

From Commitment to Action:

Towards a Disability-Inclusive Humanitarian Response in South Sudan?

Carolin Funke and Dennis Dijkzeul

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Map 1. South Sudan



Source: United Nations, Map No. 4450 Rev. 2, July 2020.

Map 2. South Sudan and its Neighbouring States



Source: Encyclopedia Britannica, Inc.



List of Acronyms

CBM	Christian Blind Mission
CRPD	Convention on the Rights of Persons with Disabilities
FGD	Focus group discussion
HI	Handicap International – Humanity & Inclusion
IASC	Inter-Agency Standing Committee
IDP	Internally displaced persons
IFHV	Institute for International Law of Peace and Armed Conflict
INGO	International non-governmental organization
IOM	International Organization for Migration
NGO	Non-governmental organization
OCHA	United Nations Office for the Coordination of Humanitarian Affairs
OPD	Organization of persons with disabilities
UNMISS	United Nations Mission in the Republic of South Sudan
WFP	World Food Programme
WHO	World Health Organization



Executive Summary

The Inter-Agency Standing Committee (IASC) Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action (2019) set out four ‘must do’ actions to identify and respond to the needs and rights of persons with disabilities. They are: 1) promote meaningful participation; 2) remove barriers; 3) empower persons with disabilities and support them, as well as development and humanitarian actors, to develop their capacities; and 4) disaggregate data for monitoring inclusion. Developed through a participatory process over three years, the Guidelines enjoy strong moral and policy support in the humanitarian community. Two years after their launch, the question is how and to what extent they have started to find practical application in the field.

This study investigates how humanitarian organizations implement the four ‘must do’ actions in South Sudan. It shows that mainstream and inclusion-focused organizations actively promote their implementation to make disability inclusion an integral part of humanitarian action, investing heavily in capacity-building and awareness-raising at all levels of the response. Thanks to these efforts, tangible progress is being made. Humanitarian actors promote the meaningful participation of persons with disabilities and the establishment of organizations of persons with disabilities (OPDs) and self-help groups, while dual-mandate non-governmental organizations (NGOs), working in both the development and humanitarian sectors, also invest in the capacity-building of OPDs. Moreover, humanitarian organizations are removing barriers by making their distribution points and service facilities more accessible and by addressing attitudinal and institutional barriers within their organizations, for example by recruiting persons with disabilities. They also invest in the empowerment of persons with disabilities and capacity-building. Furthermore, humanitarian actors increasingly incorporate the Washington Group Short Set of Questions (see Box 1) into their monitoring and evaluation tools, including needs assessments, as well as collecting data on barriers and specific risks that persons with disabilities face.

Nevertheless, serious gaps and challenges to disability inclusion remain. Humanitarian organizations still do not recognize the diversity of disability and lack strategies to include persons with intellectual and psychosocial impairments. Moreover, persons with disabilities rarely participate in the project design phase and seldom contribute to programme development due to persisting attitudinal, environmental and institutional barriers. Furthermore, the Humanitarian Country Team in South Sudan has no systematic approach for the collection, analysis and use of either disability-disaggregated data or information on risks, capacities and unmet needs of persons with disabilities. This results in important information gaps on barriers to inclusion. In addition, communication barriers and lack of 'reasonable accommodation'¹ in consultation meetings hinder the full and effective participation of persons with hearing, visual and other types of disabilities and make them dependent on family members and caregivers.

Thus, more efforts are necessary to achieve the full inclusion of persons with disabilities. It is crucial to support meaningful participation, establish accountability mechanisms, and strengthen national OPDs so that they become independent from their international partners and gain more influence as advocates for their rights. This entails encouraging the establishment of OPDs outside the capital Juba and investing in capacity-building. Moreover, international and national humanitarian organizations, in partnership with OPDs, should continue their awareness-raising activities among local traditional leaders, communities and their own staff to reduce stigma and misconceptions, particularly against persons with intellectual and psychosocial impairments. In addition, more action is necessary to offer consultations in accessible formats so that persons with all types of impairments can make their voices heard. Finally, the Humanitarian Country Team and cluster leads should approach data collection on disability in a systematic fashion to close important data gaps and encourage humanitarian actors to use this data for inclusive programming. Otherwise, the risk of persons with disabilities being excluded and left behind will remain high.

1 'Reasonable accommodation' means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms (Convention on the Rights of Persons with Disabilities, Article 2).

Key Points

- In South Sudan, the humanitarian context is challenging.
- The government has neither signed nor ratified the Convention on the Rights of Persons with Disabilities (CRPD), nor has it taken the action needed to be able to do so in the near future.
- Misconceptions and prejudices against persons with disabilities continue to persist in society and among humanitarian staff.
- Reliable, countrywide data on disability prevalence is not available.
- The COVID-19 pandemic has negatively affected disability inclusion because it has hampered capacity-building and advocacy efforts at all levels of the response.
- Despite these challenges, the OPDs have further professionalized due to support from inclusion-focused NGOs, which operate under a dual mandate, in both development and humanitarian sectors, and which also work on stabilization, inclusive governance and civil society development. In 2020, eight OPDs founded a national umbrella body, the South Sudan Union of Persons with Disabilities. However, there are only few OPDs outside Juba and many OPDs need to invest further in capacity-building to operate independently from their international partners.
- Misconceptions and prejudices, particularly against persons with intellectual and psychosocial disabilities, are widespread and communication barriers continue to exist. However, organizations have advanced significantly in terms of making their responses more inclusive for persons with disabilities. They:
 - involve community leaders and raise their awareness on inclusion

- establish and cooperate with different types of community groups and OPDs to raise awareness on inclusion in society and among humanitarian staff
 - partner with inclusion-focused NGOs to build organizational and operational capacity on disability-inclusive humanitarian action at all levels of the response
 - set up inclusion focal points to monitor, evaluate and, if necessary, adjust their performance on inclusion
 - improve the infrastructure to make their services accessible and offer consultations in multiple formats
 - disaggregate data on age, gender and disability
 - established a Disability Technical Working Group in cooperation with the health cluster to promote inclusive health services.
- Inclusion-focused organizations support disability inclusion through partnerships with United Nations agencies and mainstream NGOs and in key coordination clusters, notably protection, education, and food security clusters. They:
 - give presentations on disability inclusion in cluster meetings to inform and sensitize humanitarian staff on the rights-based understanding of disability and introduce the IASC Guidelines and other relevant documents for inclusive humanitarian action
 - organize workshops for cluster leaders to raise awareness on the rights of persons with disabilities and existing tools for disability-inclusive humanitarian action, notably the IASC Guidelines and the Washington Group Short Set of Questions learning tools
 - carry out barriers and facilitators assessments

- develop and share documents and guidelines on disability-inclusive humanitarian action, including barriers and facilitators assessments
- offer tailor-made coaching sessions to humanitarian staff at all levels of the response
- involve OPDs in capacity-building as trainers
- recruit persons with disabilities.
- Dual-mandate NGOs, which operate in the development and humanitarian sectors, also encourage the formation of OPDs and help them organize themselves, e.g. by facilitating the establishment of a national umbrella body.
- To further promote disability inclusion, special attention should be given to the following points of action:
 - promote the meaningful participation of persons with intellectual and psychosocial impairments
 - enhance meaningful participation of persons with disabilities at all stages of the project cycle, particularly in the design and development phase
 - invest in their empowerment to enable them to claim their rights
 - support the establishment of OPDs outside Juba and investment in their capacity-building
 - improve data collection and information sharing on disability at all levels of the response and encourage the use of this data as a basis for inclusive humanitarian programming.

**NO EXCUSE!
ZERO TOLERANCE FOR SEXUAL
EXPLOITATION AND ABUSE.**

**Sexual
Exploitation:**
Abuse of a position
of power or trust for
sexual purposes

**STOP
SEXUAL
EXPLOITATION
AND ABUSE!**

Sexual Abuse:
Actual or attempted
sexual assault using
force or coercion
or sex with a child
(person below age 18)

• HUMANITARIAN ASSISTANCE AND PROTECTION
• EXCHANGING MONEY, EMPLOYMENT, GOODS OR SERVICES FOR SEX IS PROHIBITED

**INTERNATIONAL
HANDICAP
INTERNATIONAL**

24
HOURS

**Transformation
and Resilience**

UNICEF
HelpAge International
International Medical Corps

UNHCR
Sustainable Development Goals

1. No Poverty
2. Zero Hunger
3. Good Health and Well-being
4. Quality Education
5. Gender Equality
6. Clean Water and Sanitation
7. Affordable and Clean Energy
8. Decent Work and Economic Growth
9. Industry, Innovation and Infrastructure
10. Reduced Inequalities
11. Sustainable Cities and Communities
12. Responsible Consumption and Production
13. Climate Action
14. Life Below Water
15. Life on Land
16. Peace, Justice and Strong Institutions
17. Partnerships for Goal Achievement

**Sustainable
Development Goals
For All**

RESOLVE



UNHCR
Refugees and Returnees



1. Introduction

1.1 The Inter-Agency Standing Committee Guidelines on Disability Inclusion in Humanitarian Action

More than 13 years after the entry into force of the Convention on the Rights of Persons with Disabilities (CRPD), persons with disabilities remain at a high risk of being neglected and marginalized in humanitarian action. However, the Agenda for Humanity from the 2016 World Humanitarian Summit, with its commitment to leave no one behind, has accelerated efforts to include persons with disabilities in all humanitarian response efforts, especially at the international policy level.

The Charter on Inclusion of Persons with Disabilities in Humanitarian Action was launched during the World Humanitarian Summit as a tool to initiate the process of developing the Inter-Agency Standing Committee (IASC) Guidelines and pressure states parties of the CRPD to meet their obligations under its Article 11, which introduces the right to protection in humanitarian emergencies and situations of risk. To date, more than 220 stakeholders have endorsed the Charter. Signatories pledge to:

1. condemn and eliminate all forms of discrimination against persons with disabilities in humanitarian programming and policy
2. promote meaningful involvement of persons with disabilities and their representative organizations in humanitarian preparedness and response programmes
3. ensure protection for persons with disabilities as required by International Law
4. ensure that services and humanitarian assistance are equally available for and accessible to all persons with disabilities, and
5. foster technical cooperation and coordination among national and local authorities and all humanitarian actors.

To facilitate the implementation of the Charter in humanitarian practice, IASC, the highest humanitarian coordination forum in the United Nations system, established a time-bound task team to support the development of system-wide guidelines on disability inclusion.² Three years later, in 2019, after numerous meetings, technical workshops, regional and thematic consultations and the evaluation of a comprehensive online survey among humanitarian, development and disability actors, the IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action were officially launched in New York and Geneva. They reflect the input of more than 600 stakeholders and have been translated into Arabic, Spanish and French, including their respective braille and easy-to-read versions. They define four key objectives, namely to: 1) provide practical guidance on disability inclusion in humanitarian programming and coordination; 2) increase the capacity of humanitarian actors; 3) raise their awareness on their accountability to include persons with disabilities; and 4) increase the participation of persons with disabilities in preparedness, response and recovery. To meet these objectives, the Guidelines establish four concrete ‘must do’ actions, which apply to all humanitarian sectors and contexts:

1. promote meaningful participation
2. remove barriers
3. empower persons with disabilities and support them to develop their capacities, and
4. disaggregate data for monitoring inclusion.³

2 The task team comprised United Nations agencies, non-governmental organizations (NGOs), organizations of persons with disabilities (OPDs), and included United Nations member states as observers. (IASC 2019, <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/launch-iasc-guidelines>, accessed 29 July 2021).

3 These points reflect the three key areas of inclusion in the Humanitarian Inclusion Standards (Age and Disability Consortium, 2018, p. 10): 1) data and information management; 2) addressing barriers; 3) participation of older people and people with disabilities and strengthening of their capacities.

The question arises of the extent to which humanitarian agencies and organizations have begun to use and apply these four ‘must do’ actions in their country operations. To shed light on this question, and to detect challenges and progress towards disability-inclusive humanitarian action, including for persons with intellectual and psychosocial disabilities, who are most at risk of exclusion, this research report examines the implementation of the four ‘must do’ actions in South Sudan, site of one of the largest and most complex humanitarian crises in the world.

1.2 The Humanitarian Situation in South Sudan

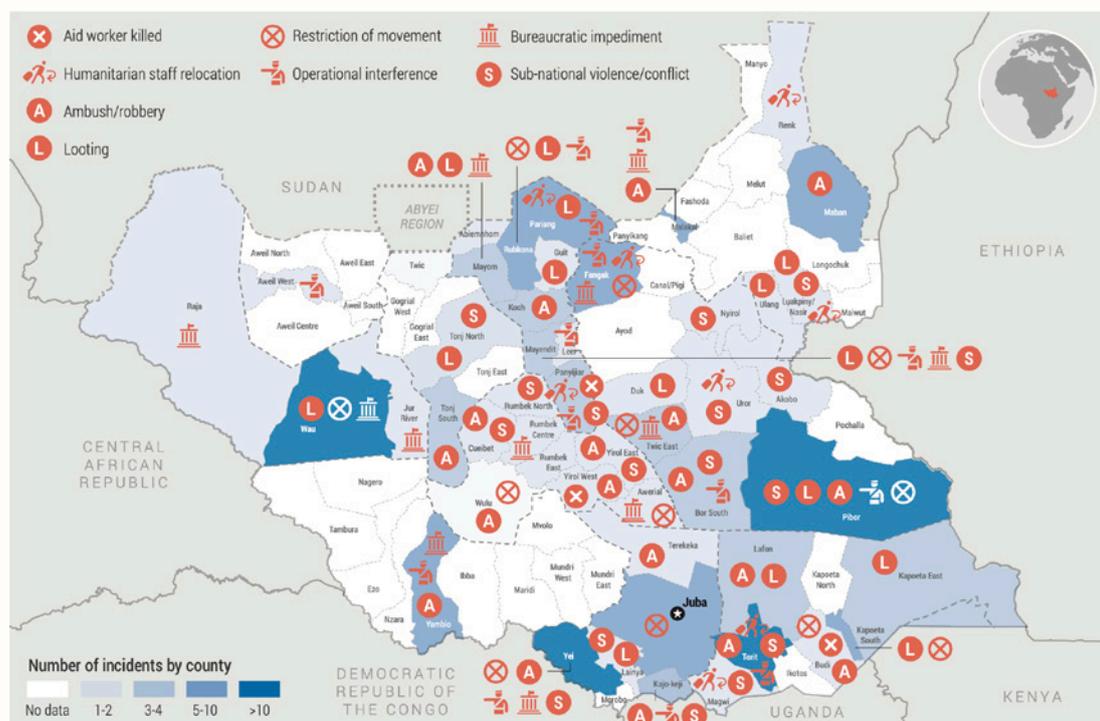
South Sudan is the world’s youngest sovereign state. After a lengthy civil war with its (now) northern neighbour Sudan, the warring parties signed a Comprehensive Peace Agreement in 2005, which paved way for a referendum on independence six years later. In January 2011, 99 per cent of the voters chose to secede. In the same year, on 9 July, South Sudan, with support from the international community, declared its independence and became the newest member of the United Nations system (International Crisis Group, 2021, p.4–5). Two years later, armed conflict broke out again and a devastating civil war followed, leaving about 1.4 million South Sudanese displaced within their own country (Internal Displacement Monitoring Centre, n.d.) and more than 2.2 million in neighbouring states (UNHCR, n.d.).

In 2018 in Addis Ababa, Ethiopia, the conflict parties signed a Revitalized Agreement on the Resolution of Conflict in the Republic of South Sudan, after attempts to implement earlier peace accords failed (Vhumbunu, 2019). With the signing of the Revitalized Agreement, fighting between armed forces loyal to the President Salva Kiir and the opposition leader Riek Machar has largely subsided, but inter-communal violence and violence between militias and between government forces and rebel groups representing different ethnic groups continues (Mednick, 2021).

Due to the cumulative effects of years of conflict and climate change—with irregular rainfall resulting in alternating floods and long droughts—South Sudan remains in a serious humanitarian crisis. In 2021, more than 8.3 million of the country’s 11.7 million inhabitants are in need of humanitarian assistance across all 78 counties (United Nations Office for the Coordination of Humanitarian Affairs [OCHA], 2021a, p.4). Infrastructure and basic services are limited or absent in many areas. Almost half of the population do not have access to primary health care services and some 2.4 million boys and girls are estimated to be out of school (OCHA, 2021a, p.27). Food insecurity is high: for 2021, an estimated 7.7 million people were expected to be in need of food assistance, with more than 1.4 million children being acutely malnourished. This is the highest level of food insecurity and malnutrition since independence (*ibid.*). The quantity of water available per day is also below standard in many locations and every fifth person is unable to collect enough for drinking (OCHA, 2021a, p.26). Subnational violence, violence against humanitarian personnel and assets, bureaucratic impediments, operational interference, and COVID-19 movement restrictions hamper people’s ability to access humanitarian action. Moreover, they create a challenging operating environment for humanitarian aid workers and aggravate the humanitarian crisis on the ground (OCHA, 2021b).

Persons with disabilities are at high risk of exclusion. South Sudan is one of the few states worldwide that has neither signed nor ratified the CRPD and legislative processes to do so have stalled. Chapter 3 will provide more details about the situation of persons with disabilities and the legal and policy context.

Figure 1. Access Incidents and Key Constraints



Source: OCHA (2021c), June 2021.

1.3 Purpose and Key Research Questions

This report presents findings from three months of remote research on disability-inclusive humanitarian action. It analyses how humanitarian actors try to address these barriers for persons with disabilities and explores whether they approach inclusion from a rights-based understanding of disability. More precisely, it examines how humanitarian organizations implement the four ‘must do’ actions of the IASC Guidelines and identifies challenges and progress in this process. The research has been guided by the following central research questions:

- How do humanitarian actors strive to ensure access to their aid and protection services for persons with disabilities (through meaningful participation, removal of barriers, empowerment, and collection and analysis of disaggregated data) and how do inclusion-focused organizations support mainstream actors in this process?

By answering these questions, this report seeks to describe and understand both challenges and progress in implementing the IASC Guidelines in an extremely challenging humanitarian context.

1.4 Relevance

The IASC Guidelines are relatively new and supplement existing international guidance documents that support the inclusion of persons with disabilities as a crosscutting issue in all humanitarian response structures. Other important guidance documents include, for instance, the Humanitarian Inclusion Standards for Older People and People with Disabilities and the United Nations Disability Inclusion Strategy. The IASC Guidelines explicitly refer to the Humanitarian Inclusion Standards for Older People and People with Disabilities but differ in that they apply to all humanitarian actors involved in policymaking, coordination and programming, and are not limited to multilateral organizations, like the United Nations Disability Inclusion Strategy (IASC, 2019, p.3). Moreover, the process of development and scope of the IASC Guidelines are ground-breaking, involving a truly participatory process that has been co-led by persons with disabilities and their representative organizations.⁴ Importantly, the IASC officially endorsed the Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action in 2019, this giving them the authority to inform humanitarian practice in all sectors and humanitarian settings.

4 The process was co-led by the International Disability Alliance of 14 global and regional organizations of persons with disabilities, the United Nations Children's Fund (UNICEF) and Handicap International – Humanity & Inclusion (HI).

In the same year, alongside the launch of the Guidelines, the IASC published a collection of case studies on the inclusion of persons with disabilities in humanitarian action. The document includes 39 examples of field practices, and lessons learned from 20 countries (Christian Blind Mission [CBM], International Disability Alliance [IDA], and Handicap International – Humanity & Inclusion [HI], 2020). Moreover, the IASC Results Group 2 on Accountability and Inclusion issued a short case study on the COVID-19 Response in Humanitarian Settings, which includes examples of Good Practices for Including Persons with Disabilities by the United Nations system (IASC, 2020). Nevertheless, despite these exceptions, empirical studies, which explore whether and how humanitarian actors use these Guidelines and consider local or contextual factors before and during their implementation, are rare. These examples and case studies mainly reflect experiences of practitioners and are not based on a comprehensive research agenda. Thus, there are still important knowledge gaps with regard to the practical application of the four ‘must do’ actions of the IASC Guidelines in particular and disability inclusion in general. This study addresses these gaps and aims to support humanitarian actors in South Sudan, and in other, similar crises, to apply and implement the four ‘must do’ actions. Moreover, it helps us better understand the potential of the IASC Guidelines in making humanitarian action truly inclusive for persons with disabilities.

1.5 The Structure of This Report

This report is divided into five chapters. Chapter 1 introduces the main purpose and contents of this report. Moreover, it describes the IASC Guidelines on Disability Inclusion and presents an overview of the humanitarian situation in South Sudan. Chapter 2 elaborates the methodology for data collection and analysis and outlines the study’s limitations. Chapter 3 describes the main barriers to disability inclusion. Chapter 4 takes the four ‘must do’ actions as a starting point to examine how mainstream and inclusion-focused organizations address these challenges and facilitate disability inclusion in South Sudan. Chapter 5 summarizes the main findings and makes recommendations to donors, national decision-makers, humanitarian organizations, persons with disabilities and OPDs, as well as to researchers to further improve disability-inclusive humanitarian action.



2. Methodology

This report takes an explorative and qualitative approach because the implementation of the IASC Guidelines into humanitarian programming and organizational structures remains under-researched. It is the second case study in the project 'Phase 2 – Leave No One Behind! Mainstreaming Disability in Humanitarian Action' and builds on the methodology and experiences of earlier field research in Cox's Bazar, Bangladesh (Funke and Dijkzeul, 2021). A qualitative approach allows for a nuanced understanding of practices and local dynamics that encourage or limit the inclusion of persons with disabilities in humanitarian action and can best reflect the participants' subjective standpoints and perspectives.

2.1 Case Selection

South Sudan was selected as a case study to explore the implementation of the four 'must do' actions for three reasons.

First, the research could focus on the use and implementation of the IASC Guidelines in one of the worst and most complex humanitarian crises worldwide. Challenges and opportunities that arise during the implementation of the four 'must do' actions – although highly context-specific – may also apply in other demanding humanitarian crises, particularly in the same region, e.g. Sudan, Somalia, the Democratic Republic of the Congo and Tigray, Ethiopia. As mentioned, ongoing communal violence, combined with the threats of the COVID-19 pandemic, drought and irregular episodes of abnormally heavy rainfall, which culminate in severe flooding, mean that humanitarian assistance is much needed and unlikely to end in the near future. In such a fragile context, it is important to consider the needs and specific requirements of persons with disabilities and to study how they can better be included in the humanitarian response in the long-term so that they have sustained access to services and can make their voices heard.

Second, humanitarian organizations have become increasingly aware of persisting barriers to disability inclusion and have scaled up their support for persons with disabilities. In 2020, the South Sudan Humanitarian Fund (2021, p.21) targeted 173,000 persons with disabilities, which is 12 per cent of the total beneficiary population.⁵ Moreover, many clusters and organizations intensified their collaboration with OPDs (ibid.). In particular, the health cluster has made important strides to improve the access and quality of services for persons with disabilities (ibid., p.52). This makes South Sudan an intriguing context to study disability inclusion, especially to assess whether and how humanitarian actors are already implementing the IASC Guidelines in their programmes and organizational structures.

Third, as both HI and CBM have been working in South Sudan for many years, they have established close partnerships with the UN, humanitarian and development NGOs, OPDs and relevant government bodies. These partnerships widened the scope of this study significantly and enabled the researchers to conduct interviews with a diverse group of humanitarian staff from different types of organizations. Moreover, HI was able to organize focus group discussions with representatives from organizations of persons with disabilities in Yei and Yambio, although these discussions did not provide much information on barriers and needs of persons with intellectual and/or psychosocial disabilities.

2.2 Data Collection Methods

Research was carried out remotely for ten weeks between June and August 2021. It involved 15 key informant interviews with representatives from United Nations agencies, international NGOs, including disability inclusion organizations, and OPDs. All but one interviews were conducted via Zoom or Skype and lasted for about 30 to 60 minutes. One interview partner, who had serious problems with the internet connection, answered the questions in writing. All interview partners on Skype or Zoom gave permission for their interviews to be recorded and transcribed.

5 OCHA manages Country-Based Pooled Funds, which allow donors to pool their contributions into single, unearmarked funds. They are available for NGOs, the Red Cross and Red Crescent Movement and UN agencies. See: OCHA (n.d.) Country-based Pooled Funds.

To ensure confidentiality, the names and affiliations of the informants are kept anonymous in this report, unless, prior to the interview, they gave permission to mention their names. HI and CBM staff in South Sudan contacted their partners in advance to inform them about the research project and the purpose of this case study.

Interviewees were first asked general questions about the mission of their respective organization, the length of their presence in South Sudan and their fields of operation. Moreover, they were asked to comment on the humanitarian situation in South Sudan and the main needs and protection gaps as well as ongoing barriers for persons with disabilities. Following this, questions centred on measures or actions that organizations have taken to include persons with disabilities, with a focus on the four 'must do' actions: 1) participation; 2) removal of barriers; 3) empowerment and capacity-building; and 4) disaggregation of data. Moreover, questioning aimed to uncover whether normative frameworks or standards inform the work of the organizations and if so, how and to what extent. Disability inclusion organizations were asked additional questions regarding their role in capacity-building of partner mainstream organizations and the empowerment of OPDs.

Moreover, as mentioned previously, HI organized two focus group discussions with a total of 21 representatives from organizations of persons with disabilities in Yei and Yambio (five women and five men in Yei; four women and seven men in Yambio). A discussion guide was shared with the facilitators in advance. Participants were asked to comment on possible challenges in accessing protection and assistance services and the role of OPDs in promoting the inclusion of persons with disabilities through the removal of barriers, fostering of participation, and empowerment of persons with disabilities. Participants could also give suggestions to representatives from the government and the humanitarian community on how to improve the situation for persons with disabilities on the ground.

Finally, this study also included a review of internal HI and CBM documents, including reports, barriers and facilitators assessments, project proposals and project information sheets.

2.3 Data Analysis Methods

Data were analysed using MAXQDA. To present the findings in a structured manner, Chapters 3 and 4 distinguish between ‘barriers’ and ‘progress towards inclusion’. Chapter 3 focuses on barriers to inclusive humanitarian action, based on categories we derived inductively from the data. During the coding process, and even more so during the writing process, we noticed multiple overlaps regarding the barriers and challenges to inclusion that pertain to all four essential ‘must do’ actions. For example, stigma and discrimination against persons with disabilities, and persisting misconceptions, which are examples of attitudinal barriers, pose a challenge to participation, to the removal of barriers and to empowerment, and sometimes hamper data collection and use.

To detect progress on inclusion, semantic categories were deductively derived from the four ‘must do’ actions of the IASC Guidelines, namely participation, addressing barriers, empowerment and capacity-building and data collection. We use these ‘must do’ actions to structure the data in Chapter 4. Sub-codes focused on different means of implementation, e.g. knowledge sharing, development of a policy guide/disability strategy and awareness-raising.

2.4 Limitations

This study has four important limitations. First, primary data collection in South Sudan was not possible due to restrictions as a result of the COVID-19 pandemic. This limited the number of interview partners significantly since interviews could not be arranged spontaneously ‘on the spot’. Moreover, the researchers were unable to participate in relevant meetings, visit intervention sites and learn from observations and informal conversations with humanitarian staff. For the study of disability inclusion, immersion in the field is extremely valuable because it leads to knowledge that it is hard to obtain by standardized data collection methods. As Krause (2021, p.331) notes: “Immersion and participant observation [...] enable researchers to study aspects of meaning-making that do not lend themselves easily to verbalization in interviews or surveys because the respondents find them too trivial, too embarrassing, or too traumatizing to mention.” Thus, the lack of ethnographic data is the main limitation of this study.

However, Dennis Dijkzeul was able to visit South Sudan for four weeks in September and October 2021 to complete data collection for another, unrelated, research assignment on food security. This was his third visit to the country. He is familiar with the overall context and some of the relevant organizations. His observations from his visit in 2021 and an interview with the OCHA head of office in Juba also inform this research report.

Second, the results of this study are mainly based on interviews with HI or CBM partner organizations or staff from HI and CBM themselves. This means that most key informants already have experience in disability inclusion. Those with only limited knowledge, awareness or experience have not been involved in the data collection. In this respect, it is important to highlight that the purpose of this study was not to measure the performance of individual organizations, programmes or projects with regard to disability inclusion, but rather to gain a general understanding of the challenges, progress and good practices involved in implementing the four ‘must do’ actions and better understand how they are applied ‘on the ground’.

Third, the approach of using the four ‘must do’ actions to structure the data sometimes hampered a differentiated presentation of the findings relating to the different levels and locations of the humanitarian response, e.g. at the central coordination level, the programme and field level, inside and outside internally displaced persons (IDP) camps, and inside and outside the capital Juba. Therefore, in the Conclusion, we briefly reflect on the usefulness of applying the four ‘must do’ actions in studies on disability-inclusive humanitarian action.

Finally, more comprehensive research on the implementation and use of the IASC Guidelines, particularly in combination with other normative tools, is necessary to better understand how human rights norms influence the work of humanitarian organizations. This requires more in-depth field research and comparative approaches that are beyond the scope of this study.



3. Barriers to Disability-Inclusive Humanitarian Action

Disability inclusion should be an integral part of humanitarian action. However, changing common practices and entrenched structures so that persons with disabilities can participate at all levels and stages of the humanitarian response and access crucial services requires time, expertise, financial resources and a solid evidence base. As a first step, it entails detecting practices and structures that impede the inclusion of persons with disabilities. This chapter therefore describes general factors impeding the inclusion of persons with disabilities, based on focus group discussions with OPDs, expert interviews and document analysis.

3.1 Persons with Disabilities

After years of conflict and armed violence, many citizens have been left with a long-term impairment. The last national census, conducted in 2008 before the country's independence, estimated that 5.1 per cent of the South Sudanese population had a disability. However, the humanitarian community and OPDs question the quality of that data and believe that the actual figures have always been significantly higher, reaching, at the very least, the global average of 15 per cent (IOM and HI, 2018, p.13; OCHA, 2021a, p.5).⁶ The proliferation of mines, unexploded ordinance, physical trauma and abuse, insufficient access to essential health and medical services, lack of protection, and general poverty increase the risk of acquiring long-term and preventable impairments (IOM and HI, 2018, p.13).

⁶ Recent studies suggest that about 40 per cent of all households have a member with a disability (IOM, 2021a and 2021b). Nevertheless, it is important to note that these figures relate to the household level and do not indicate the percentage of persons with disabilities in the total population. There are no reliable figures about the latter.

While the validity of the disability prevalence is questionable, evidence exists on the many types of barriers that persons with disabilities face in their daily lives. Some of these barriers affect certain groups more than others. Persons with physical impairments have difficulties accessing services and participating in livelihood opportunities because they have no access to assistive devices that would enable them to reach service points and meaningfully engage in community life. Some of them make their own devices from the material they can buy on the market or find on the streets, but these cannot replace quality assistive devices, such as crutches, wheelchairs and hearing aids (Focus group discussions [FGDs] Yambio and Yei, May/June 2021).

Moreover, persons with disabilities are discriminated against in the job market and lack job opportunities either because they have difficulty pursuing an education that would give them the necessary skills and qualifications to compete with other potential employees or because employers regard them as 'incomplete' or incapable of working. Some persons with disabilities do volunteer work, but they hardly ever engage in income-generating activities that would help them to sustain their families or contribute to their household income. Employment opportunities for persons with disabilities are scarce because environmental, institutional and attitudinal barriers exclude them from the job market, vocational skill development and from education in general (FGD Yei, June 2021). Consequently, they also have more difficulties in securing loans or support from financial institutions as well as legal services (ibid.).

In addition, inaccessible buildings, the lack of public transport possibilities and a poor road network prevent many persons with a physical impairment from reaching service points, as well as health and education facilities, which are often located far from the community. In particular, persons with a visual impairment struggle to locate services and service points (FGD Yambio, May 2021) and when they can access these facilities, the lack of tactile signals, railings, Braille markings, contrasting signage and other design features hamper their free movement (FGD Yei, June 2021). In addition, the negative attitudes of the service providers lead to discrimination and even harassment. Respondents reported that, in some health facilities, persons without disabilities were served first. Barriers and facilitators assessments in the health sector found that attitudes among health personnel varied according to the type of disability; persons with physical impairments faced less discrimination than persons with hearing or intellectual impairments (HI, 2017a, p.4).

The radio is the medium most commonly used to share information. However, households with persons with disabilities often do not possess a radio, which means that information does not reach them. Regular interaction between service providers and persons with disabilities is limited and persons with disabilities are rarely involved in decision-making, particularly in humanitarian coordination clusters and at the national policy level (FGDs in Yei and Yambio, May/June 2021).

Furthermore, even during needs assessments and registration exercises by the humanitarian community, persons with disabilities are not systematically identified or asked about their needs. Thus, in most cases, humanitarian operations do not meet the needs of persons with disabilities, and they may even impede persons with disabilities from receiving urgently needed health supplies (ibid.).

Women with disabilities are at a high risk of gender-based violence and other forms of abuse. In particular, single mothers, whose husbands have died or have left them after childbirth, are at a high risk of harassment and extreme poverty. Many of them have no access to income and can hardly provide for their children (ibid.).

Children with disabilities face many obstacles in relation to attending school due to physical barriers, a lack of understanding of inclusive education and the absence of tailored teaching methods, all of which prevent them from reaching their full potential and creating a better future for themselves. Where children do have access to inclusive education, this is often by chance, a result of the engagement of individual teachers, families and other pupils or students with disabilities (HI, 2017b, p.6). OPDs therefore suggest reforming the national teaching curriculum to make it inclusive for persons with disabilities, offering means of transport to schools for children with disabilities, and setting up a scholarship programme (FGDs in Yambio and Yei, May/June 2021).⁷

⁷ Most of these suggestions would be part of development work and are not strictly humanitarian.

Persons with intellectual and psychosocial disabilities are widely excluded from society and have no OPDs or self-help groups to voice their concerns. The interviews show that attitudinal and institutional barriers in particular prevent their meaningful participation in society and the humanitarian response. This will be discussed in further detail below.

To sum up, persons with disabilities are more at risk of exclusion than those without disabilities. While there are some commonly shared barriers for all persons with disabilities, for example, discrimination in the job market, some barriers affect certain groups more than others. In particular, children, women and persons with intellectual and psychosocial disabilities are exposed to high risks, which increase their vulnerabilities.

3.2 Legal and Policy Context

South Sudan has not yet ratified the CRPD and its Optional Protocol. However, it is bound to grant its citizens the same rights and entitlements as Sudan, which ratified the CRPD and its Optional Protocol in 2009. Although the South Sudanese civil society, including the OPD movement, strongly advocates ratification, renewed fighting and the deliberate obstruction of the reconstitution of parliament by the ruling party – in contradiction to the 2018 peace deal – have significantly stalled legislative processes until today (Voice of America, 2021).

On 4 August 2021, with a one-year delay, the new members of the first post-reconciliation Transitional National Legislative Assembly were sworn into office (United Nations Mission in the Republic of South Sudan [UNMISS], 2021), thus creating a new window of opportunity for civil society to push for ratification of the CRPD and influence the permanent constitution-building process to ensure that it reflects a rights-based understanding of disability. The current Transitional Constitution of the Republic of South Sudan of 2011 has several articles that are relevant for persons with disabilities. Article 6, for example, promotes the development of a sign language. Nevertheless, the Transitional Constitution takes a welfare approach to disability and only indirectly refers to persons with disabilities as part of a larger group of “persons with special needs”. Although it grants this group full participation in society and enjoyment of rights and freedoms, as well as “the right to the respect of their dignity” (Article 30), it fails to define who precisely belongs to the group of “persons with special needs”.

Policies relevant for the protection of the human rights of persons with disabilities are more advanced than the legislative procedures. In 2014, the Ministry of Education, Science and Technology, with support from the international inclusion-focused NGO Light for the World, issued a policy position paper (South Sudan, 2014) on a National Inclusive Education Policy. The position paper sets out a vision for inclusive education and seeks to ensure that all children are given the opportunity to reach their potential. However, the Ministry only adopted the policy in 2021.

Six years earlier, in 2015, the Ministry of Gender, Child and Social Welfare, Humanitarian Affairs and Disaster Management, the appointed line ministry for persons with disabilities, had passed a National Disability and Inclusion Policy (South Sudan, 2013), hence meeting one of the objectives of the 2011 South Sudan Development Plan. Unlike the Transitional Constitution, the Policy reflects a human rights-based understanding of disability and pursues a two-fold goal: 1) address and respond to the vulnerabilities of persons with disabilities; and 2) promote and protect their rights and dignity in an inclusive manner. Yet, like in many developing countries with weak state structures, implementation of these policies is stagnating and many persons with disabilities continue to face attitudinal, environmental and institutional barriers that prevent them from fully participating in society and meeting their most urgent needs.

3.3 Attitudinal Barriers: Stigma and Discrimination

In South Sudan, people widely believe that disability is a punishment from God or a curse (HI, 2017a, p.5). The society regards disability as a problem of the individual, and many people believe that persons with disabilities are a burden on their families and incapable of making a meaningful contribution to society (South Sudan Association of the Visually Impaired, 2016, p.1). Consequently, persons with disabilities are excluded and often remain invisible in the society. One respondent explains:

Many families hide members with a disability [...] Persons with disabilities are stigmatized within their own families and in the community. Even in public, people with disabilities are hardly mentioned.

Representative of an inclusion-focused NGO

These prejudices against persons with disabilities hamper their inclusion in the humanitarian response in several ways. At programme level, humanitarian organizations have to work with communities and community leaders who widely discriminate against and stigmatize persons with disabilities. This challenges meaningful participation, the removal of barriers, empowerment and data collection, particularly when humanitarian organizations are not aware of these negative attitudes in the society. For example, consultations and community discussions are regularly organized in locations that are hard to reach for persons with disabilities, or the relevant information is not available in multiple formats. This implies that humanitarian organizations need to be deliberate in targeting and reaching out to persons with disabilities and in assessing barriers in a comprehensive manner as part of their needs assessments. If they do not do so, persons with disabilities have no chance to make their voices heard in the response.

Yet, negative attitudes and/or misconceptions about persons with disabilities are not only widespread in South Sudanese society; they also persist in the humanitarian community. Humanitarian actors often fail to recognize the diversity of disability: if they include disability in their programmes and projects at all, they often focus on more 'obvious and visible' disabilities. To quote one respondent:

Of course, we need to write about disability in our proposals; we need to consider disabilities in our implementation. But often it is code for physical disabilities. We often do not consider intellectual disability. There is a lot of discrimination and bias and quite harsh treatment of persons with intellectual disabilities, both within the communities and also among humanitarian staff.

Representative of a United Nations agency

This statement highlights two important points. On the one hand, inclusion often begins as a strongly donor-driven process, guided by donor funding requirements. On the other hand, misconceptions about disability effectively exclude persons with certain types of disabilities, particularly those with an intellectual impairment. The same respondent adds:

When we say 'disability', we often just assume that this is a person who can't walk. I think that this is the approach we often take in our work.

Representative of a United Nations agency

In other words, despite a growing awareness of disability inclusion, continued efforts are needed to remove persisting attitudinal barriers, both within the society and among humanitarian staff. Inclusion must therefore become an integral part of principled humanitarian action for persons with all types of disabilities, not only at the policy level – enshrined in donor requirements and organizational strategies – but also in practice. Otherwise, persons with disabilities continue to be at a heightened risk of being excluded from the response.

3.4 Lack of Meaningful Participation and the Fragmented Presence of Organizations of Persons with Disabilities

As seen above, harsh treatment, invisibility and pervasive misconceptions hinder the inclusion of persons with disabilities in the society and the humanitarian response. In this context, OPDs play a critical role in advocating the rights of persons with disabilities. In South Sudan, OPDs have developed their organizational resources and capacities in recent years, with support from inclusion-focused NGOs. In 2020, for example, eight South Sudanese disability organizations, with support from the NGO Light for the World, founded a national umbrella body, the South Sudan Union of Persons with Disabilities.⁸ This body lobbies for the ratification of the CRPD and promotes the equal participation of persons with disabilities in all social, political and economic dimensions of public life (Light for the World, 2020). It should be noted, however, that the Union was established with the support of development actors rather than humanitarian funding programmes.

8 Members include the South Sudan Association of the Visually Impaired, the South Sudan Women with Disabilities Network, the South Sudan National Association for Deaf and the Jubeck State Union of the Physically Disabled.

Only a few OPDs operate outside the capital and persons with intellectual disabilities rarely organize themselves into self-help groups or OPDs. This partly explains why persons with disabilities are often forgotten in the response and face significant discrimination and harsh treatment. To remove attitudinal barriers and ensure inclusive programming, humanitarian actors should invest in inclusive needs assessments and other accountability mechanisms, and engage community leaders to identify, consult and engage with persons with disabilities.

Many humanitarian and development organizations value the work of OPDs and self-help groups, particularly for their strong links with the local communities and community leaders. In fact, numerous humanitarian organizations collaborate with OPDs and self-help groups during the implementation of their projects to ensure the participation of persons with disabilities in implementation and monitoring (Interview with an inclusion-focused NGO). However, persons with disabilities rarely participate in the development of new humanitarian programmes and projects (ibid.). This is surprising in light of the donor requirements, which ask humanitarian organizations to provide information on disability inclusion in their proposals. Despite these requirements, donors often do not work with precise indicators and allocation criteria that would ensure that at least 15 per cent of the beneficiaries are persons with disabilities (Interview with an inclusion-focused NGO).⁹ Moreover, their understanding of 'disability inclusion' is often not in line with international standards and some only interpret it as remodeling of infrastructure.¹⁰

9 Importantly, donor demands differ greatly, ranging very high to very low requirements for their partners on promoting disability inclusion. While some donors expect information on persons with disabilities as part of the needs assessments related to the target group and expect active consultations during the project design, implementation, monitoring and evaluation, others just request basic information on persons with disabilities and do not necessarily require active engagement with them. Further comparative research should closely investigate the effect of different donor requirements on the level of disability inclusion in humanitarian action.

10 Thanks to one of our reviewers for pointing this out.

At the cluster level, OPDs are not strongly represented. There are two main reasons for this. First, the COVID-19 pandemic forced the coordinators to conduct the (cluster) meetings online. Many OPDs do not have an office with stable access to the internet, and where they do, their participation is hampered by the absence of reasonable accommodation, such as sign language interpreters or subtitles. Second, although humanitarian organizations have been present in South Sudan for a long time, many OPDs are still not familiar with the humanitarian system and frequently lack the capacities to acquire funding, implement projects, and operate independently from their international partners. However, this does not mean that OPDs do not make a vital contribution.

One respondent explains:

Of course, capacity-building is important in order to improve their work. They are not so autonomous, but when they engage in awareness-raising, for example, when they talk about disability [...] they are really good. Their messages can be very strong and the fact that their organizations consist of persons with disabilities gives them a lot of credibility.

Representative of an international NGO [INGO]

These strong messages and credibility raise hope that humanitarian organizations will strengthen their collaboration with OPDs over time and invest in their capacity-building so that they can increase their representation in the cluster system. It seems certain that including persons with disabilities in needs assessments and regular consultations will further support inclusive humanitarian action at programme and project level.

3.5 Perceptions of Disability: an Additional Complexity in an Already Complex Context

Humanitarian action commonly takes place in protracted, severe and complex crises, but many respondents agree that the humanitarian context in South Sudan is one of the most challenging worldwide. The poor infrastructure, corruption, on-going armed violence, and climate change – resulting in both droughts and floods – make large parts of the country inaccessible for humanitarian actors. Although humanitarian organizations do their best to reach all people in need, even in remote parts of the country, they are not always successful. Persons with disabilities in particular are at a higher risk of being left behind because of environmental, institutional and attitudinal barriers in organizations and society.

The following quotes illustrate that humanitarian actors perceive the context as being too complex for engaging affected populations, including persons with disabilities:

Many humanitarian organizations put their tents on their back and walk into the woods. That is how you do a lot of humanitarian work. There is a physical barrier of getting to places. Oftentimes, you might not be able to access people who have disabilities on a face-to-face basis.

Representative of a United Nations agency

Another respondent adds:

Well, the donor guidelines are there, but you have to see the context. For example, when you are given two weeks to work on a project, some of the locations you are intervening are far away from Juba. The flight is only once a week, and you cannot spend the entire week in the field. So you end up writing from here [Juba] and just impose the project on them, or you try to convince them to accept that this is the package. Effectively, yes, the donor requests from you to consult with the beneficiaries. Again, this consultation cannot be robust, because there are other limitations, you know, you cannot travel to this place, or you cannot spend much time discussing with them.

Representative of an INGO

These quotes reflect the multiple attitudinal and institutional barriers of humanitarian actors who perceive disability as an ‘additional’ complexity in an already complex context. Clearly, there is a lack of understanding on how to design strategies for inclusive humanitarian action. If two weeks is too short to conduct the necessary consultations for proposal writing, organizations should work on the assumption that at least 15 per cent of the population have a disability. Moreover, when they operate in the country for longer periods, the organizations should have representative key informants in the project areas.

Furthermore, respondents highlighted that they struggled to include persons with intellectual or hearing disabilities. The following quote refers to this difficulty:

There is [sic] all kinds of layers of communication barriers, and when you add a disability on top of that, such as an intellectual disability or hearing disability, it gets a lot more complicated. One of the challenges is that no one has a good strategy for really dealing with that. No one has a really good strategy, particularly around hearing disabilities. There is something like a local sign language in some areas, but it is not something that anyone really knows how to do. And so you rely on caregivers who do the best they can.

Representative of a United Nations agency

At present, the school for sign language interpretation is not accessible for all those who need it,¹¹ but caregivers, teachers and social workers often act as interpreters. Moreover, there are some sign language interpreters in the capital Juba, but the number is very small. Students wishing to learn sign language interpretation and translation often need to go to Kenya or Uganda (interview with a representative of an INGO). The different local languages spoken across the country may be an additional communication barrier for humanitarian actors who wish to communicate with affected populations. However, it is vital that intellectual or hearing impairments do not lead to exclusion. Humanitarians should be aware that communication with deaf persons may require multiple layers of interpretation and should indicate additional costs in their budgets, including when caregivers, teachers and social workers act as interpreters.

¹¹ There exists a School for the Deaf and Dumb (using an outdated and stigmatizing word) where persons with hearing impairments are taught sign language. The research shows that not all humanitarian actors are aware of this.

In summary, there exist many misunderstandings of disability among humanitarian staff, which lead to the exclusion of persons with disabilities in practice. In particular, the number of persons with hearing impairments is likely to be under-reported and their needs not included in programming. At the very least, humanitarian actors should be aware of these barriers, use an informed estimate of 15 per cent of persons with disabilities for programming and request additional funding for interpretation services.

3.6 Conclusion

Persons with disabilities are at a high risk of exclusion. The legal and policy context is unfavourable and many attitudinal, environmental and institutional barriers hinder their access to services and their meaningful participation in the humanitarian response. Three major factors challenge disability inclusion in South Sudan:

- 1.** attitudinal barriers: stigma and discrimination in the society and the humanitarian community
- 2.** lack of meaningful participation, the fragmented OPD presence outside the capital, Juba, and the absence of OPDs representing the interests of persons with psychosocial and intellectual disabilities
- 3.** perceptions of disability as an ‘additional complexity’ or ‘yet another task’ in an already complex crisis.

Furthermore, the COVID-19 pandemic has hampered both the participation of OPDs in the cluster coordination meetings and capacity-building, as activities have had to move to an exclusively online format. It should be noted, however, that the representation and participation of OPDs in the clusters was limited even before the outbreak of the pandemic. Furthermore, the multidimensional crisis, characterized by poor governance, rampant corruption, the absence of peace and security, weak civil society and climate change, challenges an effective humanitarian response in general and inclusive humanitarian action in particular.

Despite these challenges, humanitarian organizations are making progress in delivering inclusive humanitarian action, with many investing time and effort in capacity-building, community outreach and advocacy. However, interviews demonstrate that misconceptions on disability are still common and need to be addressed in a systematic manner.



4. Progress towards Disability-Inclusive Humanitarian Action

There is no simple script for disability inclusion, particularly in demanding contexts such as that of South Sudan. However, the IASC Guidelines and the four ‘must do’ actions are a useful tool to rethink common practices, raise awareness on inclusion and initiate change in organizational structures and practices. Taking the four ‘must do’ actions as a starting point and a means to structure the data, this chapter describes the practices that support 1) meaningful participation, 2) removal of barriers, 3) empowerment, and 4) collection and analysis of disaggregated data on age, gender and disability.

4.1 Meaningful Participation

Meaningful participation occurs when persons with disabilities can participate in humanitarian decisions that affect them (IASC, 2019, p.19). Three actions are key: 1) enable the participation of persons with disabilities in all phases and levels of the response; 2) recruit persons with disabilities as staff at all levels of the humanitarian organizations; and 3) seek advice and collaborate with OPDs (IASC, 2019, p.20).

The previous chapter has shown that stigma and discrimination, the lack of OPD presence outside Juba, as well as environmental and institutional barriers, impede the meaningful participation of persons with disabilities. Either consultations and community discussions take place in locations that are hard to reach or the required information is not available in multiple formats, thus excluding persons with visual, hearing, psychosocial and other types of disabilities.

Humanitarian organizations pursue two main strategies to increase the participation of persons with disabilities. First, they work with community leaders to raise awareness of the rights of persons with disabilities and their inclusion, and second, they establish and cooperate with community groups inside and outside the IDP camps.¹²

4.1.1 Involve the Community Leaders

Community leaders play an important role in the society and “wield considerable socio-political influence” (Santschi, 2012, p.1). Although their competencies and functions differ across the country, and their role and responsibility in governance remains contested, many South Sudanese regard them as “legitimate representatives of their communities”. Thus, they have an important function as bridge builders between the state and the society (ibid.). Given the social standing of these ‘chiefs’, many humanitarians interact with them to provide their services. Moreover, their reputation in the society gives them a crucial function in fighting stigma and discrimination against persons with disabilities and ensuring their participation in the humanitarian response.

12 The internally displaced persons (IDP) camps, which used to be called protection of civilian sites, are officially under the control of the government and are currently being closed. The sites were formerly under United Nations protection but in 2020 South Sudan’s peacekeeping mission UNMISS decided to withdraw its peacekeepers from these sites; the World Food Programme has also been reducing its food rations (Hayden, 2020).

One international humanitarian NGO stressed the importance of involving the community leaders in the project implementation:

Of course, for us the work with OPDs is really important [...] But it is also important to involve the community leaders. Both because it is important to formalize our presence, but also because we can collaborate with them in order to share some important messages. We have to talk about inclusion with them. We have to talk about the rights of persons with disabilities with them. We have to talk about the early detection of disabilities, and we have to talk about some key messages because they [persons with disabilities] experience a lot of stigma [...] They [the community leaders] can share these in their community in the best way. Learning the proper [rights-based] language is very important, too. They can help OPDs spread their inclusion messages. They are really important persons in this process.

Representative of an INGO

4.1.2 Set up and Cooperate with Community Groups

While chiefs are important for the humanitarian response, international organizations also organize consultations with community groups, including groups of persons with disabilities.

One respondent explains:

There has been a push that people with disabilities are valued and listened to and to give them the opportunity to raise the issues that they have. It is not just a matter of saying, “Well, this person over here needs food assistance, because they have a disability and can’t leave their shelter”. It is actually a matter of making sure that they are part of the community. When you are having community meetings, they need to be included as well.

Representative of a United Nations agency

Where such groups are not present, organizations try to establish community groups or committees of persons with disabilities. Not only does this promote disability inclusion in the society, but the committees also strengthen the role of persons with disabilities in community governance, both inside and outside the IDP camps (formerly known as protection of civilian sites). A representative of an international agency summarizes:

We have disability committees inside the [protection of civilian] site. One of our key functions is to ensure that there is community governance in the sites. We help to facilitate elections; we help to make sure that each block has a representative and that there is some sort of gender balance. And having disability representatives has been really important. [...] And they engage with humanitarians on their own basis. People with disabilities can communicate their needs to humanitarians through these communities, through these representatives.

Representative of a United Nations agency

These practices help to increase the participation of persons with disabilities in society and in the overall response.

Some international organizations have also begun to recruit skilled persons with disabilities to increase their diversity and enhance their organizational expertise on disability inclusion. Yet, to ensure true diversity, it is necessary to hire persons with disabilities at all levels of the organizations, including the higher management level. These ‘inclusion experts’ can raise awareness for the needs of persons with disabilities and give them a voice in project design and implementation.

Interestingly, concrete strategies on how to enhance the meaningful participation of persons with disabilities in the clusters do not exist. HI has tried to work on this in the past, but there has been no tangible outcome. OPDs were not interested or had limited funding to support the meaningful participation of persons with disabilities. One idea to address this gap in the future is to encourage the disability working group and the mental health and socio-social support working group to operate under the protection cluster. This would increase the visibility of persons with disabilities and push all actors to consider the needs and rights of persons with disabilities, particularly because OPDs lack the capacity to be regularly present in all clusters (interview with an inclusion-focused NGO).

One respondent remarks:

Within the protection cluster, there are several areas of responsibility. This includes child protection, gender-based violence, mine action and housing land and property. Then there are other subgroups and technical working groups. But two key ones that appear in protection cluster in other country operations, specifically the working group on persons with disabilities and another working group that relates to mental health and socio-social support, they are not under the protection cluster in South Sudan. This is one of the things that many people would like to change to make sure that the protection angle is well captured throughout the response. Maybe the fact that these working groups were never under protection before is what made people forget about a need to collect data on persons with disabilities and ensure that they reach them during the response, perhaps thinking that other actors were working on inclusion, or just not even thinking about this at all.

Representative of an INGO

4.1.3 Conclusion on Meaningful Participation

In summary, these examples represent useful approaches to promote the participation of persons with disabilities in the response. Clearly, further efforts are necessary to increase the visibility and influence of persons with disabilities in the cluster system through a reorganization. This could be achieved, for example, by making sure that the mental health and psychosocial support and disability working groups operate under the protection cluster. Moreover, it is crucial to continue investing in the empowerment of persons with disabilities to enable them to claim their rights.

4.2 Remove Barriers

As long as barriers remain, meaningful participation and full inclusion is impossible for persons with disabilities. It is therefore of utmost importance that humanitarian actors identify attitudinal, environmental and institutional barriers as well as enablers to inclusion, and, in a second step, that they remove barriers and promote enablers to ensure participation and guarantee access to assistance. This report has already highlighted numerous barriers that prevent the inclusion and meaningful participation of persons with disabilities in society and the humanitarian response. Generally speaking, attitudinal, environmental and institutional barriers are widespread, which either hinder persons with disabilities from accessing services or participating in community meetings, or make them dependent on caregivers, such as family members or friends. Remarkably, all respondents demonstrate awareness of these barriers and therefore try to create a more enabling environment for persons with disabilities. The following sections elaborate how they address 1) attitudinal, 2) environmental, and 3) institutional barriers.

4.2.1 Remove Attitudinal Barriers

Raising awareness among humanitarian actors is one of the best ways to address attitudinal barriers. Consequently, inclusion-focused organizations use every opportunity to give presentations on inclusion in cluster coordination meetings, share documents and guidelines, and support capacity-building, for example, by helping organizations with the development of a disability inclusion policy or strategy. HI, in cooperation with the International Organization for Migration's [IOM] Displacement Tracking Matrix, also carried out barriers and facilitators assessments in various regions across South Sudan to increase the understanding of the situation of persons with disabilities among humanitarian actors.¹³

Moreover, in May 2020, HI South Sudan published a tip sheet for organizations on including persons with disabilities and elderly persons in the COVID-19 health response.¹⁴ In 2021, HI, together with the community engagement working group and OCHA, organized a workshop for all cluster coordinators on accountability to affected populations that also addressed the issue of accountability to persons with disabilities (interview with a United Nations agency). In the same year, HI and the community engagement working group carried out a community engagement survey, which asked 98 organizations if they included persons with disabilities in their community engagement activities. Most organizations replied that they involved persons with disabilities in community meetings and focus group discussions.

13 See HI, 2017a, 2017b, 2017c, 2017d.

14 Available at https://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/hi_south_sudan_notes_on_inclusive_covid-19_gbv_response_paper.pdf (accessed 16 September 2021).

One respondent summarizes:

We recently did a community engagement survey for our humanitarian partners. One of the questions was: “Do you include persons with disabilities in your community engagement activities? And if so, how?” Most of the 98 responses indicated some awareness on disability inclusion. They did not necessarily respond to community engagement, but about their projects in general. They were saying, “Yes, of course, when we go to the communities, we talk to persons with disabilities, and we make sure we have focus groups with them, etc.” [...] Several organizations also had projects that targeted persons with disabilities [...] There are certainly NGOs and agencies that have projects that are specifically dedicated to people with specific needs.

Representative of a United Nations agency

While the survey did not provide any evidence on precisely how organizations included persons with disabilities and whether they had the intention of empowering them, it nevertheless reconfirmed that many organizations already have some awareness on inclusion. In fact, the number of organizations engaging with persons with disabilities is quite remarkable, but their actual implementation of inclusion requires more research. Indeed, it is highly likely that persons with intellectual and psychosocial disabilities are not included in these projects. For any future community engagement surveys, instead of asking organizations about their engagement with ‘persons with disabilities’ in general, it will be important to use the Washington Group Short Set of Questions . In this way, it is possible to learn more about their activities vis-à-vis persons with different types of impairments.

Box 1. Washington Group Short Set of Questions

Six questions on short set



Do you have difficulty seeing, even if wearing glasses?



Do you have difficulty hearing, even if using a hearing aid?



Do you have difficulty walking or climbing steps?



Do you have difficulty remembering or concentrating?



Do you have difficulty (with self-care such as) washing all over or dressing?



Using your usual language, do you have difficulty communicating, for example understanding or being understood?

Source: Handicap International – Humanity & Inclusion (n.d.)

The Washington Group on Disability Statistics has developed tools to measure disability in line with the functional approach of the World Health Organization's International Classification of Functioning, Disability and Health. They avoid the term 'disability' and instead only address limitations in undertaking basic activities. Although originally designed for large-scale national questionnaires, development and humanitarian organizations increasingly use these tools for their own purposes. In particular, they apply the Washington Group Short Set of Questions, which covers six core domains: walking, seeing, hearing, cognition, self-care and communication. Each question has four response categories: 1) No, no difficulty; 2) Yes, some difficulty; 3) Yes, a lot of difficulty; 4) Cannot do it at all (Cheshire and HI, 2018, p.7).

The Washington Group also has additional tools for situations that require more detail or concern children.¹⁵

4.2.2 Remove Environmental Barriers

Although South Sudan has, as stated, an extremely challenging humanitarian context and a poor infrastructure, this should not prevent persons with disabilities from accessing crucial services. In certain settings, such as, in particular, IDP camps, organizations have made strides to reduce environmental barriers for persons with disabilities. One respondent elaborates:

The infrastructure is supposed to be accessible and inclusive, and various agencies have tried as much as possible to make them inclusive. I do not know if you have looked at some of the pictures of the camps in South Sudan, but it is muddy and people live under tarps. That is what it is. There is a limitation on what is actually possible to create, although there have been efforts to redesign latrines or redesign bridges, to level roads, so that, for people with physical disabilities, they become more accessible. The regularity that we can do those kinds of interventions depends on funding and staffing.

Representative of a United Nations agency

15 Note: The Washington Group on Disability Statistics was founded in 2001 to develop standard indicators of disability in surveys and censuses by national statistics offices. It was established under the United Nations Statistics Commission. For more information on the Washington Group, see <http://www.washingtongroup-disability.com/>.

Moreover, international organizations increasingly invest in the close monitoring of their activities to ensure that their distribution points, including those run by their implementing partners, are accessible for persons with disabilities. This also entails strengthening the capacities of the field monitors. A representative from another United Nations agency explains:

We do protection monitoring, which is, we go inside where we see beneficiaries being registered, getting food assistance, looking at how they are being served, other issues that we need to solve as WFP and take into consideration. So that at least in the next round, we can do some adjustments. [...] When we look at how best we can mainstream disability, we need to target our field monitors, staff who are having daily interaction with the beneficiaries, who go on day-to-day basis seeing what is happening, monitoring distribution. These are the key targets to benefit from this training, so we can at least start making our distribution side become more friendly to persons with disabilities.

Representative of a United Nations agency

The same agency also developed a policy to formalize this practice, but it is not clear yet whether other organizations also define concrete guidelines and hence standardize disability in organizational procedures.

4.2.3 Remove Institutional Barriers

Many organizations also work hard on the removal of institutional barriers. OPDs advocate the ratification of the CRPD, while international organizations have started recruiting persons with disabilities and updating their internal policies to incorporate disability inclusion as an integral part of their work.

As one representative of a United Nations agency highlights:

When we look at disability inclusion, it is becoming one of our strongest pillars in our new policy.

Representative of a United Nations agency

Persons with disabilities are also increasingly targeted in needs assessments, and organizations have started to disaggregate data and evaluate risks for persons with disabilities. These points will be discussed in detail in the section on data collection below.

4.2.4 Conclusion on Barriers

To sum up, removing attitudinal, environmental and institutional barriers for persons with disabilities is a major challenge, and it is still too early to evaluate the extent to which organizations have been successful in addressing persisting barriers. However, organizations have become increasingly aware of the need to create an inclusive environment for persons with disabilities. Consequently, they have started developing inclusion policies or inclusion guides, remodelling facilities in the IDP camps, and increasing their accountability to persons with disabilities, for example, by closely monitoring their registration and distribution sites to ensure that they are accessible for everyone.

4.3 Empowerment and Capacity Development

The empowerment of persons with disabilities and developing the capacities of OPDs and other humanitarian stakeholders in disability-inclusive humanitarian action is another central element to ensure that persons with disabilities are not left behind.¹⁶ It entails raising awareness among persons with disabilities about their rights and supporting them to build their knowledge and leadership skills to contribute to the humanitarian response. Simultaneously, humanitarian organizations have to build their knowledge, skills, tools and financial means to design and implement inclusive humanitarian programmes. This entails strengthening their understanding of the rights of persons with disabilities and familiarizing themselves with practical approaches that promote inclusion (IASC, 2019, p.20). In short, capacity-building requires that both persons with disabilities and humanitarian workers strengthen their knowledge, skills and understanding of inclusive humanitarian action (IASC, 2019, p.20).

The data show that humanitarian stakeholders in South Sudan attach great importance to their capacity-building and the empowerment of persons with disabilities. In fact, it is a prerequisite for ensuring meaningful participation, removal of barriers and data collection on disability. All organizations in this study had either developed or engaged in capacity-building activities with their international and local partners or had themselves participated in training courses, coaching sessions and sensitization. Instead of stressing obstacles or challenges to aspects of empowerment and capacity-building, the respondents mostly highlighted good practices and important benefits for their organization and the inclusion of persons with disabilities (see section below). Where they did identify challenges for this action point, these mainly related to the empowerment of persons with disabilities and their representative organizations. Three main factors were a hindrance to their empowerment: 1) stigma within the society, which leads to their exclusion; 2) limited funding; and 3) coordination issues among inclusion-focused NGOs. These points will be elaborated in the following paragraphs.

16 Developing and strengthening capacities is also a part of the removal of barriers. For descriptive and analytical purposes, the four 'must do' actions of the IASC Guidelines are not always useful because there are overlaps in these four actions.

Empowerment could be far more effective if persons with disabilities were not systematically excluded from the society and organizations collected more solid data on disability. Needs assessments should reflect the views, priorities and preferences of all affected people, including persons with disabilities. In addition, persons with disabilities need to have more opportunities to become aware about their rights.

Some organizations have started to invest in the capacity-building of OPDs, to enhance their knowledge about the CRPD, international humanitarian law and the functioning of the humanitarian system. This also entails providing OPDs with skills related to humanitarian programming and coordination, including budgeting and proposal writing.

Donors do not always fund these activities because they see them as part of development rather than humanitarian action. Thus, it is crucial that donors do fund these capacity-building activities for OPDs as part of humanitarian action as it could facilitate inclusion more generally.

Finally, disability and inclusion-focused organizations that engage in OPD empowerment and capacity-building could be more effective if they improved their coordination. This would reduce costs and either help to identify gaps or address the duplication of activities. One respondent remarked:

In South Sudan, we have an OPD strengthening programme. And there are other organizations on the same programme. And we're using the same OPD and the same activities but we are lacking coordination. If we coordinated better and worked together, we could save money and have a meaningful impact. So, this is the gap from inclusion-focused organizations.

Representative of an inclusion-focused NGO

Despite these gaps, the empowerment of persons with disabilities has moved ahead. The best example is perhaps the aforementioned establishment of the national umbrella organization, the South Sudan Union of Persons with Disabilities, in September 2020 (Light for the World, 2020). Although its establishment is only a first step, and it depends on financial and technical support from Light for the World, it shows that the disability movement is gaining political influence in South Sudan. CBM has also supported the national Union by organizing a General Assembly, which brings together persons with disabilities across the whole country and also involves knowledge sharing and exchange of experiences, with speakers from the National Union of Persons with Disabilities in Kenya, Uganda and Tanzania (interview with CBM). However, these activities tend to be more development-related and are not a core part of humanitarian action.

Moreover, CBM and HI advocate a stronger representation of OPDs in the cluster system. Some OPDs give training courses on inclusion to mainstream organizations, while others raise awareness on disability rights in IDP camps. Simultaneously, inclusion-focused organizations further invest in OPD capacity-building, for example through ‘on the job training’. One respondent explained:

Once a week, our head of finance spends time in the office of our three partner OPDs to train them on financial management to make sure that they learn how to report to donors. Thanks to his ‘on-the-job’ coaching, we are confident that by the end of this year, or next year, they will have the capacity to report to donors without our support.

Representative of an inclusion-focused NGO

OPDs in Juba are also gaining influence, and more and more OPDs are establishing themselves in other parts of the country, but the exact numbers are not known. However, persons with disabilities in the IDP settlements rarely organize themselves into self-help groups to represent their interests. Some inclusion-focused and mainstream organizations therefore set up projects that encourage the formation of informal groups and build the capacities of the participants. One respondent elaborates:

We have a women's participation project, which is designed to promote women's participation in the community, in camp life. But part of that project has always been, as much as possible, to include women with disabilities. It is a very small project and targeted less than 100 people in the last couple of years. But part of that has been to include women with disabilities, to make sure that they are getting leadership training and business skills training. Often there is also a small-scale cash-based intervention and livelihood support.

Representative of a United Nations agency

Such initiatives demonstrate an increased awareness of the rights of persons with disabilities, as well as of the principles and practical approaches to inclusion. To build on this momentum, disability and/or inclusion-focused organizations engage in capacity-building of mainstream humanitarian actors. They offer training and learning sessions on inclusive humanitarian action, they coach and mentor staff at various levels of the response, engage in knowledge and experience sharing, conduct assessments and give advice, for example with regard to inclusive programme design and management and development of inclusive policies or strategies. Respondents confirmed that disability and/or inclusion-focused NGOs are very committed.

CBM gives our staff training and helps to improve our policy. Sometimes they do so by sharing best practices, even from those in other parts of the world. I think this is really, really important.

Representative of an INGO

The courses and coaching sessions mainly focus on disability mainstreaming in existing projects and programmes. One respondent explains:

We make sure that we do not create separate programmes for persons with disabilities but that their various programmes incorporate disability, and that disability is considered in their various plans and the different programmes that they are implementing. We believe that this is an effective approach, which can have some positive results.

Representative of an inclusion-focused NGO

There are two routes by which mainstream actors become engaged in capacity-building. First, they approach inclusion-focused organizations because their donors, senior management or even headquarters have requested the inclusion of persons with disabilities in programmes and organizational structures. Second, inclusion-focused NGOs approach mainstream organizations with whom they feel there is mutual trust and sincere commitment to change practices (interview with an inclusion-focused NGO). In 2019, for example, a United Nations agency began a partnership with HI on its own initiative because it realized that it lacked expertise on disability inclusion.

One respondent summarizes:

We had a bilateral discussion with HI back in 2019 to detect areas of work that can benefit from HI's expertise on disability inclusion. We had strong support from the programme management and this helped us a lot in terms of becoming more inclusive. [...] When we look at our new protection policy, inclusion is something that became a mandatory task in every part of our work.

Representative of a United Nations agency

However, the extent to which the publication of the United Nations Disability Strategy and the IASC Guidelines in 2019 have influenced the decision to expand this partnership with HI are hard to assess.¹⁷ Interviews nevertheless confirm that United Nations agencies have been pushed to accelerate their efforts to include persons with disabilities:

There are some organizations that are stronger and easier to work with because they are having a push, I think, within their strategies, within their own organization or plans to have inclusion in place. So, you will find organizations like IOM, UNICEF, WFP. Some have a big push towards inclusion.

Representative of an inclusion-focused NGO

¹⁷ Light for the World experienced an upsurge in demand for capacity-building after the signing of the Inclusive Education Policy that was developed with their support. Particularly, the Ministry of General Education and Instruction has begun to refer UN agencies and international NGOs to the organization for partnership and capacity-building. Until mid-July, they had received requests of seven organizations (Interview Light for the World).

Disability and/or inclusion-focused organizations provide capacity-building to staff at all levels of the response and ensure that training and coaching is tailored to the needs and expectations of different departments and levels of programming.

One respondent explains:

When we engage with senior management, we tend to focus on inclusive programming, for example, on issues related to universal design¹⁸ and the participation of persons with disabilities in the development of programmes and projects. Whereas our engagement with frontline staff in various organizations focuses on inclusive language, for example, the language that they are supposed to use when addressing people with disabilities. [...] We try to ensure that they have a positive language when they are dealing with persons with disabilities.

Representative of an inclusion-focused NGO

18 “Universal design means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. ‘Universal design’ shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.” (Convention on the Rights of Persons with Disabilities, Art. 2).

Mainstream organizations evaluate existing cooperation with disability and/or inclusion-focused organizations positively, and some indicate that inclusion has become a priority in their work.

Our organization has benefited a lot in terms of the capacity-building, trainings, and from gap assessment in terms of inclusion. It has helped us to come up with a new disability guide for the country office, which will inform our programming.

Representative of a United Nations agency

Nevertheless, South Sudan is a big country with violent conflicts, a failing government and weak civil society. Consequently, the needs of the population are considerable, and most organizations have only recently started to work on inclusive humanitarian action. INGOs in particular, unlike United Nations agencies, cannot rely on technical support from their own headquarters, which means that inclusion-focused organizations have to invest more time and financial resources to train and coach international and national staff (interview with an inclusion-focused NGO). Inclusion-focused NGOs would like to invest more time and resources in capacity-building of humanitarian staff, but the amount of available funding is too small.

We would be able to do quite [sic] more, but now with how things are, usually the allocation even from the donors, from the pooled funds, from most of the donors, the funding is usually small.

Representative of an inclusion-focused NGO

4.3.1 Conclusion on Empowerment and Capacity Development

In summary, the South Sudanese disability movement is still in its infancy and more efforts are necessary to empower persons with disabilities, particularly those with an intellectual or psychosocial disability. Humanitarian organizations continue to build their own capacity on disability inclusion through training, coaching, experience sharing and gap assessments. Disability and/or inclusion-focused organizations are important cooperation partners in this respect. Many mainstream actors emphasize that the exchange with and support from CBM, HI or Light for the World has had a tangible effect on their work, as reflected in new disability-inclusive guides and strategies, increased awareness of humanitarian staff at all levels of the response and the removal of barriers for persons with disabilities. Yet, in many cases, the long-term impact of this cooperation is still hard to assess and requires a deeper examination.

4.4 Data Collection and Monitoring

Qualitative and quantitative data play a key role in monitoring the inclusion of persons with disabilities. Data should be disaggregated on gender, age and disability and contain information on risks and barriers as well as perceptions and coping mechanisms of persons with disabilities. This will enable humanitarians to make informed decisions on the design, implementation, monitoring and evaluation of an inclusive humanitarian response (IASC, 2019, pp.23–31).

Almost all respondents highlighted the dearth of data on persons with disabilities as a significant impediment to inclusion. The country figures from the latest national census of 2008 are not reliable, and the government lacks the expertise and the financial means to conduct a new countrywide census.

Moreover, at the humanitarian coordination level, lead agencies, above all OCHA, have so far missed the opportunity to include disability systematically in inter-agency coordination mechanisms. Consequently, robust data on disability for all sectors and areas is unavailable and depends on the efforts of single agencies and organizations. The annual needs overviews, on which the response plans are based, only reflect fragmented data accumulated from individual organizations and projects. One respondent comments on the process and explains:

Every year we have the annual Humanitarian Needs Overview and the humanitarian response plan that comes out of that. There is always the question: “Where are we going to get the data from?” When I say “we”, I mean humanitarians in general. We borrow in piecemeal ways from different surveys but there is no kind of one consolidated approach. I think that the reason why we have this lack or this dearth of information is that the top level does not have a strategy for demanding it.

Representative of a United Nations agency

However, the very fact that the Humanitarian Coordinator with the Humanitarian Country Team started to recognize the gap in data collection and started requesting information from organizations is in itself a sign of progress towards inclusive humanitarian action. Before 2020, Humanitarian Needs Overviews did not include any data on disability at all.

Another respondent, a cluster coordinator, confirms the assessment that data on disability is still lacking, but simultaneously highlights the progress and achievements in comparison to the previous year:

Up until at least last year, we did not collect data on persons with disabilities. Last year, we have collected information on how many persons with disabilities we are reaching out to in our interventions, but this is just information provided by partners. So maybe it is not so representative but at least we tried to collect it for the last one year, if I am not mistaken. Now we are definitely making more of an effort to ensure that the assessments have more substantive information. [...] The aim has been to try to put Washington Group Questions into the protection-monitoring tool that is under development. So at least it would get us a better idea of who among the affected communities is a person with a disability.

Representative of an INGO

The health cluster already introduced such a tool in 2019. However, cluster members did not apply it systematically until donors began demanding data on disability (interviews with representatives from an INGO and a United Nations agency).

Although the gaps in the collection, analysis and use of data are significant at all levels, there have been attempts to address these gaps. For example, two annual countrywide surveys, the Food Security and Nutrition Monitoring Survey and the Multi-Sector Needs Assessment, have integrated the Washington Group Short Set of Questions. The latest Food Security and Nutrition Monitoring Surveys for the capital Juba and Bentiu/Rubkona Town reveal that more than 40 per cent of all households have a member with a disability (IOM 2021a and 2021b).¹⁹

At the organizational and project level, some United Nations agencies have dedicated focal points or protection-mainstreaming officers who have the task of reviewing internal documents with respect to disability inclusion. For example, they try to ensure that all their assessments incorporate the Washington Group Short Set of Questions (interview with a United Nations agency). In addition, they work with disability and/or inclusion-focused organizations to train enumerators on their correct usage. IOM, in cooperation with HI, has also published comprehensive barriers and facilitators reports on accessible education and health and now, a few years later, respondents confirm that reporting on disability has become a component of many humanitarian projects.

19 The Food Security and Nutrition Monitoring Survey are carried out by the IOM Displacement Tracking Matrix South Sudan and WFP, in collaboration with the Shelter Non-Food Items Cluster, the Camp Management and Camp Coordination Cluster, Protection Cluster, Gender-Based Violence Sub-Cluster, Child Protection Sub-Cluster, Education Cluster, Food Security Cluster, Water Sanitation and Hygiene Cluster and the Health Cluster.

One respondent says:

The awareness and knowledge of the necessity to collect data is there because donors are quite strict and ask for such data. Sometimes there are many challenges in reporting effectively on disability. But it's certainly always a component of our work. The requirement and request has been made by donors. You cannot submit a project proposal without talking about how your project is going to take into consideration the persons with disabilities.

Representative of a United Nations agency

These examples give hope that more reliable figures on disability, and assessments on ongoing needs and protection gaps, will soon become part of humanitarian practice. To support organizations in this process, inclusion-focused organizations, such as HI and CBM, also provide dedicated training courses to their mainstream and government partners (interview with an inclusion-focused NGO). Donors also play a crucial role in promoting these endeavours and could use their power of the purse to push for the systematic collection, analysis and use of data in humanitarian needs assessments and response plans, as well as in humanitarian programming more generally.²⁰

20 For example, in 2020, the United Kingdom Department for International Development (DFID, now the Foreign Commonwealth and Development Office, FCDO) published its Guidance on Strengthening Disability Inclusion in Response Plans. FCDO also established an in-house disability inclusion helpdesk with over 60 disability inclusion experts to support the implementation of the Strategy for Disability Inclusive Development 2018–2023 (Social Development Direct, 2021).

4.4.1 Conclusion on Data Collection and Monitoring

Disaggregated data are indispensable for inclusive humanitarian action. Many organizations have already started to collect data on age, gender and disability to respond to donor demands. Some of them have also worked on barriers and facilitators assessments. Still, respondents could not specify how they use such data for inclusive humanitarian programming. Interview partners point out that a comprehensive strategy for systematic data collection at the national and humanitarian coordination level would facilitate the inclusion of persons with disabilities in the society and the humanitarian response. However, it is important that organizations also collect their own data for inclusive programming and do not only rely on a comprehensive, country-wide strategy. Experts on the situation in South Sudan believe that a strategy for data collection at the coordination level is neither feasible in such a complex emergency context nor explicitly recommended in the IASC Guidelines. However, inter-cluster data management working groups could agree on certain standards, including the use of the Washington Group Short Set of Questions in needs assessments.²¹ On a positive note, some national surveys already integrate the Washington Group Short Set of Questions, although these surveys are only a first step and require consistent follow-up.

4.5 Conclusion: Progress towards Inclusion

Based on a semi-structured questionnaire focusing on the four 'must-do' actions and the South Sudanese context, the interviews reveal that humanitarian actors in South Sudan are committed to disability inclusion. In relation to the first action, inclusion-focused NGOs encourage the establishment of OPDs and support the participation of persons with disabilities in community structures and project implementation. In relation to the second action, mainstream actors remodel the infrastructure to make their services accessible for persons with physical impairments, participate in awareness-raising sessions of inclusion-focused NGOs to reduce misconceptions and hence attitudinal and institutional barriers, and revise internal policies.

²¹ We would like to thank one of our reviewers for pointing this out.

Moreover, in partnership with inclusion-focused NGOs, they address the third action, investing in the empowerment of persons with disabilities to raise awareness on their rights. Simultaneously, they support capacity-building at all levels. Many humanitarian organizations have also begun to tackle the fourth action by collecting disability-disaggregated data that can inform the countrywide needs assessments. Nonetheless, important gaps remain.

Our research shows that more efforts are necessary to increase the visibility and influence of persons with disabilities in the cluster system, particularly those with an intellectual and psychosocial disability. They should be involved from the very beginning of the programme development and have access to accountability mechanisms.

The humanitarian needs assessments do not yet approach data collection and analysis in a systematic manner and organizations did not indicate how they use disability data for inclusive programming. Moreover, disability inclusion is not yet an integral part of the cluster coordination structure; national and local OPDs must become more involved in all clusters and sectors, and inclusion can be further fostered by appointing a dedicated focal point on disability inclusion for each cluster. Clearly, in addition to the efforts of individual organizations, a broader approach is needed.

Inclusive humanitarian action will become easier the better the humanitarian system and the government function. This is especially the case for humanitarian action in remote areas outside Juba. As long as corruption, violence and instability exist, persons with disabilities remain at a high risk of being excluded in the society. Importantly, humanitarian organizations have taken crucial steps to include persons with disabilities in needs assessments and humanitarian programmes, but the road towards their meaningful participation, full protection and unhindered access to humanitarian services is still long.



5. Conclusions

This study sheds light on the questions of how humanitarian actors strive to ensure access to their aid and protection services for persons with disabilities (through meaningful participation, removal of barriers, empowerment, and collection and analysis of disaggregated data) and how inclusion-focused organizations support mainstream actors in this process. This final part of the report will present the main findings of this study and give recommendations to donors, decision-makers, humanitarian organizations, persons with disabilities and their representative organizations, and researchers.

5.1 Main Findings

Despite significant attitudinal, environmental and institutional barriers to disability inclusion in South Sudan, humanitarian actors currently demonstrate a high level of awareness of the gaps and challenges that hinder access to services and prevent the meaningful participation of persons with disabilities at all levels and in all stages of the response. This report identifies three main challenges to the inclusion of persons with disabilities:

1. attitudinal barriers: stigma and discrimination in the society and humanitarian community
2. lack of meaningful participation and the fragmented presence of OPDs outside Juba
3. perceptions of disability: an 'additional complexity' in an already complex context.

Moreover, all respondents stressed that the COVID-19 pandemic and the measures to contain the spread of the virus have limited the meaningful participation of persons with disabilities and reduced opportunities for capacity-building. Some interventions continued with an online format, but the absence of reasonable accommodation and stable internet access have contributed to the exclusion of persons with disabilities from cluster coordination and consultation meetings.

However, and quite remarkably, all organizations that participated in this study had taken at least some measures to address this exclusion and to promote meaningful participation, removal of barriers, empowerment, and collection and analysis of disaggregated data. The organizations involve community leaders (usually called local 'chiefs') in awareness-raising sessions and support the establishment of community groups or OPDs. Inclusion-focused NGOs give presentations on disability inclusion in cluster meetings, for example, in the health, protection, food security and livelihood clusters, organize workshops for all cluster leaders, develop documents and guidelines on inclusion, engage in coaching for mainstream partners, conduct barriers and facilitators assessments, and provide training to senior management and field monitors. Some mainstream organizations have begun to update their organizational policies at the country level, while donors have made inclusion a requirement for funding, though the extent to which they pressure their partners to promote meaningful participation, removal of barriers, empowerment, capacity-building and data collection on disability varies. All of these efforts have yielded positive results: OPDs in Juba founded a national umbrella organization; persons with disabilities have begun to act as inclusion trainers to humanitarian organizations; and some international organizations have set up dedicated focal points within their own structures to change their organizational practices. Unsurprisingly, respondents highlighted improvements in terms of data collection on disability, cooperation with OPDs and the participation of persons with disabilities in project implementation and monitoring. Moreover, the number of informal groups and OPDs in remote regions outside Juba and in the IDP camps is slowly increasing.

Despite this progress, much work remains to be done. First, humanitarian organizations still fail to recognize the diversity of persons with disabilities. In particular, persons with intellectual and psychosocial disabilities have no chance to have their voices heard because they are absent from the national disability movement and the humanitarian response. Second, and related to the first point, structural barriers, such as the lack of local sign language interpreters, the poor infrastructure and deep-rooted prejudices and misconceptions, are hard to overcome for individual organizations and require investment from donors and the national government. Third, initial steps have been made by the humanitarian country team to include disability in Humanitarian Needs Overviews and response plans, but data on disability still needs to better reflect the local reality and be integrated into programming.

Donors play an essential role in further pushing (lead) agencies, such as OCHA and IOM, and NGOs to take a more strategic approach and integrate disability as a cross-cutting issue in all clusters. Currently, donors themselves often do not have a good understanding of disability or strategies with clear indicators against which humanitarian organizations can report progress on inclusion.

Moreover, this study reveals that inclusion-focused NGOs, such as CBM, HI and Light for the World enabled organizational change towards disability inclusion. Their advocacy and capacity-building activities have strengthened OPDs and self-help groups, contributed to their empowerment, raised awareness of the rights of persons with disabilities among humanitarian organizations, both at senior management and field level. In this way, they contributed to the removal of attitudinal, environmental and institutional barriers. All mainstream organizations benefited from formal partnerships and consortia with inclusion-focused NGOs, although some of them established their own focal points for disability inclusion. Clearly, the human and financial capacity of these mainstream organizations is limited. It is therefore important to strengthen the capacities of OPDs and other local organizations so that they can advocate the rights of persons with disabilities and, when desired, also give technical support, particularly in areas that are hard to access.

In summary, since the publication of the IASC Guidelines in 2019, humanitarian organizations have made solid progress towards becoming disability inclusive, in particular at the national level. However, the actual impact of the Guidelines on humanitarian practice is hard to assess. The work of disability and/or inclusion-focused NGOs and OPDs remains indispensable to further promote the implementation of the Guidelines. If we consider the four 'must do' actions, most progress has been achieved with regard to the participation of persons with disabilities and empowerment/capacity-building, while the collection, analysis and use of disaggregated data and the removal of attitudinal and environmental barriers remain ongoing concerns.

Nonetheless, it should be stressed that in terms of data collection, some action has been taken to include persons with disabilities in countrywide surveys and needs assessments. Compared to two years ago, before the publication of the IASC Guidelines, when no robust data were collected and analysed, this represents a crucial step forward.

Gaps remain in the use of these data for inclusive programming. Awareness-raising activities have also contributed to this progress in data collection and the removal of barriers for persons with disabilities. Yet, the interviews show that misconceptions among humanitarian staff persist.

Although the ‘must do’ actions are not always useful as an analytical framework to capture all the challenges and good practices of inclusive humanitarian action at various levels of the response, they have been helpful to evaluate progress on disability inclusion in different areas. In fact, for this report and other studies, they serve as a useful means to structure the data. Most importantly, they illustrate that ‘inclusion’ is not an abstract, technical term, but consists of key actions for all levels, sectors and actors.

5.2 Recommendations

To further enhance the capacities of mainstream actors in disability-inclusive humanitarian action and ensure the inclusion of persons with disabilities in the humanitarian response, this study has produced the following set of recommendations.

5.2.1 Donors

Donors play an important role in promoting the inclusion of persons with disabilities. Although many respondents were convinced that the inclusion of persons with disabilities should be an integral part of their operations, they confirmed that donor demands account for significant changes in organizational practice. The donor demands also encouraged managers from mainstream organizations to seek support and advice from disability and/or inclusion-focused NGOs. However, many donors still do not have precise indicators, markers and allocation criteria to promote inclusion, and they often have a poor understanding of disability inclusion. Moreover, time remains a scarce resource for humanitarian organizations, and adapting practices so that persons with disabilities can contribute to programming, even during the design and planning stage, often requires additional investments. Donors should therefore:

- Invest in staff training on inclusion.

- Provide long-term and reliable funding to ensure the meaningful participation of persons with disabilities and OPDs and to allow humanitarian organizations to invest in capacity-building.
- Allocate sufficient funding for sign language and local language interpretation, as well as other types of reasonable accommodation.
- Develop precise indicators, markers and allocation criteria on disability inclusion and insist on disaggregation of data in proposals, evaluations and other reporting tools.
- Continue supporting robust data collection.
- Use their diplomacy and power of the purse to advocate disability inclusion at the governmental level. This includes
 - stressing the necessity of signing and ratifying the CRPD
 - investing in capacity-building of decision-makers to remove attitudinal, environmental and institutional barriers in all parts of the country to create an enabling environment.

Clearly, some of these activities will be more development-oriented rather than strictly humanitarian.

5.2.2 National Decision-Makers

Ideally, the current government will conscientiously implement the peace accords. However, at this moment, progress has stalled and different forms of violence continue in the country. This hampers humanitarian action in general and inclusive humanitarian action in particular. The government should:

- Sign and ratify the CRPD.

- Reduce barriers to inclusion, which entails improving the infrastructure and investing in capacity-building of civil servants in order to remove institutional and attitudinal barriers.
- Cooperate with the Humanitarian Country Team to collect reliable data on disability. Ideally, this entails organizing a new national census that uses the Washington Group Short Set of questions.

More generally, the more progress is made with the peace process, the easier humanitarian action and inclusion will become. Currently, most South Sudanese citizens are highly skeptical about the haphazard peace process.

5.2.3 Local Traditional Leaders

Local traditional leaders play an important role in society. They should:

- develop their capacities on disability inclusion
- familiarize themselves with the human rights of persons with disabilities
- encourage the meaningful participation of persons with disabilities in community structures
- continue their cooperation with humanitarian agencies to further promote inclusion at all levels and sectors of the humanitarian response.

5.2.4 Humanitarian Country Team

The Humanitarian Country Team brings together representatives from the United Nations, IOM, NGOs and the Red Cross/Red Crescent Movement. It should:

- make sure that data collection on disability is part and parcel of the Humanitarian Needs Overviews, and inform the humanitarian response plan in a structured manner

-
- help to further raise awareness about progress on and obstacles to inclusive humanitarian action.

5.2.5 Humanitarian Organizations

The complex humanitarian operational environment should not serve as an excuse for not targeting persons with disabilities or for excluding them from projects. Humanitarian organizations should therefore:

- further invest in capacity-building on disability inclusion of their humanitarian staff at all levels of the response
- continue their awareness-raising activities among local traditional leaders, communities and their own staff and involve persons with disabilities in this process
- promote the meaningful participation of persons with disabilities, including those with intellectual and psychosocial disabilities, at all levels and stages of the humanitarian response
- empower persons with disabilities and inform them about their rights
- in inaccessible regions, identify representatives as key informants to have access to qualitative and quantitative data on disability
- use the Washington Group Short Set of Questions in needs assessments and community engagement questionnaires to identify persons with disabilities
- where no evidence on disability is available, assume that at least 15 per cent of the population have a disability
- remember that multiple layers of communication are often needed to consult with persons with disabilities, also taking into account the number of local languages spoken in South Sudan, and include any additional costs in the project proposals/budgets

- support the establishment of OPDs and self-help groups and enhance the cooperation with them, especially in the regions
- make sure that all humanitarian services become fully accessible
- document good practices and engage in knowledge exchange.

5.2.6 Persons with Disabilities and Organizations of Persons with Disabilities

Persons with disabilities can make an important contribution to society and to the humanitarian response. Either with or without international support, they should:

- further familiarize themselves with their rights, international humanitarian law, and the humanitarian system
- increase their confidence as active contributors to society and continue to advocate the ratification of the CRPD and inclusive humanitarian action
- organize themselves in self-help groups or OPDs, in particular outside Juba, and join the national umbrella organization
- contribute to capacity-building and provide technical support and other inputs to mainstream humanitarian staff and government officials
- invest in capacity-building on humanitarian action and programming.

5.2.7 Further Research

The publication of the Disability Inclusion Charter in 2016 has increased scientific interest in disability inclusion in humanitarian action, although studies that explore how humanitarian actors implement inclusive programmes are still scarce.

In particular, there are only a few studies that take a comparative approach.²² Moreover, the COVID-19 pandemic has also created significant obstacles to ethnographic research in the field. Future research should:

- Become more comparative, in particular on how the four ‘must do’ actions are being implemented in different parts of South Sudan. These studies could also examine how differences in donor requirements affect disability inclusion in humanitarian practice.
- Conduct long-term ethnographic and impact studies on disability-inclusive humanitarian action.
- Identify more obstacles, good practices and lessons learned.
- Explore how the IASC Guidelines can be operationalized further to inform humanitarian programming.

Overall, humanitarian action in South Sudan is slowly becoming more inclusive for persons with disabilities, but humanitarian organizations still have much work ahead to become fully inclusive.

22 For one such study, see [Inclusive Futures \(2021\) Consequences of Exclusion: A Situation Report on Organisations of People with Disabilities and COVID-19 in Bangladesh, Nigeria, and Zimbabwe.](#)



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Annex

Breakdown of Expert Interviews

Type of organization	Number of interviews	Male	Female
United Nations agency	3	2	1
International non-governmental organization	7	5	2
Inclusion-focused non-governmental organization	4	2	2
Organization of persons with disabilities	1	1	-

Breakdown of Focus Group Discussions with Persons with Disabilities

Geography	Male	Age range	Female	Age range
Yei	5	35–65	5	22–40
Yambio	7	18–65	4	18–65

