition, disability-focused INGOs contribute to inclusive humanitarian action by strengthening OPDs' capacities in key areas. They enhance OPDs' understanding of international policy, human rights frameworks and humanitarian operations, while also building practical skills in project implementation, financial management and resource mobilization – enabling more meaningful participation in humanitarian responses.

In conclusion, OPDs often perceive their role in protection programming as limited. While some INGOs actively partner with OPDs, others continue to underestimate their capacity and potential contributions. OPD participation is often symbolic, positioning them as beneficiaries rather than as active partners. Hence, OPDs remain an underutilized resource to identify barriers and contribute to implementation and evaluation. While ongoing empowerment efforts are in place, challenges remain, particularly in how capacity is defined and measured. Re-examining capacity assessments – along with a commitment to the four 'must-do' actions – is needed to ensure that OPDs become meaningful partners in protection programming.

3.3 National Government

The recent ratification of the CRPD in South Sudan demonstrates the country's commitment to protect the rights of persons with disabilities progressively. The Ministry of Humanitarian Affairs and Disaster Management has introduced measures – such as the National Disaster Risk Management Policy and disability-inclusion frameworks – to coordinate protection efforts. However, despite initial efforts at the policy level, it is international actors who primarily implement protection programming.

Box 1: Main South Sudanese policies relevant for disability inclusion

- Child Act, 2008
- National Gender Policy, 2013
- National Disability & Inclusion Policy (NDIP), 2015
- National Social Protection Policy Framework, 2016
- National Inclusive Education Policy, 2020
- National Plan of Action for Children, 2022
- National Action Plan for the implementation of United Nation CRPD and its optional protocol 2024–2029

Hence, protection services in refugee and internally displaced person (IDP) camps rely primarily on international actors, with United Nations organizations and NGOs taking the lead. Agencies such as the United Nations Population Fund (UNFPA), UNICEF, World Food Programme (WFP) and UNMISS provide broad humanitarian assistance, while specialized organizations like HI and CBM focus on disability-inclusive programs. The relevant ministry joins coordination meetings but lacks the resources to run full-scale responses. Through the Ministry of Humanitarian Affairs' Relief and Rehabilitation Commission, the government has established a formal framework for accrediting and supervising INGOs. Additionally, the creation of a Disability Desk in the Office of the Vice President signals the government's commitment – though its influence on protection programming

and coordination is rather limited. The National Disability and Inclusion Policy (NDIP) is insufficiently disseminated for now and, as a result, remains largely unknown outside urban centers. This gap between national policy and state-level practice means that disability-inclusion activities are mainly confined to urban areas and camps and rely on international organizations.

3.4 Local NGOs and Disability Inclusion

Local NGOs play a limited role in disability-inclusive protection programming. These organizations often act as first responders during crises, implementing protection monitoring, facilitating referrals and conducting protection risk analyses. Their engagement is crucial, especially in addressing the immediate protection needs of persons with disabilities.

For example, ACROSS, a local NGO, implements a multisectoral disability-inclusive resilience-building project in Central Equatoria State, targeting over 36,000 people in Juba, Yei, Lainya and Morobo counties (ACROSS, 2025). The organization integrates protection mainstreaming and disability inclusion across sectors, including food security; health; education; protection programming; water, sanitation and hygiene (WASH); and protection programming. Other local NGOs working in consortiums with disability-focused international organizations show improved capacity in disability inclusion. For example, the Coalition for Humanity operates across various sectors, including WASH, gender-based violence (GBV) protection, food security and livelihoods. However, resource constraints and limited technical expertise restrict its ability to expand disability-inclusive protection programming.

Community Empowerment for Progress Organization (CEPO), another local NGO, stands out as a prominent national human rights organization advocating for disability rights by lobbying for the signing of CRPD and inclusive-education policies. CEPO implements protection monitoring and case management services. Like many NNGOs, it faces challenges in mainstreaming protection due to limited funding and technical capacity. However, through the technical support mechanism on disability inclusion, local NGOs are strengthening their capacity to mainstream disability inclusion across protection projects and humanitarian programming.

The NGO Forum functions as an umbrella organization for both national and international NGOs. Although some OPDs are part of the NGO Forum, the number of persons with disabilities actively participating in its meetings remains relatively low. The NGO Forum is a membership-based organization that includes development and humanitarian actors but does not specifically focus on disability inclusion. Thematic areas of interest are determined by their members, such as localization. Disability inclusion has not yet emerged as one of their themes.

Local NGO respondents generally have limited knowledge of the CRPD and the *IASC Guidelines*. Familiarity with DRG's online modules on disability inclusion is also limited. However, local actors – such as ACROSS and the Province of the Episcopal Church of South Sudan (ECSS) – that have collaborated with disability-focused organizations exhibited a strong understanding of the *IASC Guidelines* and its four 'must-do' actions.

The localization agenda faces challenges in humanitarian practice. Local NGOs struggle to access funding and participate meaningfully in the implementation of protection responses. For example, the South Sudan Humanitarian Fund (SSHF) is designed to assist humanitarian actors, including local NGOs. However, application processes for humanitarian funding and the associated due diligence requirements remain difficult for local NGOs to fulfill. The SSHF mandates that local NGOs form consortiums led by United Nations organizations or INGOs. Although this consortium approach facilitates knowledge transfer and capacity-building, local NGOs rarely lead disability-inclusive humanitarian programming independently. Additionally, high staff turnover and limited expertise in protection response also hinder the development of sustainable technical capacity.

Box 2: Localization and disability inclusion in humanitarian contexts

The concept of localization in humanitarian action officially represents a shift from traditional aid-delivery models toward community-led humanitarian action. Local OPDs and local NGOs hold contextual knowledge regarding the specific challenges faced by persons with disabilities within their communities, such as ethnic differences, social barriers and other overlooked obstacles that may impede access to humanitarian assistance and protection. However, there are challenges associated with the implementation of localization. Many local organizations lack the requisite resources and technical expertise to fully engage in humanitarian responses. This situation raises critical questions regarding the balance between localization efforts and the need for specialized disability expertise. Furthermore, it necessitates a re-evaluation of the role that international actors should play in building local capacity and how funding mechanisms can be restructured to better support local disability-focused organizations and NGOs. Addressing these challenges calls for the development of innovative funding mechanisms that directly support local disability-focused organizations and NGOs. It also calls for a reconfiguration of partnerships between international and local actors to facilitate bidirectional knowledge transfer, and for meaningful inclusion of persons with disabilities in decision-making processes as leaders and experts in their own right. For the humanitarian sector, it is crucial to recognize that true inclusion extends beyond the provision of accessible aid; it necessitates a fundamental transformation of the humanitarian system to create space for diverse voices and experiences, including those of local NGOs and OPDs. While the journey towards localization and disability inclusion presents major challenges, it offers the potential for a more equitable and effective humanitarian response that better serves all affected populations.

3.5 Disability-focused INGOs

Disability-focused INGOs – HI, CBM, LFTW and OVCI – play a crucial role in advancing disability-inclusive protection programming and coordination. These organizations are well-versed in *IASC Guidelines* and consistently implement the four 'must-do' actions. They all employ persons with disabilities.

HI actively integrates disability inclusion into its protection programming, addressing sectors such as Mental Health and Psychosocial Support (MHPSS), protection, rehabilitation, sexual and reproductive health, peace building, basic needs, resilience and economic inclusion. HI supports the Technical Support Mechanism Team on Disability Inclusion of GITT to foster collaboration and knowledge exchange among humanitarian actors, including OPDs, to mainstream disability. HI's approach in humanitarian response is centered on the four 'must-do' actions. It promotes meaningful participation by supporting the formation and functioning of OPDs and self-help groups, and by recruiting persons with disabilities as co-facilitators for awareness sessions, enumerators for assessments, project staff and key contributors in project management committees. With SSHF funding, HI established a consortium with the Coalition for Humanity to implement a disability-inclusive project in Panyijar and Pibor. Additionally, HI addresses physical and attitudinal barriers by making service facilities more accessible, fostering inclusion within organizational structures and highlighting the value of staff with disabilities in humanitarian programming. HI also invests in empowerment and capacity-building – for example, for GBV survivors – through tailored MHPSS and ongoing efforts to enhance disability inclusion among humanitarian stakeholders. Finally, HI promotes data disaggregation by incorporating WG-SS into monitoring and evaluation tools.

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Description: Community leaders and chiefs posed for group photos after three-day training on basic concepts of disability inclusion and awareness on the rights of persons with disabilities in Pibor (2022).

While CBM's work in South Sudan has traditionally centered on development, in response to the rapid growth of humanitarian needs – particularly for persons with disabilities – CBM has also started to increase its humanitarian work over the last three to four years. This development coincided with the establishment of the 'Inclusive Humanitarian Action Initiative' humanitarian department at CBM's headquarters, which supports in-country staff to mainstream inclusion in key humanitarian contexts. CBM adheres to *IASC Guidelines* and the four 'must-do' actions, consistently training partners on disability inclusion and crisis response. It actively responds to natural disasters and protracted emergencies, focusing on specific groups such as persons with disabilities, refugees and IDPs. It partners with the Province of the Episcopal Church of South Sudan and ACROSS to address the basic needs of flood-affected communities, especially in Upper Nile State, including Renk. In Upper Nile, CBM supports IDPs, host communities and returnees by providing inclusive WASH services, along with inclusive health services such as MHPSS and assistive devices. In Central Equatoria State, interventions emphasize inclusive WASH – illustrated by projects drilling boreholes in Gorom Camp for refugees and host communities – as well as food security programs that include the provision of agricultural seeds, the promotion of good agronomic practices and cash transfers. Additionally, CBM promotes peacebuilding and social cohesion that enhances community resilience and fosters social integration.

© CBM
Description: A surgeon conducts a medical examination for a waiting patient at Bentiu State Hospital, South Sudan (2021).

OVCI promotes disability inclusion through a dual approach. It provides specialized rehabilitation services – including physical, occupational and speech therapy – at its rehabilitation center and primary health care facility while also implementing community-based rehabilitation programs. Through five dispensaries and a mobile clinic, OVCI also provided disability-inclusive health care to 55,000 refugees and IDPs fleeing violence and host community members in urban Juba (OVCI, 2024). OVCI prioritizes active engagement with OPDs, incorporating two OPD representatives into

program monitoring to ensure ongoing feedback and responsiveness. Additionally, OVCI has signed a Memorandum of Understanding (MoU) with SSUPD to fight discrimination against persons with disabilities, particularly through the implementation of the CRPD.

LFTW, which traditionally focuses on development, has adapted to the humanitarian context of South Sudan. As the Country Director of LFTW stated in a KII:

> Internationally, our work is predominantly development-focused, but in South Sudan, the reality is fundamentally humanitarian. Every initiative – whether it is fostering inclusion, driving economic empowerment, or delivering health services – requires a balanced, 50/50 approach that equally embraces humanitarian action and development.

LFTW applies a disability-inclusion approach in community development (formerly known as community-based rehabilitation) in its humanitarian and protection programming within IDP camps. This facilitates access to aid for parents and children with disabilities and involves partnerships with mainstream organizations to implement inclusive protection measures. Additionally, it provides rehabilitation services – such as assistive devices, medical referrals and home-based rehabilitation – while employing 32 disability-inclusion facilitators who act as role models and trainers. In supporting OPDs, LFTW established SSUPD with full financial backing until it was registered in 2019. It continued to provide technical and financial support until the SSUPD became self-sufficient.

Several interconnected factors underscore the ongoing demand for protection programming by disability-focused INGOs, as well as the need to improve protection programming and coordination further. First, the lack of disability-disaggregated data creates information gaps about barriers and unmet needs, especially in rural areas like Greater Pibor where such data is rare. Second, attitudinal, environmental and institutional barriers prevent persons with disabilities from meaningfully participating in the HPC. Third, there is limited recognition of diversity among persons with disabilities, with few strategies in place to include persons with intellectual and psychosocial disabilities. Fourth, while South Sudan has an NDIP, implementation remains weak because of limited awareness, inadequate monitoring and multiple forms of exclusion. Fifth, as mentioned earlier, in remote regions like Pibor, OPDs are not well-organized and struggle to represent persons with disabilities. Lastly, funding cuts compromise disability-inclusive protection programs, which are frequently the first to suffer from budget reductions. For example, OVCI's recent 10 percent budget cut has directly impacted its operations. Such reductions jeopardize the long-term sustainability of programs and undermine progress toward inclusive protection programming.

Improved coordination among disability-focused INGOs is also needed. Although some co-operation is formalized through MoU – such as LFTW's MoUs with CBM and OVCI – co-operation can be intensified by participating in the protection cluster and/or technical support mechanism. This could enable further coordination in terms of sharing information and expertise and improving coherence. Overall, disability-focused organizations should explore opportunities to strengthen collaboration in response to the decline in funding.

3.6 United Nations Organizations

United Nations organizations are increasingly committed to disability inclusion across their programs. Their engagement with the *IASC Guidelines* differs, leading to diverse approaches. This variance highlights opportunities to strengthen systematic approaches, especially in recognizing and addressing diverse impairments within humanitarian programming and coordination.

OCHA promotes disability inclusion in humanitarian action through a range of efforts. It supports the cluster coordination system, allocates funds through the Country-based Pooled Funds (CBPFs) and the Central Emergency Response Fund (CERF), manages information systems and leads advocacy efforts to ensure humanitarian action is comprehensive and inclusive. In South Sudan, it manages SSHF – a CBPF that allocated $55.6 million to 33 partners in 2023, supporting 1.2 million people across 56 projects (SSHF, 2024). Of these beneficiaries, 8 percent were persons with disabilities. In terms of coordination, OCHA also leads the ICCG, which brings together 11 clusters – including Protection, Health, Food Security and Livelihoods (FSLC), WASH, Shelter and Non-Food Items (NFI), and Camp Coordination and Camp Management (CCCM) – in an effort to ensure coordinated humanitarian response across clusters.

OCHA's commitment to inclusive humanitarian response is reflected in its emphasis on needs-based assessments and disaggregated data. For example, the 2025 South Sudan HNRP aims to reach 14.3 million people, including 2.2 million persons with disabilities, with life-saving aid (OCHA, 2024a). Specifically, HNRP's strategic objective 2 addresses the protection needs of 3.5 million people – including 0.5 million persons with disabilities – while strategic objective 3 focuses on the well-being of 4.3 million vulnerable individuals, with targeted support for 0.6 million persons with disabilities. Although the HNRP sets a numerical target for disability inclusion, this approach remains rather generic. While some data on disability and needs has been collected, it has not yet been sufficiently disaggregated by disability type. This gap is especially apparent at the local level, where persons with multiple disabilities are frequently excluded due to a lack of identification, as well as various other barriers, including challenges in communication and negative attitudes. It would be ideal if OPDs and disability-focused actors were given a more structured role in disability-disaggregated data collection and analysis, as has been done successfully in some data collection and analysis (see the paragraph on IOM later in this section).

Assessment tools, such as the Multi-Sectoral Rapid Needs Assessment, incorporate specific questions to identify the needs of persons with disabilities (IASC, 2015). WG-SS has been increasingly incorporated. OCHA uses the ActivityInfo reporting tool for ongoing monitoring, enabling data disaggregation by gender, age and disability, which is crucial for identifying and addressing barriers to access and participation. Accountability is maintained through minimum standards guided by the *IASC Accountability Framework* for clusters, with clusters completing annual self-assessment checklists. However, the accountability framework primarily relies on self-assessment rather than external control. This approach promotes ownership of performance and improvements within clusters but may lack the external pressure needed for rapid or substantial changes.

UNICEF's commitment to disability inclusion was strengthened with the adoption of its *Disability Inclusion Policy and Strategy 2022–2030*, which outlines six strategic priorities and sets clear organizational targets globally (UNICEF, 2023). UNICEF South Sudan works to protect the rights of all children, especially those who are most vulnerable, and has a designated disability-inclusion focal point. Although it does not yet have a country-specific disability strategy, disability inclusion is integrated into its programs. For example, for education initiatives targeting disaster- and conflict-affected areas, temporary learning spaces and related facilities – including WASH facilities – are constructed or rehabilitated to be disability-friendly. During humanitarian crises, emergency responses are designed to reach everyone, including persons with disabilities, by modifying distribution points and facilities to remove physical barriers. However, accessible design is only an initial step; the mere presence of accessible facilities does not guarantee their use. Consequently, UNICEF is strengthening its monitoring and evaluation systems to collect data on how facilities are used and to identify barriers that may still prevent children with disabilities from accessing services. These insights enable programs to be adapted to more effectively reach and protect all children.

© CBM
Description: A female student from South Sudan is playing with her friends after school. She has a physical disability and uses a wheelchair (2024).

In 2024, UNICEF and HI were implementing a three-year project that aimed to strengthen disability-inclusive protection programming and build OPDs' capacity. It focused on two main areas: empowering OPDs in Juba, Wau and Malakal to address the needs of children and youth with disabilities, and enhancing GBV prevention and response in Pibor. The project also sought to establish a grant-funding mechanism for OPDs to conduct assessments and refer children with disabilities to appropriate protection services. In Pibor, a women-and-girls' safe space was

operational, offering specialized support such as case management and psychosocial services for survivors. This initiative contributed to creating a safer environment for women and girls at risk of or affected by GBV. The project followed the *IASC Guidelines* and its four 'must-do' actions.

IOM South Sudan implements comprehensive disability-inclusion strategies through its Protection and Inclusion unit, focusing on both direct assistance and capacity-building. It adopts a dual approach that integrates disability inclusion into its mainstream emergency response while also working directly with OPDs to build their capacity through joint training sessions and mentorship. It provides protection support through assistive devices such as wheelchairs, white canes and walking sticks while actively collaborating with local OPDs to address the daily challenges faced by persons with disabilities (IOM, 2023). For instance, IOM has trained over 200 persons with disabilities in English braille, sign language, and orientation and mobility through a comprehensive six-week program in Tonj South (IOM, 2022b). IOM's strategy follows the *IASC Guidelines*, which stress the removal of barriers to inclusion, the empowerment of persons with disabilities and their active participation in humanitarian action. IOM secured an 18-month grant from the CERF for a disability-inclusive project in Tonj South and Rumbek South that aligns with *IASC Guidelines*.

IOM's disability-inclusion work in South Sudan began in 2017 through a partnership with HI and driven by the need for disability-related data for programming. This collaboration led to joint surveys that identified barriers to service access and participation of displaced populations, particularly among women with disabilities, prompting IOM to launch targeted women's participation initiatives. Its mainstreaming approach emphasizes staff training on disability inclusion, promoting a rights-based model rather than a medical or charity approach.

Through its Rapid Response Fund (RRF), IOM has initiated efforts to support emergency response projects. However, funding has not been extended to OPDs due to weak capacities. Under the RRF, IOM provides NGOs with a three-day training on disability inclusion, gender and protection. IOM chairs the MHPSS Technical Working Group at national and state levels, promoting the mainstreaming of support services across clusters. IOM also implements protection mainstreaming through site planning that ensures access for persons with special needs, the establishment of community representative structures, and the regular conduct of safety audits. Despite funding constraints, IOM maintains its commitment to disability inclusion by employing specialists like physical therapists for rehabilitation assessments in operational areas. The organization's approach reflects a broader commitment to protection mainstreaming, ensuring that disability inclusion remains integrated within its humanitarian response framework (IOM, 2023). It also employs the Displacement Tracking Matrix and collects additional data for the HNRP.

Box 3: Inclusion starts at the gate: Transforming attitudes of security personnel toward persons with disabilities

A security guard's interaction can make or break a person's entire experience with an organization. For persons with disabilities, an insensitive or discriminatory encounter at the gate can be deeply discouraging, potentially deterring them from seeking vital services or participating in important decision-making processes. However, a welcoming and respectful interaction can empower individuals, affirming their right to access and participate fully in organization's activities. In this light, security guards are not just protectors of physical space but also guardians of inclusivity and equal opportunity.
Proper training will help guards understand that persons with disabilities are valuable members of the community, who may visit humanitarian organizations to access services, advocate for their rights or contribute as stakeholders. This shift in perspective toward protection is crucial for creating an environment where persons with disabilities feel respected, valued and empowered from the moment they approach the organization.

To ensure accountability and continuous improvement, a structured reporting mechanism should be established to address any incidents of abuse or mistreatment by security personnel toward persons with disabilities. This system should be easily accessible, confidential and responsive, demonstrating the organization's commitment to upholding the rights and dignity of all visitors. Without these measures, exclusionary attitudes among security guards will deepen the marginalization of persons with disabilities, undermining the very principles of inclusion and protection. True inclusion is not achieved merely through policy but must be reflected in the actions and attitudes of every individual within an organization, starting at the security gate. By investing in training and accountability measures for security personnel, organizations can ensure that their commitment to disability inclusion is evident from the very first point of contact, setting the stage for meaningful participation and empowerment of persons with disabilities throughout their engagement with the organization.

4. Coordination for Inclusive Humanitarian Action

Coordination of disability inclusion in the humanitarian response from South Sudan presents both progress and persistent challenges. While various coordination mechanisms exist at national, subnational and local levels, there are variations in the ways in which they strive to engage persons with disabilities meaningfully. Progress is evident in the increasing recognition of disability inclusion as a crucial cross-cutting issue, with growing efforts to collect disaggregated data and incorporate disability-specific considerations into needs assessments and response planning. The following section discusses the coordination of inclusive humanitarian action in South Sudan. It explores both what has been achieved and the areas requiring further attention, with regard to advancing disability inclusion, as recommended in the *IASC Guidelines*.

4.1 Protection Cluster

The protection cluster plays a pivotal role in leading the coordination and the promotion of protection mainstreaming, monitoring, advocacy and overall adherence to the centrality of protection. It coordinates protection efforts among humanitarian organizations – including United Nations organizations, INGOs and local partners – to promote, adhere to and uphold the protection principles, and therefore human rights and dignity. By ensuring coordination and promoting inter-agency collaboration between multiple actors in protection, the cluster conducts inter-agency risk monitoring and assessments. It attempts to ensure that humanitarian responses address the diverse needs of at-risk groups. Its broad mandate includes advocating for the protection of marginalized groups such as women, children and persons with disabilities, alongside overseeing emergency responses that protect the well-being of affected communities.

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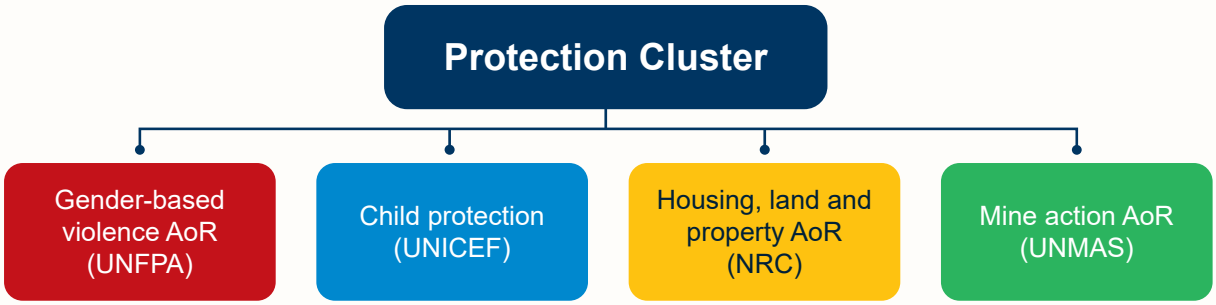
Description: OPD members and protection cluster partners posed for group photos during the general kick-off meeting for the Phase 3 LNOB project at the Juba Grand Hotel on 16 November 2022, Juba, South Sudan (2022).

To manage its extensive responsibilities, the cluster is divided into four specialized areas of responsibility (AoRs): GBV, child protection (CP), mine action (MA), and housing, land and property (HLP). Each AoR operates rather independently, addressing different protection needs. UNHCR chairs the protection cluster, and the Norwegian Refugee Council (NRC) is the co-chair. The protection cluster's official role in humanitarian contexts is to deliver a coordinated, principled and effective response that keeps protection at the heart of every humanitarian activity. In practice, this means prioritizing and upholding the rights, safety and dignity of affected people across the response, consistent with international human rights and humanitarian law. NRC also plays a pivotal role in advocacy, monitoring and reporting. Ideally, coordination fosters a more inclusive, accountable and transparent governance structure within the cluster, ensuring that all stakeholders – including OPDs – are actively engaged and represented in decision-making processes. There is, however, no disability AoR; this brings up the question of what the best way is to include disability inclusion systematically in protection programming and coordination. Disability-focused organizations cannot do this work alone (see Figure 1 for alternatives).

Figure 1. Protection cluster architecture



Note. From Global Protection Cluster. (2024). *The four areas of responsibility.* **https://globalprotectioncluster.org/about/our-structure/the_four_areas_of_responsibilities**

Specialized organizations, like HI, bring technical expertise into the cluster's work in South Sudan, helping to mainstream disability inclusion, enhance capacity development for disability-inclusive protection programming across humanitarian activities, and foster an environment where disability-related needs are more consistently addressed. However, OPDs rarely attend protection cluster meetings. When OPDs are absent, disability-focused organizations are often regarded as the representative voices of persons with disabilities. As mentioned, the representation of persons with disabilities is often limited to Juba and does not extend to subnational levels, leaving disability-specific needs underrepresented. Moreover, the clusters are built and intended to coordinate operational actors, which may pose challenges for representative structures, such as OPDs, without operations to find their role and engage effectively. To address the gap, the rapid needs assessments and protection monitoring focus on gathering disability-specific data. This process ideally involves OPDs and persons with disabilities, ensuring that their protection needs are integrated into protection programming and adequately represented in inter-cluster coordination and decision-making processes. The establishment of the Protection Monitoring System (PMS) has been a notable success, enabling systematic data collection and analysis that informs humanitarian

responses and facilitates the identification of protection risks faced by vulnerable populations, including persons with disabilities. Moreover, a protection analytical update in 2023 focused on the specific risks faced by persons with disabilities and older persons. However, there is no localized, agreed guidance on quality data collection on persons with disabilities in protection programming that would advance the quality and comparability of data between protection actors in South Sudan.

HI participates in the protection cluster and GBV AoR meetings as an operational protection actor. It also shares its disability-inclusion expertise and facilitates capacity development on the *IASC Guidelines* with regard to protection programming. There is further scope to advance the regular representation of disability-focused data on disability-specific protection risks by the protection cluster in the ICCG and to ensure that disability inclusion is adequately represented as a cross-cutting inter-cluster theme. A recent positive development is the protection cluster's commitment to present such issues at both the ICCG and the HCT. Additionally, the NGO Forum has indicated its openness to advance disability inclusion, further demonstrating a collective willingness to promote disability inclusion across various coordination forums. United Nations could strengthen its overall strategy by integrating specialized disability-inclusion advisers – especially within the protection cluster – thereby also supporting consistent representation of disability-specific issues within the ICCG and other coordination bodies.

4.2 Local-Level Coordination

Ideally, local-level humanitarian coordination in Pibor, South Sudan, bridges country-level strategies and field-level responses. Subnational coordination forums are currently inactive. The protection cluster in Pibor, led by Oxfam, also oversees subclusters covering general protection, GBV and child protection, each meeting on different schedules. In practice, however, the limited knowledge and application of the *IASC Guidelines* – beyond HI's advocacy – means that disability inclusion is only partially addressed in local coordination efforts. Oxfam itself does not implement specific disability-focused projects in Pibor. While there is an informal network of persons with disabilities, no formally recognized OPD exists to represent their interests in coordination meetings consistently.

Several additional factors hamper effective protection coordination in Pibor. Floods, conflict and poor infrastructure challenge both logistical planning and service delivery. Meeting schedules are communicated through informal channels, often failing to reach key groups such as women's organizations, youth groups and persons with disabilities. Many cluster members also struggle to attend due to short notice and the region's remoteness. Recent efforts to improve attendance at coordination meetings by involving the Ministry of Gender have yielded better participation, illustrating the importance of government engagement. Although some discussions about persons with disabilities do occur, the challenges faced by informal networks to attend and engage in decision-making and meaningful participation, and possibly the absence of a more formalized OPD limits disability inclusiveness of the local protection coordination. Physical accessibility receives some attention – particularly in GBV response, safe space and distribution centers – but protection actors do not yet consistently embed disability considerations in service design or outreach. Furthermore, the participation of persons with disabilities in needs assessments is not comprehensive enough, given the dominance of individuals with physical impairments in the loose network and the general lack of visibility of other types of disabilities.

HI is the sole disability-focused organization in Pibor, supporting informal disability networks and offering critical inputs to the local protection cluster. While this has fostered progress – especially in strengthening community-based structures and GBV prevention and support activities – major gaps persist. Without recognition of informal structures of persons with disabilities to represent them at local clusters, persons with disabilities rely on HI to raise their concerns. This can sometimes limit the breadth of information shared during coordination and affect the design of specialized, inclusive services. More must be done to embed disability inclusion as a central feature of local-level protection programming, ensure data is collected across all types of disability and barriers, and integrate the *IASC Guidelines* across all clusters.

Plan International is responsible for coordinating joint inter-cluster coordination in Pibor. These activities help assess what has been accomplished, the impacts generated and the challenges faced. Following the meetings, recommendations are reviewed, compiled and reported to OCHA in Juba. However, several issues remain unsolved at the local level. Previously, an OCHA focal point for coordination was stationed on the ground, with field coordinators rotating every two weeks to ensure continuous support. Currently, there is no such dedicated focal point for coordination. In addition, poor turnout in individual cluster coordination meetings in various clusters diminishes the voice of persons with disabilities at inter-cluster coordination mechanisms.

In Pibor, disability inclusion faces operational challenges due to limited awareness of the *IASC Guidelines*' four 'must-do' actions among humanitarian actors, partly because of the absence of training programs and competing priorities. Moreover, a generalized approach to vulnerability, while well-intentioned, overlooks the specific needs of persons with disabilities, leaving disability considerations largely absent from inter-cluster agendas.

The impact of weak inter-cluster coordination became clear during a blanket registration process for food assistance: the food security cluster did not integrate protection, gender or disability considerations, exposing persons with disabilities and other at-risk groups to preventable hardships. In response, OCHA mandated that all clusters share information about upcoming activities with the protection cluster – a step that helped avert similar risks when new displacements required multi-cluster assessments. However, despite these corrective measures, gaps in disability inclusion persist. As stated above, persons with disabilities primarily rely on support from HI, which remains the only disability-focused organization in the region. With limited or no representation within the various clusters, these informal disability networks lack the formal authority or resources to influence decision-making.

Inadequate information flow between clusters, gaps in data and weak feedback loops between field and national levels create barriers to effective protection programming and coordination. Additionally, Pibor's remote nature compounds these challenges. In summary, coordination in Pibor can advance integrating disability inclusion by addressing these gaps while also promoting and finding practical ways to systematically engage informal groups of persons with disabilities in coordination mechanisms.

4.3 Coordination by GITT

GITT operates as a dedicated mechanism, endorsed by the ICCG, to advance the Gender Equality Programming in Emergencies Roadmap. Chaired on a rotational basis by representatives from WFP, IOM, UNFPA and UNICEF, it brings together key humanitarian stakeholders – including Cluster Gender and Disability Focal Points – to strengthen gender equality and inclusion across the HPC. The GITT's leadership reports to the HCT (as is discussed later in this section), ensuring regular visibility of its activities at the highest coordination levels. In principle, this structure also helps with promoting the *IASC Guidelines*, emphasizing the collection of sex, age and disability disaggregated data and the mainstreaming of disability perspectives throughout program design, implementation and monitoring.

In practice, however, disability inclusion tends to receive less focused attention than gender-related issues. Although OPDs and the need for disability-disaggregated data are explicitly mentioned, the GITT's tasks are wide-ranging and often concentrate on women's participation, GBV prevention and the use of the Gender with Age Marker (GAM). As a result, efforts related to disability sometimes appear as an add-on rather than an equally prioritized domain. This is partly because disability is frequently grouped under a broader 'inclusion' umbrella within GITT's documents. Consequently, OPDs and specialized disability actors are not always consistently allocated focal points or given substantial space for advocacy, limiting the practical application of the *IASC Guidelines* at both cluster and local coordination levels.

Nevertheless, the terms of reference for Cluster Gender and Disability Focal Points provide a clear framework on how disability can be strengthened within GITT processes. These focal points are expected to attend GITT meetings regularly, share inter-cluster opportunities related to gender and disability inclusion, and actively report relevant updates back to their respective clusters. Moreover, they serve as critical technical advisors – offering support, in collaboration with GenCap and other GITT members, to develop strategies and indicators that are sensitive to both gender equality and disability-specific needs. They also guide cluster partners on correct compliance with the GAM, encourage the integration of disability measures in programming, and ensure accountability and feedback mechanisms are inclusive of persons with disabilities. Ideally, focal points advocate for affirmative action by promoting partnerships with OPDs and showcasing best practices at multiple coordination levels – ranging from the GITT and ICCG to the HCT. Finally, they play a key role in enhancing sectoral analysis tools by ensuring the inclusion of disability parameters in the cluster system (or individual organizations) and assisting with comprehensive data analysis that reflects both gender and disability concerns.

Overall, GITT is a valuable forum for mainstreaming gender and disability inclusion, linking its diverse membership to the ICCG and HCT and thereby keeping the Gender Equality Programming in Emergencies Roadmap commitments visible at higher decision-making levels. However, to strengthen alignment with the *IASC Guidelines*, it is important to emphasize disability as an integral part of GITT processes, rather than a secondary issue, and reinforce the role of Cluster Gender and Disability Focal Points. Steps such as greater OPD engagement, expanded data collection on disability-specific challenges and stronger accountability measures would help ensure that persons with disabilities are meaningfully included across all clusters and throughout the HPC.

Box 4: Addressing intersectional vulnerabilities in disability inclusion

The intersection of disability with other aspects of identity creates specific experiences of vulnerability and exclusion in humanitarian contexts. Women with disabilities face heightened risks of violence and limited access to health care services compared to both men with disabilities and women without disabilities. Humanitarian programming and coordination must recognize that barriers are not experienced uniformly. Persons with psychosocial or intellectual disabilities often face additional layers of discrimination and exclusion from humanitarian programming. This intersectional nature demands targeted interventions that consider how gender, age, disability type and other vulnerabilities combine to create distinct experiences of marginalization. Effective disability inclusion requires moving beyond singular approaches to embrace strategies that address multiple, overlapping forms of discrimination. This includes ensuring that humanitarian coordination mechanisms, data collection systems and program design reflect the diverse needs and experiences of persons with disabilities. Without such an intersectional approach, humanitarian efforts risk perpetuating existing inequalities and failing to reach those most marginalized within the disability community.

4.4 Coordination in the ICCG

ICCG, supported by OCHA, serves as the platform for inter-cluster coordination. It brings together all cluster chairs to address cross-sectoral issues, mainstreaming issues such as gender and disability. Officially, the ICCG applies the *IASC Guidelines* and its four 'must-do' actions. Disability is included in the HNRP; although the data is not disaggregated, it still uses the WHO's estimated figure of 15 percent. Disability-specific considerations are also included in assessment tools like the Initial Rapid Needs Assessment.

Within the ICCG, disability inclusion falls under the GITT. While this setup consolidates various inclusion issues, it can dilute the focus on disability-specific needs. On paper, the ICCG's role is to integrate disability concerns across clusters, backed by accountability mechanisms under the IASC Accountability Framework for Clusters, which requires each cluster to self-assess against minimum standards. However, the small number of dedicated disability focal points means relying on other clusters, like protection, to raise disability issues. This reliance, combined with limited field-to-national information flows, can restrict attention to disability-specific issues. The lack of technical disability experts in many United Nations organizations and NGOs also limits attention on disability inclusion.

In addition, disability is frequently perceived solely as a protection issue rather than a cross-sectoral concern, which further hinders its integration into humanitarian responses. This is compounded by the use of varied tools across different clusters to capture disability-related data, resulting in

different approaches to disability inclusion. A coordinated approach – developing standardized, inclusive questionnaires, indicators and guidelines – would enhance inclusion outcomes. Moreover, the limited awareness of the HPC among OPDs, combined with a lack of disability-inclusion skills among regular humanitarian personnel, further hampers meaningful participation and the effective implementation of follow-up measures.

A recent effort by HI for a standalone disability-inclusion mechanism highlighted differing views: the protection cluster preferred to keep disability under the GITT, reflecting wider debates over how best to secure systematic attention for disability inclusion. One promising way forward can be the transformation of the Technical Support Mechanism on Disability Inclusion into a dedicated Disability-Inclusion Task Team (DITT) alongside the GITT, ideally co-led with OPDs and a United Nations organization. DITT can leverage GITT's existing coordination framework to ensure their respective efforts are mutually reinforcing. This can be achieved through regular meetings dedicated to workplan alignment, identifying concrete programming and coordination synergies, and fostering collaborative opportunities. This initiative could further enhance the integration of disability inclusion within humanitarian coordination, but it may be hard to realize given the current decline in donor funding.

© CBM
Description: A mother pushes her daughter's wheelchair on the way to school in Juba. She has lived with a physical impairment since being born prematurely (2023).

While the ICCG has made progress, a more holistic approach is needed so that disability considerations permeate all areas of inter-cluster coordination. Although agencies like IOM and UNICEF work with OPDs, a unified strategy is still lacking, which hinders consistent and comprehensive meaningful participation and empowerment. Pooled funds (such as CERF and SSHF) paying growing attention to disability inclusion, as well as more advanced disability inclusion in data collection (including needs assessments and resource mobilization) can be seen as the first indications of the humanitarian program cycle becoming more disability inclusive in South Sudan.

4.5 Coordination in the Humanitarian Country Team

The HCT is the key coordinating body responsible for strategic planning and coordination in humanitarian action. It leads and coordinates the overall response by building consensus among a diverse range of organizations, including United Nations organizations, donors and NGO representatives. Its primary function is to set the strategic direction and priorities, ensuring that cluster response plans align with this overarching strategy. This includes not only establishing the strategy but also ensuring compliance from the various clusters and their members. While the HCT plays a crucial role in overseeing the HPC and coordinating efforts to address the needs of the affected population – including persons with disabilities – disability inclusion is only one of its many points of attention.

The HCT's ability to effectively address disability inclusion hinges on the strong engagement and advocacy of the protection cluster and the ICCG, and therefore also GITT. These bodies serve as channels for voicing disability-related concerns. Consequently, the ultimate effectiveness of the HCT's strategic direction on disability inclusion directly relies on how the protection cluster and the ICCG integrate disability inclusion across all sectors and, ultimately, how strategically the HCT prioritizes it within the broader humanitarian response.

While the HCT previously lacked a structured system for gathering, analyzing and utilizing data disaggregated by disability – including information on the risks, capacities and unmet needs of persons with disabilities – the current HNRP incorporates some disability-related data. However, a more structured and systematic approach to gender, age and disability disaggregated data, can help close remaining information gaps and promote the utilization of data for more inclusive programming. Collaboration between the HCT and disability-focused organizations can be instrumental not only in refining tools, indicators and guidelines but also in providing necessary training to humanitarian workers, equipping them to better serve the needs of persons with disabilities.

There are challenges associated with the implementation of the *IASC Guidelines* at HCT due to the varying guidelines used by different United Nations organizations. United Nations personnel often favor their own organizational guidelines over the *IASC Guidelines*, resulting in a fragmented approach that hampers cohesive implementation. Despite efforts to promote disability inclusion, these different approaches hinder unified strategic coordination and the prioritization of the *IASC Guidelines*. It remains unclear how thoroughly the *IASC Guidelines* are integrated into HCT discussions, though it is notable that all United Nations organizations address the four 'must-do' actions, albeit using different terminology and frameworks.

Effective coordination within the HCT depends on a flow of information that reflects on-the-ground realities, with state-level data guiding country-level humanitarian strategies. The HCT's top-down structure and restricted membership – which do not currently include dedicated representation from disability-focused INGOs – limit attention to disability concerns. When disability concerns arise, they must be channeled through other clusters, such as the protection cluster coordinator, or the ICCG can weaken the focus on disability-specific issues. This indirect approach highlights a broader challenge in achieving direct representation for disability inclusion, which impacts the HCT's ability to steer humanitarian action toward greater inclusivity and effectiveness.

5. Recommendations

The following recommendations emphasize the vital role that each type of actor can play in ensuring disability-inclusive protection programming and improving coordination in accordance with the *IASC Guidelines*. These recommendations seek to encourage meaningful participation, eliminate barriers, empower OPDs and support data disaggregation in a structured manner. Although specific contexts and capacities may vary, all stakeholders have the chance to engage in local efforts that position persons with disabilities at the center of humanitarian protection and coordination. The ultimate goal is to systematically address disability as a cross-cutting priority, ensuring that persons with disabilities not only receive equitable protection services but also actively shape and assess them. Furthermore, enhancing coordination in the field and nationally is fundamental to fostering timely and appropriate implementation of such initiatives.

OPDs should/can:

- **Collaborate in data collection:** Proactively partner with humanitarian agencies to ensure data on disability is accurately collected, disaggregated and analyzed, including the full range of impairments.
- **Expand local outreach for emergency preparedness:** Strengthen grassroots networks and informal organizations for persons with disabilities in remote areas, thereby broadening representation in protection programs.
- **Empower and build capacity:** Deliver targeted training on protection standards to empower and enhance capacity in line with *IASC Guidelines*.
- **Engage in co-implementation:** Advocate to co-implement protection initiatives with NGOs and United Nations organizations, positioning OPDs as equal partners with capacities.
- **Making accountability to the affected population (AAP) more inclusive:** Engage OPDs and/or affected persons with disabilities in making existing AAP mechanisms accessible to all.

Local NGOs should/can:

- **Advance partnerships:** Collaborate closely with OPDs to co-design, implement and monitor inclusive programming.
- **Capacity development:** Create mentorship opportunities that enable OPDs to lead or co-lead initiatives, enhancing both employment prospects and community ownership.
- **Build on existing good practices:** Proactively identify and remove structural, attitudinal and environmental barriers that limit meaningful participation of persons with disabilities in all programming stages.

- **Enhance disability awareness and programming skills:** Train staff on the *IASC Guidelines*, including the four 'must-do' actions and practical ways to identify and support persons with disabilities, including creating referral pathways from affected regions to rehabilitation centers.

Disability-focused INGOs should/can:

- **Strengthen representation in key NGO representation and humanitarian coordination forums:** Actively seek and advocate for consistent representation in key coordination forums, such as the NGO Forum and the protection cluster, as well as the technical support mechanism within GITT, to ensure disability inclusion as a cross-cutting theme in humanitarian responses.
- **Dedicated disability-inclusion funding:** Expand advocacy in collaboration with OPDs to engage donors in establishing earmarked budget lines that support disability-inclusive humanitarian programming based on unmet needs.
- **Support OPD registration:** Assist OPDs in registering with national administrations as part of emergency preparedness and humanitarian action. This step enables them to receive funding, form official partnerships and facilitate participation in international humanitarian efforts.
- **Local empowerment:** In partnership with interested OPDs, continue supporting localization of disability-inclusion expertise through mechanisms such as the localized technical support mechanism and similar peer-learning efforts targeting local protection NGOs.
- **Engage informal disability networks:** Meaningfully involve informal networks of persons with disabilities in protection programming and, where applicable, in coordination meetings in the absence of a formal OPDs.

United Nations organizations should/can:

- **Mainstream the four 'must-do' actions in all programming:** Integrate the four 'must-do' actions in all proposals (protection and others), training materials and partnership agreements to ensure consistency across agencies.
- **Removal of barriers:** Ensure partners in protection programming are supported and adhere to advancing disability inclusion within protection programming efforts.
- **Capacity development:** Ensure field offices and teams have sufficient disability-inclusion expertise to advance protection programming to reach those most at risk.
- **Strengthen protection programming:** Further integrate protection programming with the *IASC Guidelines* and its four 'must-do' actions, and partner with OPDs to maximize protection outcomes.
- **Foster collaborative initiatives:** Partner with OPDs and disability-focused INGOs to pilot joint protection projects, using lessons learnt to inform larger-scale programming.

The protection cluster should/can:

- **Support OPD participation more systematically:** Identify measures to support OPDs' participation and ensure disability is a standing agenda item in cluster meetings to amplify the perspectives and priorities of persons with disabilities in protection risk monitoring and response.
- **Support guidance on data collection and information sharing:** In partnership with OPDs and disability-focused actors, encourage cluster partners to agree on quality data-collection guidance, such as the use of the WG-SS, and to integrate disability-specific barriers into existing protection risk and needs assessments, monitoring efforts, protection analytical updates and centrality of protection reporting.
- **Conduct capacity-building:** Continue regular refresher training on *IASC Guidelines*, disability-inclusive protection programming and barrier-removal strategies, targeting cluster members, and integrate disability in other existing protection training initiatives.
- **Establish disability focal points:** When possible, appoint dedicated disability focal points within the cluster to advance disability inclusion, including by supporting the protection cluster coordinator in advocating for the unmet needs and protection risks of persons with disabilities.

GITT should/can:

- **Strengthen disability-focused indicators:** Incorporate more detailed indicators, including disability indicators and other relevant tools, to measure progress on disability inclusion and hold clusters accountable.
- **Foster partnerships with disability-focused NGOs:** Encourage clusters and GITT members to partner formally with disability-focused NGOs, leveraging their expertise and networks with OPDs.
- **Hold annual disability-focused reviews:** Conduct an annual review of the GITT's disability-inclusion work, assessing achievements, gaps and lessons learnt, and feeding results back into the roadmap.
- **Highlight disability in funding strategies:** Advocate with donors and the HCT to emphasize the importance of dedicated funding for disability inclusion, preventing it from being overlooked amid other priorities.
- **Establish DITT:** Establish a dedicated DITT on equal footing with the GITT and attached to the ICCG. The DITT should work in close coordination with the GITT to ensure synergies are leveraged and gaps are addressed in inter-agency cooperation and information sharing, supporting a people-centered response that is accountable to the diverse needs and protection concerns faced by men, women, boys and girls, with and without disabilities.

ICCG should/can:

- **Advance disability inclusion as cross-cutting theme in inter-cluster coordination:** Assess the level of integration of the *IASC Guidelines* recommendations within the inter-cluster work. According to findings, integrate steps to address gaps within ICCG annual planning to ensure disability is mainstreamed as a cross-cutting theme in inter-cluster strategies and in the HPC, aligned with the *IASC Guidelines*.
- **Invite inclusion specialists on key protection concerns:** Extend invitations to disability-inclusion experts from OPDs or specialized INGOs to participate in high-level ICCG meetings and strategic discussions.
- **Develop shared inter-cluster disability data collection guidance:** Task the Information Management Working Group and the GITT to facilitate a process that results in an inter-agency guidance on quality disability-inclusion data collection, monitoring and information sharing for programming.
- **Conduct annual reviews:** Discuss practical ways to monitor the progress of integrating disability across the clusters, aligned with the *IASC Guidelines*.

HCT should/can:

- **Discuss steps to advance disability inclusion in the HCT:** Identify key gaps and enablers in advancing a humanitarian response that ensures targeting and monitoring the inclusion of persons with disabilities, based on the *IASC Guidelines* and the NDIP across areas of work of the HCT. Establish a roadmap and resources to address gaps.

6. Conclusions

Humanitarian actors in South Sudan have made progress in recognizing disability as an important theme in both protection programming and coordination. Notably, many actors – ranging from disability-focused INGOs to United Nations organizations – have begun to adapt modalities of delivery, often focusing on physical accessibility and incorporating disability-specific support services (e.g., rehabilitation and assistive technology). Likewise, coordination forums – such as the protection cluster and ICCG – increasingly highlight disability inclusion. Despite these encouraging trends, the systematic integration of *IASC Guidelines* recommendations and its four 'must-do' actions has remained a work in progress.

Moreover, the financial outlook for humanitarian action in South Sudan (and globally) is dire. While progress (albeit uneven) has been achieved despite reduced funding, further advancement in disability inclusion still requires sustained investment in capacity strengthening and adjustments to delivery modalities. Incorporating disability-inclusive data collection, which may involve additional costs, poses particular challenges in this context of shrinking financial resources. As a result, humanitarian actors face the tough dual task of not only maintaining momentum toward inclusive programming but also securing the necessary funding to ensure that the commitments outlined in international guidelines can be fully realized.

A central challenge is that disability is often treated as a sub-theme within protection rather than as a genuinely cross-cutting priority in humanitarian programming and coordination. This difference in approaches contributes to uneven protection programming and coordination; in some cases, partners tackle attitudinal barriers, ensuring that persons with disabilities are included in decision-making forums, while in others, disability is overlooked completely. The absence of a dedicated DITT, coupled with an unclear mandate for integrating the *IASC Guidelines* into cluster activities, further undermines consistency and therefore efficiency in responding to diverse needs.

Discourse in humanitarian action frequently positions disability inclusion as an additional component rather than a cross-cutting theme to be systematically addressed, which is particularly evident in how protection clusters and coordination bodies frame disability issues within broader humanitarian planning. Resource constraints and competing priorities often reduce disability inclusion to a narrative of limitations rather than possibility. At the same time, the intersectionality with other humanitarian concerns frequently results in disability considerations being marginalized in broader humanitarian programming and coordination.

The shortage of reliable granular data is a concern across the clusters and other coordination bodies. Though some organizations (attempt to) use the WG-SS, data analysis seldom reflects on the intersectionality between gender, age and disability. This is because it rarely disaggregates findings, especially among people with different functional difficulties. These gaps become visible in conflict-affected or remote locations like Pibor, where local services and the presence of OPDs are very limited. Without robust data to determine who is being reached and how, it is difficult to tailor interventions to the diverse needs of persons with disabilities.

Issues around knowledge and capacity also limit the realization of inclusive practices. While disability-focused NGOs – such as HI, CBM, LFTW and OVCI – are well-versed in the *IASC Guidelines*, many other humanitarian actors lack familiarity with the four 'must-do' actions. This is partly due to the high turnover of staff across NGOs, United Nations organizations and donor offices, disrupting institutional memory. OPDs mentioned that even when training is offered, it often takes the form of one-off workshops rather than sustained capacity-development programs that could embed disability inclusion in organizational culture and practice. Most OPDs and humanitarian organizations are insufficiently aware of the DRG's online modules on disability inclusion, and only a few of them have followed the HI Review, Adapt and Action Learning Labs (as part of the LNOB project). Moreover, insufficient or inconsistent funding further complicates attempts to promote disability inclusion, such as by making infrastructure accessible or procuring necessary assistive devices. The existing coordination mechanisms have played a crucial role in promoting disability mainstreaming, but they are often hampered by resource constraints and varying levels of expertise among humanitarian actors.

Meaningful participation of persons with disabilities is an aspirational goal rather than an across-the-board reality. While some progress has occurred – which has enabled more persons with physical impairments to participate in consultations – those with hearing, psycho-social, intellectual or multiple disabilities are frequently excluded, especially outside Juba (e.g., Pibor). This exclusion stems from stigma, inadequate outreach (as many remain unidentified in needs assessments) and a dearth of accessible communication methods (such as sign language, braille, or adapted psychosocial support). Additionally, even when persons with disabilities attend humanitarian meetings, reasonable accommodations and services – such as sign language interpretation – are rarely available.

On the policy level, there is also some progress. The ratification of the CRPD and the existence of national disability and inclusion policies have laid the foundation for more decisive action. Ministries such as the Ministry of Gender, Child and Social Welfare have taken steps toward recognizing the rights of persons with disabilities, but weak interministerial coordination and a lack of budget allocations limit the influence of these policy measures. Both the ICCG and the HCT have signaled general support for inclusive approaches, but systematic mainstreaming remains elusive. Disability-focused NGOs frequently provide technical expertise, but their engagement in key forums is insufficiently institutionally guaranteed.

Meanwhile, OPDs – particularly at the state and local levels – face constraints. They have limited resources and depend on partnerships with disability-focused NGOs or donor-funded projects. Their presence in coordination structures outside Juba, like in Pibor, is minimal, preventing local-level feedback and perpetuating service gaps. Although some OPDs in urban centers have grown stronger in advocating for disability inclusion, underrepresentation in regions like Pibor undermines implementation of the 'must-do' actions. OPDs in Juba, particularly their leadership, show greater awareness and responsiveness. Local NGOs often lack disability-inclusive projects and familiarity with the *IASC Guidelines* unless they collaborate with disability-focused NGOs and/or OPDs or have committed leadership that supports the adjustment of programming modalities.

In sum, while humanitarian actors in South Sudan have taken noteworthy steps to integrate disability into protection programming and coordination, these efforts remain uneven and hampered by multiple obstacles. Fragmented implementation of the *IASC Guidelines*, insufficient data disaggregation, lack of funding and the underrepresentation of persons with disabilities in HPC and coordination forums all contribute to a system insufficiently fulfilling the rights-based and inclusive vision encapsulated by the *IASC Guidelines*. Strengthening coordination mechanisms, ensuring sustainable capacity-building and mobilizing the necessary technical and financial resources are essential next steps. Above all, consulting persons with disabilities in project design, needs assessments and HPC will be critical if the humanitarian response by South Sudan is to align with the CRPD and the *IASC Guidelines*.

6.1 Future Research Directions on Disability Inclusion in South Sudan

This section indicates some areas for further research that can help foster disability inclusion and coordination.

- **Evaluating disability inclusion in resource-constrained contexts:** Research should prioritize monitoring and evaluation of disability-inclusion implementation, specifically within resource-limited humanitarian settings. This requires developing context-appropriate performance indicators and frameworks that go beyond general inclusion metrics. The focus should be on identifying what specific changes in coordination, data collection, data use, programming and operations demonstrably lead to meaningful participation of persons with disabilities in coordination mechanisms and equitable access to sector-specific humanitarian assistance. This research needs to be conducted in close partnership with OPDs, local actors and humanitarian responders to ensure relevance and practicality, with the goal of identifying scalable and adaptable best practices.

- **Longitudinal studies on the impact of capacity-building initiatives for OPDs in humanitarian contexts:** While capacity-building for OPDs is recognized as fundamental for effective participation in humanitarian action, there is a need for longitudinal studies to evaluate the long-term effectiveness of these initiatives. Future research should focus on tracking the progress of OPDs engaged in humanitarian response over several years, analyzing how leadership development, financial training and technical support influence their advocacy, organizational stability and impact on humanitarian policy and practice. This research should also examine the specific challenges OPDs face in sustaining gains from such initiatives within the often volatile and resource-constrained humanitarian context, and what additional support mechanisms are needed to ensure their sustained engagement and influence in humanitarian action, both in general and protection programming and coordination practices.

- **Exploring the intersection of disability with gender, age and geography:** Future research should delve deeper into how factors like gender, age and regional disparities influence the experiences of persons with disabilities. Investigating how women, children and other individuals with disabilities from remote or conflict-affected areas navigate barriers to inclusion could provide valuable insights into how policies can be better tailored to meet the diverse needs of different groups within the disability community.

- **Evaluation of coordination mechanisms within humanitarian action:** Research on the effectiveness of coordination mechanisms in humanitarian response is limited. Future studies could assess the current state of cross-cluster coordination and the role of disability inclusion within these frameworks.

- **Comparative studies on disability inclusion across conflict zones:** Given that South Sudan is a conflict-affected country, research could compare the challenges and successes of disability-inclusion efforts in different regions of South Sudan or with those in other conflict or post-conflict settings.

- **Technology and innovation for disability inclusion:** Research on digital innovations for disability inclusion remains limited in humanitarian action. Studies could explore how technologies like assistive devices, mobile health platforms and inclusive digital education improve access, examine adoption barriers in rural areas and identify partnership opportunities with tech companies.

- **The influence of regional and international frameworks on disability inclusion in humanitarian crises:** Future research should explore how regional bodies like the African Union and the African Disability Forum, as well as international forums such as the International Disability Alliance and the European Disability Forum, shape disability-inclusion policies in humanitarian crises. Comparative studies on policy adaptation – especially in conflict-affected regions like South Sudan – could offer valuable insights into how these forums can cooperate and collaborate, ultimately promoting more inclusive humanitarian action.

Bibliography

Accord. (2013, July 12). *Interethnic conflict in Jonglei State, South Sudan*. **https://www.accord.org.za/ajcr-issues/interethnic-conflict-in-jonglei-state-south-sudan/**

ACROSS. (2025). *Summary of ACROSS projects in South Sudan*. **https://across-ssd.org/summary-of-across-projects-in-south-sudan/**

Felix da Costa, D. (2018). *Changing power among Murle chiefs: Negotiating political, military and spiritual authority in Boma State, South Sudan*. Rift Valley Institute. **https://www.refworld.org/reference/countryrep/rvi/2018/en/121831**

Felix da Costa, D. (2023). The politics of being Murle in South Sudan: State violence, displacement and the narrativisation of identity. *Journal of Eastern African Studies, 17*(3), 404–423. **https://doi.org/10.1080/17531055.2023.2259547**

Funke, C. (2023). No context is too challenging: Promoting, doing and achieving inclusion in the humanitarian response in South Sudan. *International Review of the Red Cross, 105*(922), 375–395. **https://doi.org/10.1017/S1816383122000546**

Global Protection Cluster. (2023). *PC SSD 2024 Protection needs and response plan strategy, highlights and detailed information*. **https://globalprotectioncluster.org/index.php/publications/1665/coordination-materials/response-plan/pc-ssd-2024-protection-needs-and-response**

Global Protection Cluster. (2024). *The four areas of responsibility*. **https://globalprotectioncluster.org/about/our-structure/the_four_areas_of_responsibilities**

Harpur, P. (2012). Embracing the new disability rights paradigm: The importance of the Convention on the Rights of Persons with Disabilities. *Disability & Society, 27*(1), 1–14.

Human Rights Watch. (2025). *South Sudan: Events of 2023*. **https://www.hrw.org/world-report/2024/country-chapters/south-sudan**.

Inter-Agency Standing Committee (IASC) (2015). *Multi-sector initial rapid assessment (MIRA) guidance*. IASC. **https://interagencystandingcommittee.org/sites/default/files/migrated/2019-02/mira_manual_2015.pdf**

International Organization for Migration (IOM). (2022a). *Disability and Inclusion Survey Tonj South County, Warrap*. IOM. **https://dtm.iom.int/es/node/21586**

International Organization for Migration (IOM). (2022b, 5 August). *IOM empowers more than 200 persons with disabilities with functional literacy and mobility skills*. **https://southsudan.iom.int/news/iom-empowers-more-200-persons-disabilities-functional-literacy-and-mobility-skills**

International Organization for Migration (IOM). (2023). *Disability and inclusion survey: Aweil South County, Northern Bahr El Ghazal*. IOM. **https://dtm.iom.int/reports/south-sudan-disability-access-inclusion-survey-aweil-south-county-july-august-2022**

Integrated Food Security Phase Classification (IPC). (2023). *South Sudan: IPC Acute Food Insecurity and Malnutrition Analysis September 2023 – July 2024*. IPC. **https://www.ipcinfo.org/fileadmin/user_upload/ipcinfo/docs/IPC_South_Sudan_Acute_Food_Insecurity_Malnutrition_Sep2023_July2024_report.pdf**

Lough, O., Barbelet, V., & Njeri, S. (2022). *Inclusion and exclusion in humanitarian action: Findings from a three-year study*. Humanitarian Policy Group. **https://odi.org/en/publications/inclusion-and-exclusion-in-humanitarian-action-findings-from-a-three-year-study/**

Organismo di Volontariato per la Cooperazione Internazionale (OVCI). (2023). Promotion of access and inclusion for empowerment of people with disability in Juba South Sudan. **https://ovci.it/index.php/en/what-we-do/south-sudan/promotion-of-access-and-inclusion-for-empowerment-of-people-with-disability-in-juba-south-sudan**

Organismo di Volontariato per la Cooperazione Internazionale (OVCI). (2024, 9 July). *South Sudan – completed projects*. **https://ovci.org/index.php/en/87-cat-cosa-facciamo/sud-sudan/1391-south-sudan-completed-projects**.

Oxfam International. (2024, 29 July). *South Sudan: People in Pibor County resort to eating wild vegetables as hunger crisis deepens*. **https://www.oxfam.org/en/press-releases/south-sudan-people-pibor-county-resort-eating-wild-vegetables-hunger-crisis-deepens**

Protection Cluster South Sudan (2023). *South Sudan Protection Analysis Update*. Global Protection Cluster. **https://globalprotectioncluster.org/index.php/publications/1610/reports/protection-analysis-update/south-sudan-protection-analysis-update**

REACH Initiative. (2024). *Food Security Assessment: Pibor*. **https://repository.impact-initiatives.org/document/impact/1f0a1f60/REACH_SSD_Brief_Pibor-Qualitative-FSL-Assessment_August-2024_final-1.pdf**

Sphere Association. (2018). *The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response* (4th ed.). Sphere Association.

South Sudan Humanitarian Fund (SSHF) (2024). *2023 South Sudan Humanitarian Fund Annual Report*. SSHF. **https://mptf.undp.org/sites/default/files/documents/2024-05/sshf_ar_2023_final_0.pdf**

United Nations Development Programme (UNDP). (2024). *Human Development Report 2023/2024: Breaking the gridlock: Reimagining cooperation in a polarized world*. UNDP. **https://hdr.undp.org/content/human-development-report-2023-24**

United Nations High Commissioner for Refugees (UNHCR). (2023). *Protection analysis update: Protection risks facing persons with disabilities and older persons*.

United Nations International Children's Emergency Fund (UNICEF). (2023). *Disability inclusion policy and strategy (DIPAS) 2022–2030*. UNICEF. **https://www.unicef.org/unicef-disability-inclusion-policy-and-strategy-dipas-2022-2030**

United Nations Office for the Coordination of Humanitarian Affairs (OCHA). (2024a). *South Sudan: Humanitarian Needs and Response Plan 2025*. OCHA. **https://www.unocha.org/publications/report/south-sudan/south-sudan-humanitarian-needs-and-response-plan-2025-december-2024**

United Nations Office for the Coordination of Humanitarian Affairs (OCHA). (2024b, July). *South Sudan: Humanitarian snapshot (July 2024)*. **https://www.unocha.org/publications/report/south-sudan/south-sudan-humanitarian-snapshot-july-2024**

United Nations Office for the Coordination of Humanitarian Affairs (OCHA). (2024c, December). *South Sudan: Humanitarians appeal for $1.7 billion to assist 5.4 million people in need*. **https://www.unocha.org/publications/report/south-sudan/south-sudan-humanitarians-appeal-17-billion-assist-54-million-people-need**

World Health Organization (WHO). (2011). *World Report on Disability*. WHO. **https://documents1.worldbank.org/crated/en/665131468331271288/pdf/627830WP0World00PUBLIC00BOX361491B0.pdf**

World Health Organization (WHO). (2022). *Global report on health equity for persons with disabilities*. WHO. **https://www.who.int/publications/i/item/9789240063600**