

From Commitment to Action:

# Towards a Disability-Inclusive Humanitarian Response in South Sudan?

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# 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'<sup>1</sup> 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.

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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.

## Research Methods

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.

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.

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.

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.



