

# No context is too challenging: Promoting, doing and achieving inclusion in the humanitarian response in South Sudan

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## Abstract

*Disability inclusion has become a crucial issue for humanitarian action, at least at the international policy level. However, little is known about how humanitarian actors are “doing inclusion” in practice. With a case study on South Sudan, this article examines whether the increase in publications, policy tools and guidelines has made humanitarian action more inclusive for persons with disabilities, and how*

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*stakeholders can overcome persisting barriers for persons with disabilities. The article demonstrates noticeable progress in data collection, capacity-building, the removal of barriers and meaningful participation, but humanitarians still lack the skills, confidence and resources to address many persisting barriers. To advance inclusion, donors and humanitarian organizations must invest more time and resources in capacity-building and coordination.*

**Keywords:** disability inclusion, humanitarian action, South Sudan, armed conflict.

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## Introduction

Armed conflicts and civil wars devastate societies and cause immense human suffering, even beyond the period of active warfare.<sup>1</sup> They disproportionately affect persons with disabilities, who are exposed to heightened risks to their mental and physical well-being, safety and survival. Persons with disabilities often have difficulties fleeing attacks because they lack evacuation support, do not have assistive devices, or lack access to emergency shelter, or because they face communication barriers in accessing information about attacks or might be separated from their support persons or caregivers.<sup>2</sup> Moreover, multiple environmental, attitudinal and institutional barriers also prevent persons with disabilities from accessing crucial protection and other humanitarian services. This increases their vulnerability. In many instances, the heightened, aggravated and multiple risk factors result in higher levels of psychosocial distress among persons with disabilities.<sup>3</sup> Furthermore, their meaningful participation in humanitarian programme design, implementation, monitoring and evaluation is extremely limited.<sup>4</sup> The exclusion of persons with disabilities infringes upon fundamental human rights principles, as well as international humanitarian law and related protection principles.<sup>5</sup>

In 2016, over seventy humanitarian stakeholders launched the Charter on Inclusion of Persons with Disabilities in Humanitarian Action (Humanitarian

1 Hazem Adam Ghobarah, Paul Huth and Bruce Russett, “Civil Wars Kill and Maim People – Long After the Shooting Stops”, *American Political Science Review*, Vol. 97, No. 2, 2003, p. 189.

2 Inclusion Europe, “Weeks of Horror. And We Cannot Possibly Leave”, press release, 2022, available at: [www.inclusion-europe.eu/weeks-of-horror-and-we-cannot-possibly-leave/](http://www.inclusion-europe.eu/weeks-of-horror-and-we-cannot-possibly-leave/) (all internet references were accessed in August 2022).

3 Human Rights Watch, “UN: High Risk in Conflicts for Children with Disabilities. Urgently Strengthen Protection, Assistance, Inclusion”, press release, New York, 2 February 2022, available at: [www.hrw.org/news/2022/02/02/un-high-risk-conflicts-children-disabilities](http://www.hrw.org/news/2022/02/02/un-high-risk-conflicts-children-disabilities).

4 Handicap International, *Disability in Humanitarian Context: Views from Affected People and Field Organisations*, Lyon, July 2015, p. 24.

5 International human rights law: Convention on the Rights of Persons with Disabilities, Convention on the Rights of the Child. Human rights principles: dignity, non-discrimination, participation and inclusion, accessibility, age and gender equality. International humanitarian law: 1949 Geneva Conventions and their Additional Protocols. Humanitarian principles: humanity, impartiality, neutrality. Existing and emerging global humanitarian standards: Humanitarian Charter and Minimum Standards in Disaster Response (Sphere Standards), Minimum Standards for Age and Disability Inclusion in Humanitarian Action, Minimum Standards for Child Protection in Humanitarian Action.

Disability Charter).<sup>6</sup> By signing the Charter, they expressed their commitment to the protection, safety and respect for the dignity of persons with disabilities in situations of armed conflict and other situations of risk, and affirmed their commitment to eliminating all forms of discrimination. The launch also initiated the process of developing United Nations (UN) Security Council Resolution 2475 on the protection of persons with disabilities in armed conflict, which was adopted unanimously in 2019.<sup>7</sup> Moreover, it led to the publication of the *Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action* (IASC Guidelines) in the same year. Endorsed by the Inter-Agency Standing Committee (IASC), the highest coordination body for humanitarian affairs in the UN system, and developed by more than 600 stakeholders across the disability, humanitarian and development sectors in a three-year process, the IASC Guidelines enjoy strong international support. They define four key “must-do” actions to facilitate the inclusion of persons with disabilities in humanitarian programming, namely (1) meaningful participation, (2) removal of barriers, (3) empowerment and capacity-building, and (4) and the collection, use and analysis of disaggregated data for monitoring inclusion.<sup>8</sup> Yet, three years after the publication of the Guidelines, questions emerge as to whether humanitarian action has become more disability-inclusive and how relevant stakeholders can close persisting barriers for persons with disabilities in situations of armed conflict.

This article explores these questions with a case study on the humanitarian response in South Sudan. Building on document analysis, two focus group discussions with persons with disabilities and expert interviews with fifteen representatives from international and national organizations with and without disabilities, this contribution demonstrates that the publication of the IASC Guidelines has given humanitarian actors a push to commit themselves to inclusive humanitarian action. However, humanitarian staff still lack the knowledge, skills and resources to implement the four “must-do” actions in demanding operational environments. This limits the organizational capacity to design and implement inclusive programmes and projects. To meet their strategic goals and commitments on inclusion, humanitarian organizations and their donors need to invest more time and resources in capacity-building and coordination.

This article is divided into eight parts. After this introduction, the second part of the article gives a brief overview of different models of disability and the accepted definition of “disability inclusion” in humanitarian action. The third part explains the reasons for selecting South Sudan as a case study and describes the methods of data collection and analysis employed. Subsequently, the fourth part gives an overview of the humanitarian context, the civil war and the security environment. The fifth part describes the situation of persons with disabilities

6 Charter on Inclusion of Persons with Disabilities in Humanitarian Action, available at: <https://humanitariananddisabilitycharter.org/>.

7 UNSC Res. 2475, 20 June 2019.

8 IASC, *IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action*, 2019 (IASC Guidelines), available at: <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>.

and the legal and policy framework in place to protect their rights. After this, the sixth part explores how donors, UN agencies and non-governmental organizations (NGOs) promote the inclusion of persons with disabilities in their policies and guidelines. Taking the four “must-do” actions as a starting point, the seventh part then analyzes how humanitarian actors are “doing inclusion”, with a focus on the progress being made, and the gaps still existing, in implementing inclusive humanitarian action; it then discusses how humanitarian organizations can build on the progress already made and meet the remaining operational challenges. Finally, the conclusion summarizes these findings.

## Disability inclusion and humanitarian action

The humanitarian principles of humanity and impartiality, to which all humanitarians must subscribe, entail that human suffering must be addressed wherever it is found (humanity), and that aid must be provided on the basis of need alone, giving priority to the most urgent cases of distress (impartiality). However, the task of protecting and providing assistance to persons with disabilities has long been assigned to specific disability-focused organizations or has been part of targeted programmes geared towards medical treatment, rehabilitation and care. Such an approach reflects the outdated medical and charity models of disability, which understand disability as a problem of the individual that needs to be treated, fixed or cured.<sup>9</sup>

With the UN Convention on the Rights of Persons with Disabilities (CRPD), a human rights model established itself that regards persons with disabilities as equal rights holders. This entails overcoming structural and institutional as well as direct and indirect forms of discrimination.<sup>10</sup> Many humanitarian organizations committed themselves to the human rights approach by signing the 2016 Humanitarian Disability Charter. A system-wide UN Disability Strategy<sup>11</sup> and the IASC Guidelines followed in 2019 to facilitate the implementation of the Charter into practice. They clarify the meaning of inclusive humanitarian action, according to which “disability inclusion is achieved when persons with disabilities meaningfully participate in all their diversity, when their rights are promoted, and when disability-related concerns are addressed in compliance with the CRPD”.<sup>12</sup> Furthermore, and as mentioned, the IASC Guidelines define four key “must-do” actions, which apply in all sectors and at all stages of the humanitarian response.

However, only few studies examine how humanitarians seek to make their programmes and services more inclusive for persons with disabilities.<sup>13</sup> Hence, it

9 Brigitte Rohwerder, *Disability Inclusion: Topic Guide*, GSDRC, University of Birmingham, November 2015, p. 5.

10 Theresia Degener, “Disability in a Human Rights Context”, *Laws*, Vol. 5, No. 35, 2016, p. 13.

11 UN, *UN Disability Inclusion Strategy*, 2019, available at: [www.un.org/en/content/disabilitystrategy/](http://www.un.org/en/content/disabilitystrategy/).

12 IASC Guidelines, above note 8, p. 9; UN, above note 11, p. 20.

13 For exceptions, see Carolin Funke and Dennis Dijkzeul, *From Commitment to Action: Towards a Disability-Inclusive Humanitarian Response in South Sudan*, 2022, available at: <https://tinyurl.com/>

remains unclear how humanitarian actors are “doing inclusion”, particularly in situations of violence. This article will examine this question by focusing on disability inclusion in South Sudan.

## Methods and case selection

South Sudan has been chosen to explore disability-inclusive humanitarian practices in armed conflict for three main reasons. First, South Sudan has long been grappling with inter-communal violence, inter-group conflict and regular violent attacks against civilians and aid workers. This requires humanitarian actors to operate in an environment of limited statehood “in which central authorities (governments) lack the ability to implement or enforce rules and decisions and/or in which the legitimate monopoly over the means of violence is lacking”.<sup>14</sup> Consequently, humanitarian organizations have undertaken a central role and responsibility in offering basic services to the population, including internally displaced persons (IDPs), even in hard-to-reach areas. However, there is hardly any research on disability inclusion. Thus, this article can make a significant contribution towards a better understanding of challenges and good practices in disability-inclusive humanitarian programming.

Second, disability is no longer a marginal issue for humanitarian organizations in South Sudan. Persons with disabilities are included in the Humanitarian Needs Overviews and Humanitarian Response Plans, and many organizations cooperate with inclusion-focused NGOs to build their capacity and make their services more accessible for persons with disabilities. Simultaneously, persons with disabilities organize themselves and contribute to the humanitarian response and to development activities – a process that started in 2010, even before the national referendum that led to the country’s independence. They are involved in advocacy and engage in the political processes of the country, for instance by contributing to national efforts to develop a disability inclusion policy.<sup>15</sup> In 2020, eight organizations of persons with disabilities (OPDs) founded an umbrella body, the National Union of Disabled People’s Organisations, which promotes the equal participation of persons with disabilities in all social, political and economic dimensions of public life.<sup>16</sup>

<sup>426jn43z</sup>; Flora Cohen and Lauren Yeager, “Task-Shifting for Refugee Mental Health and Psychosocial Support: A Scoping Review of Services in Humanitarian Settings through the Lens of RE-AIM”, *Implementation Research and Practice*, Vol. 2, 2021; Carolin Funke and Dennis Dijkzeul, *Mainstreaming Disability in Humanitarian Action: A Field Study from Cox’s Bazar, Bangladesh*, 2021, available at: <https://tinyurl.com/mv2w8yna>; Jura L. Augustinavicius, M. Claire Greene, Daniel P. Lakin and Wietse A. Tol, “Monitoring and Evaluation of Mental Health and Psychosocial Support Programs in Humanitarian Settings: A Scoping Review of Terminology and Focus”, *Conflict and Health*, Vol. 12, No. 9, 2018.

14 Stephen D. Krasner and Thomas Risse, “External Actors, State-Building and Service Provision in Areas of Limited Statehood: Introduction”, *Governance*, Vol. 27, No. 4, 2014, p. 549.

15 E-Mail exchange with inclusion expert from HI (on file with author).

16 Light for the World, “A First for South Sudan’s Disability Movement”, press release, 2020, available at: [www.light-for-the-world.uk/news/a-first-for-south-sudans-disability-movement/](http://www.light-for-the-world.uk/news/a-first-for-south-sudans-disability-movement/). Members include the

Third, the research for this article has been carried out with support of the inclusion-focused NGOs Humanity & Inclusion (HI) and Christian Blind Mission. Both organizations have a long-standing presence in South Sudan and were able to organize focus group discussions with persons with disabilities, establish contact with potential interview partners and share grey literature with the author. This facilitated the data collection considerably, given that the COVID-19 pandemic prevented data collection on the ground.

The data were acquired through two focus group discussions with twenty-one representatives of OPDs in the cities of Yei and Yambio,<sup>17</sup> and fifteen expert interviews with representatives from UN agencies, international mainstream NGOs, OPDs, and three inclusion-focused organizations. Unfortunately, government officials who were contacted for interview did not respond despite repeated requests.<sup>18</sup>

## **Background: Civil war and the security environment in South Sudan**

South Sudan has a relatively long history of political turmoil and civil war with its (now) northern neighbour Sudan. After a referendum on independence, with 99% of the votes in favour and with the referendum being perceived to have met international standards, South Sudan formally became an independent State on 9 July 2011. Hopes for a secure, free and stable country soon vanished, however, with the outbreak of another brutal civil war two years later. The 2018 peace deal, the so-called Revitalized Agreement on the Resolution of Conflict in the Republic of South Sudan, ended the fighting between armed forces loyal to President Salva Kiir and to opposition leader Riek Machar, but numerous inter-group conflicts and inter-communal violence in many parts of the country challenged government control and the State's monopoly on the use of force.<sup>19</sup> In February 2020, the two political adversaries formed a unity government, but the elite struggle for political dominance continues.<sup>20</sup> In fact, many provisions of the peace accord and much-needed political reforms remain unimplemented to this

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

17 In total, five women and five men participated in Yei and four women and seven men participated in Yambio. These focus group discussions were facilitated by HI staff, and notes of the discussions were shared with the author afterwards.

18 Several interview partners had a disability, and some organizations had a dual mandate, which means that they were active in both the humanitarian and development sectors. All interviews were recorded, transcribed and analyzed using the MAXQDA software application. The names and affiliations of the interview partners will remain anonymous. Although the data are not representative for the whole humanitarian response in South Sudan, they still provide useful insights into the work of various key actors on disability inclusion, remaining gaps, ongoing challenges and progress, as well as inviting more in-depth and longitudinal field research.

19 Bertelsmann Stiftung, *Transformation Index BTI 2022 Country Report: South Sudan*, Gütersloh, 2022.

20 International Crisis Group, *South Sudan's Splintered Opposition: Preventing More Conflict*, Juba, Nairobi and Brussels, 25 February 2022.

day, hampering progress towards sustainable peace and long-term development. Moreover, South Sudan has neither signed nor ratified various major international human rights instruments, including the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, and the CRPD.<sup>21</sup>

Basic service delivery is mainly in the hands of UN agencies and NGOs,<sup>22</sup> but the negative effects of climate change (particularly heavy rain and severe flooding), renewed fighting among local non-State armed groups and insecurity are hampering development efforts and localization. Moreover, frequent attacks against aid workers threaten security and make South Sudan one of the deadliest places for aid workers worldwide.<sup>23</sup> Since 2013, at least 130 humanitarian workers, most of them South Sudanese nationals, have been killed on duty.<sup>24</sup>

Eleven years after independence, South Sudan became a protracted crisis context, with the balance tipping back to increasing humanitarian and reducing development efforts. Of the country's 12.5 million inhabitants, 8.9 million are in dire need of assistance; this is an increase of 600,000 since 2021, largely due to the effects of the COVID-19 pandemic and inflation.<sup>25</sup> Among those people are 2.1 million women, 4.7 million children and 1.3 million people with disabilities.<sup>26</sup> Poverty rates are extremely high, despite abundant natural resources. An estimated 2 million people are expected to be acutely malnourished in 2022.<sup>27</sup> Furthermore, large parts of the population have only limited or no access to adequate health services, safe water, education and electricity.<sup>28</sup>

In 2021, South Sudan hosted some 300,000 refugees and asylum-seekers, mainly from Sudan, and had 2 million IDPs.<sup>29</sup> Some 2.3 million South Sudanese have found refuge in neighbouring countries, mainly Ethiopia, Kenya, Sudan and Uganda.<sup>30</sup> The resurgence of violence in certain parts of the country has led to ever-more expulsions and displacements. In December 2021, for example,

21 "Ratification Status for South Sudan", *UN Treaty Body Database*, available at: [https://tbinternet.ohchr.org/\\_layouts/15/TreatyBodyExternal/Treaty.aspx?CountryID=215&Lang=en](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?CountryID=215&Lang=en).

22 South Sudan Human Rights Defenders Network, Human Rights Watch and Amnesty International, *South Sudan: Human Rights Priorities for the Government of the South Sudan*, 3 February 2022, p. 2, available at: [www.amnesty.org/en/documents/afr65/5196/2022/en/](http://www.amnesty.org/en/documents/afr65/5196/2022/en/).

23 Care International, "10 Years from Independence and South Sudan Is One of the Deadliest Places to Be an Aid Worker", 19 August 2021, available at: [www.care.org/news-and-stories/press-releases/10-years-from-independence-and-south-sudan-is-one-of-the-deadliest-places-to-be-an-aid-worker/](http://www.care.org/news-and-stories/press-releases/10-years-from-independence-and-south-sudan-is-one-of-the-deadliest-places-to-be-an-aid-worker/).

24 Nyagoah Tut Pur, "Surge in Attacks on Aid Workers in South Sudan. Authorities Should Improve Protection, Investigate Attacks", press release, Human Rights Watch, 4 March 2022, available at: [www.hrw.org/news/2022/03/04/surge-attacks-aid-workers-south-sudan](http://www.hrw.org/news/2022/03/04/surge-attacks-aid-workers-south-sudan).

25 UN Office for the Coordination of Humanitarian Affairs (OCHA), *Humanitarian Needs Overview: South Sudan*, February 2022, p. 6.

26 *Ibid.*

27 *Ibid.*

28 *Ibid.*, p. 16.

29 Office of the UN High Commissioner for Refugees (UNHCR), "South Sudan", 2022, available at: [www.unhcr.org/south-sudan.html](http://www.unhcr.org/south-sudan.html).

30 *Ibid.*



violence in Tonj North County, Warrap, displaced thousands of people, while 80,000 people were displaced from Tambura.<sup>31</sup>

## Disability in South Sudan

Reliable and representative data on persons with disabilities in South Sudan do not exist. The last national census, conducted in 2008 before the country's independence, estimated that 5.1% of the population who lived in the region that is now South Sudan had a disability.<sup>32</sup> This clearly contradicts global estimates, by which at least 15% of any population are persons with disabilities.<sup>33</sup> In fact, after years of civil war and armed violence – and the concomitant side effects, including the proliferation of mines, unexploded ordinance, physical trauma and abuse, insufficient access to essential health and medical services, lack of protection, and general poverty – it is likely that the percentage of citizens with a long-term impairment is even higher than the global estimate.<sup>34</sup>

Legally, persons with disabilities are protected under the Transitional Constitution of the Republic of South Sudan of 2011, which has several articles relevant for persons with disabilities. However, the 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”. Articles 30(1) and (2) stipulate that the government has the obligation to ensure that “persons with special needs and the elderly” are able to enjoy their rights and freedoms and to participate in society. Moreover, it reaffirms the duty to ensure that persons with disabilities have access to public utilities, suitable education, and employment. Furthermore, the elderly and persons with disabilities have the right to the respect of their dignity and the right to be provided with necessary medical services. Other articles, including Article 29 on the right to education, Article 31 on the right to health, and Article 139(1)(d) on basic values and guidelines for civil services, indirectly address disability.<sup>35</sup>

In 2013, the Ministry of Gender, Child and Social Welfare, Humanitarian Affairs and Disaster Management, the appointed line ministry for persons with disabilities, passed a National Disability and Inclusion Policy to better protect the rights of persons with disabilities.<sup>36</sup> Moreover, the Ministry of Education, Science and Technology, with support from the international inclusion-focused NGO

31 OCHA, “South Sudan Humanitarian Snapshot”, December 2021, available at: [https://reliefweb.int/sites/reliefweb.int/files/resources/south\\_sudan\\_humanitarian\\_snapshot\\_december\\_0.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/south_sudan_humanitarian_snapshot_december_0.pdf).

32 South Sudan Association of the Visually Impaired (SSAVI), *South Sudan UPR Report – 2016: Coalition of Organizations of Persons with Disabilities*, 2016, p. 1.

33 World Health Organization and World Bank, *World Report on Disability*, Geneva, 2011.

34 OCHA, above note 25, p. 14.

35 For a comprehensive overview of South Sudan's legal obligations vis-à-vis persons with disabilities, see Innocentia Mgiijima-Konopi, Theophilus Odaudu and Reshoketswe Mapokgol, “Country Report: South Sudan”, *African Disability Rights Yearbook*, Vol. 7, Pretoria University Law Press, Pretoria, 2019.

36 Republic of South Sudan, Ministry of Gender, Child and Social Welfare, Humanitarian Affairs and Disaster Management, *South Sudan National Disability and Inclusion Policy*, 2013, p. 13.



Light for the World and Save the Children, launched an inclusive education policy in 2021 to ensure equal access to education and provide the ministry with a tool to monitor progress.<sup>37</sup> Yet, the absence of a comprehensive human rights agenda and action plan and gaps in governance and security challenge the implementation of these policies.

To further promote the human rights of persons with disabilities in law, policy and practice, it is crucial to appoint members of the disability movement to the national constitutional review commission that is tasked with drafting a permanent constitution for South Sudan. The process resumed in 2020 after a year-long suspension, but critics point out that it needs to be revised at its core to become participatory and inclusive for all.<sup>38</sup>

Disability and inclusion surveys<sup>39</sup> in the Protection of Civilians sites (PoCs) in Wau, Malakal and Bentiu reveal that persons with disabilities face numerous barriers to accessing humanitarian services. The IDP camps, which used to be called PoCs under the protection of South Sudan's peacekeeping mission, UNMISS, are now officially under the control of the government, except in Malakal. The sites were formerly under the protection of the UN, but in 2020 UNMISS decided to hand over control of all but one of them to the authorities. Most IDPs in these camps belong to the country's ethnic minority groups and live in areas dominated by forces that had previously fought against them.<sup>40</sup> Particularly, survey respondents remarked that the long distances to service and distribution points, lack of information, lack of physical access, discrimination, harassment and safety concerns in the process of accessing services (for example, through emotional and physical abuse from other IDPs in the PoC) represented the most severe barriers. In Malakal, respondents expressed a fear of verbal violence and physical violence when accessing services. In Wau, almost a quarter of respondents cited fear of physical abuse when accessing services. In Bentiu, persons with disabilities faced higher risks of physical violation, bribery and coercion than persons without disabilities. Service providers in Bentiu explained that persons with disabilities are more often the target of various offences such as robbery, rape and harassment. Persons with disabilities lacked access to specialized services and assistive devices, and in Malakal, almost every second individual with a disability also reported at least one mental health concern.

37 Daniel Danis, "Save the Children Supports the Review of Education Policy Document", press release, Save the Children, Juba, 30 October 2021, available at: <https://southsudan.savethechildren.net/news/save-children-supports-review-education-policy-document>.

38 Mark Deng, "South Sudan's Constitution Making Process Is on Shaky Ground: How to Firm It Up", *The Conversation*, 10 March 2022, available at: <https://theconversation.com/south-sudans-constitution-making-process-is-on-shaky-ground-how-to-firm-it-up-177107>.

39 International Organization for Migration (IOM) Displacement Tracking Matrix South Sudan, HI and South Sudan CCCM Cluster, *Disability and Inclusion Survey: Wau PoC AA*, 31 October 2019; IOM Displacement Tracking Matrix South Sudan, HI and South Sudan CCCM Cluster, *Disability and Inclusion Survey: Malakal Protection of Civilians Site*, 15 February 2021; IOM Displacement Tracking Matrix and HI, *Access to Humanitarian Services for People with Disabilities: Situational Analysis in Bentiu Protection of Civilians Site, South Sudan*, 2018.

40 Daniel P. Sullivan, *Do Not Forget: Aiding and Protecting Civilians in South Sudan*, Refugees International, South Sudan, 13 January 2022, p. 2.

Furthermore, respondents demanded more support for family members and caregivers and access to livelihoods; they also expressed a need for access to clean water and to water, sanitation and hygiene facilities. Moreover, the survey found that the majority of persons with disabilities did not live in shelters that were suitable for their specific needs and essential requirements. Low participation of people with disabilities in camp coordination, leadership and management structures was considered a problem in all three disability and inclusion surveys.<sup>41</sup>

Outside the PoCs, barriers and facilitators assessments in the education sector in Juba, Torit and Bor found that most of the basic accessibility features, such as ramps, cemented pathways and handrails, were not in place in the schools under examination. Initiatives to make education more accessible for persons with disabilities came from individual teachers and administrators but were not part of an overarching policy approach.<sup>42</sup> Similar findings could be observed in barriers and facilitators assessments in the health sector, which revealed that health services were barely accessible for persons with disabilities.<sup>43</sup> In the hospitals, doors were too narrow, door handles were too high and not painted in bright colours, signs were too small for those with visual impairments, and information was not available in accessible formats such as Braille or large print. Many buildings did not have ramps, tactile markings or accessible signage. Moreover, staff members were not trained in sign language.<sup>44</sup>

Focus group discussions with representatives from OPDs showed comparable results.<sup>45</sup> Participants remarked that inaccessible buildings, lack of public transport options and a poor road network prevent many persons with a physical impairment from reaching service points, as well as health and education facilities. Moreover, persons with a visual impairment struggle to locate services and service points. In addition, the negative attitude of some service providers leads to discrimination and harassment. Persons with disabilities had few opportunities to earn a living since livelihood and employment opportunities were rare, as were possibilities for skill development and learning; this increases their risk of a life in poverty. Furthermore, lack of access to assistive devices and information in multiple formats and exclusion of persons with disabilities in community activities and social gatherings increase their dependence on family members and caregivers and hamper their participation in social life.<sup>46</sup>

Women with disabilities face particularly high risks of harassment, rape and sexual exploitation, and are thus vulnerable to unwanted pregnancies and

41 See above note 39.

42 HI, *Barriers and Facilitators Assessment Report for Accessible Education in Buluk A1 Primary School, South Sudan*, 2017, p. 6; HI, *Barriers and Facilitators Assessment Report for Accessible Education in Torit East Primary School, South Sudan*, 2017, p. 6.

43 HI, *Barriers and Facilitators Assessment Report for Accessible Health Services in Juba Teaching Hospital, South Sudan*, 2017, pp. 11–13; HI, *Barriers and Facilitators Assessment Report for Accessible Health Services in Torit State Hospital, South Sudan*, 2017, pp. 11–13.

44 HI, *Juba Teaching Hospital*, above note 43, pp. 11–13; HI, *Torit State Hospital*, above note 43, pp. 11–13.

45 Focus group discussions with persons with disabilities and OPD representatives, Yambio, May 2021 (on file with author).

46 *Ibid.*

sexually transmitted disease.<sup>47</sup> Many of them have to raise their children alone, and due to their lack of skills and employment opportunities, women with disabilities struggle to provide their children with adequate shelter, food, clothes and education.<sup>48</sup>

Because South Sudan is a conflict setting, it is not surprising that grave human rights abuses also occur. Amnesty International, Human Rights Watch and South Sudan Human Rights Defenders Network reported deliberate attacks on civilians and extrajudicial killings, including persons with disabilities, and inhuman and degrading treatments of persons with psychosocial disabilities who were under arrest or in detention.<sup>49</sup>

Summing up, South Sudan represents a challenging humanitarian context, where persons with disabilities face serious risks of exclusion and marginalization. Although humanitarian organizations have little influence on the conflict dynamics and concomitant human rights violations, the following sections show that they work hard to promote inclusion and to make their services more accessible for person with disabilities.

## Promoting Inclusion through donor and organizational policies

The precarious humanitarian conditions in South Sudan demand a massive and sustained humanitarian response. As of December 2021, 104 organizations were implementing emergency programmes in nine different sectors.<sup>50</sup> Most organizations offered health and nutrition services, while four organizations were involved in camp coordination and management<sup>51</sup> and only two were responsible for logistics.<sup>52</sup> In total, donors spent \$1.2 billion on humanitarian assistance,<sup>53</sup> this makes South Sudan one of the largest recipients of humanitarian aid worldwide.<sup>54</sup> Most donations for the 2020 Humanitarian Response Plan came from the United States (\$714.5 million), the United Kingdom (\$88.9 million),

47 OCHA, above note 25, p. 29.

48 Focus group discussion with persons with disabilities and OPD representatives, Yei and Yambio, May and June 2021 (on file with author).

49 South Sudan Human Rights Defenders Network, Human Rights Watch and Amnesty International, above note 22, p. 8.

50 OCHA, *South Sudan: Reporting Organizations Operational Presence (3W: Who Does What, Where)*, December 2021, available at: [www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/ss\\_20220130\\_3wop\\_county\\_level\\_december\\_final.pdf](http://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/ss_20220130_3wop_county_level_december_final.pdf). The sectors are: (1) health; (2) nutrition; (3) food security and livelihoods; (4) protection; (5) water, sanitation and hygiene; (6) education; (7) shelter and non-food items; (8) camp coordination and camp management; and (9) logistics. In total, fifty-two international NGOs, forty-six national NGOs and six UN agencies were involved in the response.

51 These were ACTED, the Danish Refugee Council, UNHCR and the IOM.

52 These were the IOM and World Food Programme.

53 OCHA, *South Sudan: 2020 Humanitarian Response in Review*, 2020, p. 1, available at: [https://reliefweb.int/sites/reliefweb.int/files/resources/south\\_sudan\\_humanitarian\\_response\\_in\\_review\\_2020.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/south_sudan_humanitarian_response_in_review_2020.pdf).

54 The five largest recipients of aid were, in descending order, Syria, Yemen, Lebanon, South Sudan and the Democratic Republic of the Congo. See Development Initiatives and Global Humanitarian Assistance, *Global Humanitarian Assistance Report 2021*, 2021, p. 10.

Germany (\$75.3 million), and the European Commission’s Directorate General for European Civilian Protection and Humanitarian Aid Operations (DG ECHO) (\$67 million).

The policy environment for inclusive humanitarian action is comparatively favourable. The four largest donors – the United States, the United Kingdom, Germany and DG ECHO – actively support the inclusion of persons with disabilities in all of their funded aid operations, and major international humanitarian organizations have also begun to develop policies and strategies on disability inclusion. The growing demand for more data and information on disability by donors has most likely contributed to this trend. In 2020, the International Committee of the Red Cross introduced its Vision 2030 on Disability; in 2019, the UN – as mentioned – published a system-wide Disability Inclusion Strategy; and major NGOs, such as Médecins Sans Frontières, Save the Children, World Vision International and the International Rescue Committee, have developed guidelines and policies to strengthen inclusion of persons with disabilities.<sup>55</sup> Moreover, relevant stakeholders expressed their commitment to inclusive humanitarian action at the 2022 Global Disability Summit. In total, they made 1,413 commitments, of which 180 relate specifically to the thematic area of “Situations of Conflict and Crises”.<sup>56</sup> This leaves no doubt that disability inclusion has become an integral part of humanitarian action – at least at the strategic and policy level. Yet, the question arises as to whether the publication of policies and guidelines has also changed humanitarian practice on the ground.

## “Doing inclusion” in South Sudan

Looking closely at the activities of humanitarian actors in South Sudan, one will notice significant progress, but also significant gaps in the implementation of the four “must-do” actions of the IASC Guidelines. Going in reverse order, the following sections will examine the progress and the gaps in the collection of data; empowerment and capacity-building; removal of barriers; and the participation of persons with disabilities.

### Progress on inclusion

Until 2019, Humanitarian Needs Overviews did not consider the rights, needs and vulnerabilities of persons with disabilities. The 2018 Humanitarian Needs Overview

55 Médecins Sans Frontières, “Inclusion of Persons with Disabilities: 6 Keys for Inclusion”, Geneva, available at: [https://disabilityinclusion.msf.org/assets/files/IPWD\\_Guideline\\_KeyPPLs\\_EN.pdf](https://disabilityinclusion.msf.org/assets/files/IPWD_Guideline_KeyPPLs_EN.pdf); Save the Children International, *Save the Children’s Disability Inclusion Policy: Lifting Barriers, Realizing Equality*, London, 2021; World Vision International, *Guidelines on Inclusion of Persons with Disabilities*, Monrovia, CA, available at: [www.wvi.org/sites/default/files/Guidelines\\_on\\_Inclusion\\_of\\_Persons\\_with\\_Disabilities.pdf](http://www.wvi.org/sites/default/files/Guidelines_on_Inclusion_of_Persons_with_Disabilities.pdf); International Rescue Committee, *Inclusive Client Responsiveness: Focus on People with Disabilities and Older People*, New York, May 2021.

56 Global Disability Summit, “Commitments”, 2022, available at: [www.globaldisabilitysummit.org/commitments](http://www.globaldisabilitysummit.org/commitments).

only mentions persons with disabilities twice, alongside other “vulnerable” groups, including children, older people, and people living with HIV/AIDS or tuberculosis.<sup>57</sup> With the upsurge in new guidelines, policies and commitments, however, this changed radically. Four years later, the term “persons with disabilities” appears fifty-six times, indicating a heightened awareness of their needs and vulnerabilities.<sup>58</sup> In fact, cluster leaders have an increased interest in data on persons with disabilities, and some clusters (such as health and protection) have developed or are in the process of developing monitoring tools that incorporate the Washington Group Questions Short Set (WGQ-SS).<sup>59</sup> As one interview partner explained:

Up until at least last year, we did not collect data on persons with disabilities. Last year, we have collected [*sic*] 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 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 we would get a better idea of who among the affected communities is a person with a disability.

Moreover, the International Organization for Migration (IOM) Displacement Tracking Matrix South Sudan and World Food Programme, in collaboration with several clusters, have incorporated the WGQ-SS into two annual country-wide surveys, the Food Security and Nutrition Monitoring Survey and the Multi-Sector Needs Assessment. The latest Food Security and Nutrition Monitoring Surveys for the capital Juba and for Bentiu/Rubkona, for example, reveal that more than 40% of all households have a member with a disability.<sup>60</sup>

At the programme level, UN agencies have established dedicated focal points or protection mainstreaming officers who are tasked with ensuring that all their assessments incorporate the WGQ-SS.<sup>61</sup> Furthermore, inclusion-focused

57 OCHA, *Humanitarian Needs Overview: South Sudan*, 2018.

58 OCHA, above note 25.

59 The Washington Group on Disability Statistics has developed tools for measuring 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 only address limitations in undertaking basic activities. The WGQ-SS focuses on six domains, namely seeing, hearing, walking, remembering or concentrating, self-care, and communicating. See Washington Group on Disability Statistics, *WG Short Set on Functioning (WG-SS)*, 2020, available at: [www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/](http://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/).

60 In collaboration with the Shelter Non-Food Items Cluster, 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 Health Cluster. IOM Displacement Tracking Matrix South Sudan and World Food Programme, *Urban Multi-Sector Needs, Vulnerabilities and COVID-19 Impact Survey (FSNMS+): Juba Town*, 31 March 2021 (Juba Impact Survey), p. 11; IOM Displacement Tracking Matrix South Sudan, *Urban Multi-Sector Needs, Vulnerabilities and COVID-19 Impact Survey (FSNMS+): Bentiu/Rubkona Town*, 12 August 2021 (Bentiu/Rubkona Impact Survey), p. 12.

61 Interview with a representative of a UN agency, June 2021 (on file with author).

organizations train enumerators on the correct usage of the WGQ-SS; this has led to comprehensive barriers and facilitators reports, which are also quoted in the Humanitarian Needs Overviews.<sup>62</sup>

Indeed, some humanitarian organizations have invested in capacity-building to raise awareness on the rights of persons with disabilities and increase their own skills on inclusive practices. Inclusion-focused organizations offer training and learning sessions on inclusive humanitarian action, coach and mentor staff at various levels of the response, engage in knowledge and experience sharing, conduct assessments, and give advice on inclusive programme design and management and the development of inclusive policies. In most cases, mainstream actors approach inclusion-focused organizations for training and coaching sessions because their staff lack the expertise to meet donor demands or their self-defined inclusion standards. Particularly, UN agencies have expanded their partnerships with inclusion-focused NGOs. The latter offer tailor-made capacity-building to staff at all levels of the response, as one interviewee confirms:

When we engage with senior management, we tend to focus on inclusive programming – for example, on issues related to universal design<sup>63</sup> and the participation of persons with disabilities in the development of programmes and projects – whereas our engagement with front-line staff in various organizations focuses on inclusive language – for example, the language that they are supposed to use when addressing people with disabilities.<sup>64</sup>

Besides mainstream humanitarian actors, inclusion-focused organizations also support the capacity-building of OPDs. Specifically, they try to enhance OPDs' 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. 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.<sup>65</sup>

These efforts contributed to tangible progress in removing barriers for persons with disabilities – for example, by making distribution points more accessible for persons with a walking or visual impairment.<sup>66</sup> Moreover, they have led to more meaningful

62 Juba Impact Survey, above note 60, p. 8; Bentiu/Rubkona Impact Survey, above note 60, p. 9.

63 “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”: see Convention on the Rights of Persons with Disabilities, 13 December 2006 (entered into force 3 May 2008), Art. 2.

64 Interview with HI staff member, June 2021 (on file with author).

65 Interview with a representative of Light for the World, July 2021 (on file with author).

66 Interview with a representative of a UN agency, June 2021 (on file with author).

participation of persons with disabilities in project activities and cluster meetings. Some international organizations have even begun to recruit persons with disabilities in order to increase their organizational diversity and expertise on disability inclusion and to raise awareness for the needs of persons with disabilities and give them a voice in project design and implementation.<sup>67</sup> Furthermore, humanitarian organizations encourage and support the establishment of community groups or committees of persons with disabilities in order to help them communicate their needs to humanitarian actors through these governance structures.<sup>68</sup>

Despite this remarkable progress, however, gaps in the inclusion of persons with disabilities remain.

### Explaining the remaining gaps in inclusion

So far, most information on disability in the 2022 Humanitarian Needs Overview for South Sudan is either anecdotal or based on a few interviews or surveys from UN agencies and inclusion-focused NGOs. In many instances, persons with disabilities are mentioned as part of a list of particularly vulnerable people, without defining the parameters of their vulnerability. Moreover, the 2022 South Sudan Humanitarian Needs Overview applies the global estimate of 15% to all sectors of the response because clusters do not systematically collect data on disability. The health cluster, for example, has a data-monitoring tool for disability inclusion, but does not apply the tool consistently in its assessments. Hence, data on disability is patchy, and the needs, risks and vulnerabilities of persons with disabilities, particularly those with intellectual and psychosocial impairments, are not well understood.

Adding and contributing to the incomplete data is the fact that people in South Sudan widely believe that disability is a punishment from God or a curse.<sup>69</sup> 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 are incapable of making a meaningful contribution to society.<sup>70</sup> Consequently, persons with disabilities often remain invisible. In this light, it is hardly surprising that consultations and community discussions are still regularly organized in locations that are hard to reach for persons with disabilities. Moreover, the meeting invitations are often not available in multiple formats and there is no reasonable accommodation, such as sign language interpretation, to facilitate interaction between persons with disabilities and humanitarian staff.

Furthermore, OPDs with strong financial and human resources are hardly present outside the capital Juba, effectively limiting their ability to communicate the needs, risks and vulnerabilities of persons with various types of impairments to

67 Interview with HI staff member, August 2021 (on file with author).

68 *Ibid.*

69 HI, *Torit East Primary School*, above note 44, p. 6.

70 SSAVI, above note 32, p. 1.



humanitarian actors and other relevant stakeholders in the response.<sup>71</sup> Their participation in cluster meetings is also negligible. Unstable internet access and the absence of reasonable accommodation hampers communication, and OPDs are still not familiar enough with the humanitarian system; this latter issue limits their ability to acquire funding, implement projects and operate independently from their humanitarian partners.<sup>72</sup>

Of course, and as mentioned, mainstream humanitarian actors are working on closing data gaps, reducing misconceptions, and enhancing the participation of persons with disabilities in their programme activities and cluster meetings, although a quantification of how many do so is not possible. Yet, at present, the information base on the needs, risks and concomitant vulnerabilities of persons with different types of impairments is small, prejudices and misperceptions are common, and participation rarely extends to the project design and evaluation phase. Hence, a mixed picture emerges when assessing the way humanitarians are “doing inclusion”.

Generally, humanitarians found the context too challenging to make the response truly disability-inclusive. In particular, lack of access and the concomitant inability to physically reach persons with disabilities was widely cited as one of the major impediments for inclusion. As one respondent explained:

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.<sup>73</sup>

In such a context, humanitarian staff simply did not know how to reach persons with disabilities and collect robust data, empower them, remove barriers and enhance participation in project design, implementation and monitoring.

Where physical access was possible, humanitarians felt they lacked the skills and confidence to target persons with disabilities, including those with intellectual or hearing disabilities.<sup>74</sup> The number of sign language interpreters in South Sudan is considered too small, and the many different local languages spoken across the country represented additional communication barriers – one respondent admitted that, so far, “no one has a good strategy for really dealing with that”.<sup>75</sup> Moreover, tight submission deadlines for project proposals and issues with commuting and long-distance travel were seen as severe obstacles to “robust consultations” with persons with disabilities:

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 proposal, some of the locations where you are intervening are far away from Juba. The flight

71 Interview with a representative of a mainstream NGO, June 2021; interview with a representative of HI, August 2021; interview with a representative of Christian Blind Mission, July 2021 (all on file with author).

72 Interviews with a representative of an international mainstream NGO and cluster co-lead, June 2021; interview with a representative of an OPD, August 2021 (both on file with author).

73 Interview with a representative of a UN agency, June 2021 (on file with author).

74 *Ibid.*

75 *Ibid.*

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.<sup>76</sup>

Humanitarians therefore demand more guidance and support from the Humanitarian Country Team and/or the government. Requests to the government include signing and ratifying the CRPD, improving infrastructure, removing attitudinal and institutional barriers in public institutions, and designing a new national census that uses the WGQ-SS. Some humanitarians are also looking for a “strategy” or “consolidated approach” from the Humanitarian Country Team to support the systematic collection of data and the engagement of persons with disabilities in the response.<sup>77</sup>

These demands are comprehensive, and the urgency of signing and ratify the CRPD is undisputed among inclusion experts and humanitarians. However, these steps alone will not create a more favourable environment for persons with disabilities. First, and as mentioned, the State lacks the monopoly of force in remote regions of the country and the government struggles with the implementation of laws and policies. Second, a national census, while helpful for identifying persons with disabilities and recognizing their full diversity, needs to be planned well in advance and does not offer immediate solutions to the existing data gaps; moreover, it will not deliver crucial qualitative data on the needs, specific requirements and vulnerabilities of persons with disabilities. Third, a “strategy” of the Humanitarian Country Team will not remove humanitarians from their responsibility to make their services accessible and inclusive.

Such demands rather reveal a lack of skills and confidence to implement inclusive projects. Moreover, they convey a perception whereby humanitarian staff see the reasons for the gaps in inclusive humanitarian practice in the external environment rather than in their own operational capacity. Hence, as noted, we see a mixed picture when assessing the way humanitarians are “doing inclusion”. Humanitarians recognize the need to be disability-inclusive and are trying their best to reach all persons in need, but the conditions in their operational environment, including access constraints, deficiencies in infrastructure, and unrealistic expectations from donors, are considered insurmountable obstacles to inclusion in humanitarian practice.

## Achieving inclusion in a challenging context

Without doubt, widespread violence, regular attacks against civilians and aid workers, dysfunctional State structures and catastrophic climate shocks represent

76 Interview with a representative of an international NGO, June 2021 (on file with author).

77 Interview with a representative of a UN agency, June 2021 (on file with author).

enormous obstacles to humanitarian action in general and inclusive humanitarian action in particular. However, it is important to ensure that the complex operational environment does not become a pretext for the exclusion of persons with disabilities, particularly those with intellectual and hearing impairments. In fact, no context is too challenging when humanitarians know what steps to take and have the financial, human and other resources needed to make their services accessible and inclusive.

With respect to more robust and reliable data, all cluster leads in South Sudan could establish inter-cluster data management working groups to agree on certain standards for data collection, including the use of the WGQ-SS in all community engagement surveys and other questionnaires. Regular experience sharing on their application and use in the field could generate confidence among humanitarian staff and increase knowledge on the challenges of identifying persons with disabilities. In regions that are not physically accessible, humanitarian organizations should assume that at least 15% of the population has a disability. Partially this is already happening, but organizations need to make corresponding adjustments in their budgets – otherwise they will lack the financial means for reasonable accommodation, and this will effectively limit their ability to communicate and engage with persons with disabilities. Moreover, humanitarian organizations could identify key informants in inaccessible regions and train them to collect and interpret data on disability; this would enable these organizations to better deal with tight donor deadlines and travel restrictions.

Clearly, reliable and robust data are necessary to enhance the visibility of persons with disabilities in South Sudanese society. This will help humanitarians to organize consultations and community discussions in locations that are accessible for persons with disabilities. Ideally, these discussions will accommodate the needs of persons with all kinds of impairments and linguistic backgrounds, and not just those with a walking disability. To quote another respondent: “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.”<sup>78</sup>

Sometimes, multiple layers of interpretation may be required in areas where different local languages are spoken. Although the small number of sign language interpreters in South Sudan can be a challenge, in practice, caregivers, teachers and social workers frequently act as interpreters. Project proposals and budgets should reflect these additional costs for consultation meetings, including when caregivers, teachers and social workers act as interpreters or translators. The same is true for cluster meetings, accountability mechanisms and material for information sharing and knowledge exchange, which may also require modifications and adjustments for persons with hearing, visual and other types of impairments.

Reasonable accommodation will be indispensable for meaningful participation and reducing attitudinal, environmental and institutional barriers. This means making necessary modifications and adjustments to avoid

78 Interview with a representative of a UN agency, online, July 2021 (on file with author).

discrimination and end exclusion. For example, organizations should provide interpreters, readers and other personal assistance in meetings and training sessions, ensure that distribution and service points, training sites and compounds are accessible for persons with visible and other types of physical impairments, and design documents, training material and evaluation tools in alternate formats such as Braille, large print or audio tape. Regular consultations and participation in programme design and implementation will also empower persons with disabilities to act as agents of change and stand up for their rights. Simultaneously, humanitarian organizations should encourage the establishment of OPDs and self-help groups and support their professionalization, particularly outside the capital of Juba. However, these adjustments carry additional costs and require sufficient funding. Particularly in a multilingual context such as South Sudan, it is crucial that donors allocate dedicated funding to sign language and local language interpretation in addition to other types of reasonable accommodation, such as subtitles in online cluster meetings. Moreover, precise indicators and funding allocation criteria by donors can create strong incentives for humanitarians to be more systematic in including those with “hidden” disabilities, such as persons with intellectual or psychosocial impairments. This could also enhance the transparency of expenditures on inclusive humanitarian action. At present, many donors do not work with precise indicators and funding allocation criteria, although, and as mentioned, many require data on disability.<sup>79</sup>

Importantly, donors should be aware that humanitarian staff need to have the knowledge and skills to implement inclusive humanitarian projects. Thus, they should provide for long-term and reliable funding for capacity-building as a stand-alone activity, which is one of the four “must-do” actions of the IASC Guidelines. In fact, many inclusion-focused NGOs would like to invest more time into the capacity-building of their mainstream partners, but they often lack funding for these activities because donors see them as part of development rather than humanitarian action.<sup>80</sup> This is especially detrimental for mainstream NGOs, which, unlike UN agencies, often lack the financial and technical support from their own headquarters to train national and local staff on inclusive humanitarian action.

Finally, humanitarian organizations could establish a disability inclusion coordination mechanism to strengthen their performance and accountability vis-à-vis persons with disabilities. Such a mechanism could articulate strategic priorities and key deliverables and provide technical and advisory functions to the UN Office for the Coordination of Humanitarian Affairs (OCHA) team, cluster leads, working groups, focal points, and the humanitarian needs assessment programme. This will allow humanitarian organizations to pool resources, maintain continuity when staff changes, and monitor impact, and will provide them with a forum for sharing information.

79 E-mail exchange with a representative of HI (on file with author).

80 Interview with a representative of an inclusion-focused NGO, August 2021 (on file with author).

Summing up, the inclusion of persons with disabilities in humanitarian action does not depend on a “grand strategy” of the Humanitarian Country Team. Inclusion can succeed in complex operational environments as long as humanitarians possess the skills, knowledge and funding to apply the four “must-do” actions of the IASC Guidelines. Better coordination through regular knowledge exchange and experience sharing among mainstream organizations, inclusion-focused NGOs and OPDs, the provision of reasonable accommodation in consultation and cluster meetings, accessible accountability mechanisms and, not least, a serious investment into capacity-building at all levels of the response will establish the necessary conditions to make humanitarian action inclusive and accessible for all.

## Conclusion

The publication of the Humanitarian Disability Charter and the concomitant publication of the IASC Guidelines have encouraged humanitarian actors to become more disability-inclusive. Many of them have distinct policies and internal guidelines that promote the inclusion of persons with disabilities in humanitarian practice. In South Sudan, humanitarian organizations have taken concrete steps to collect data on disability, invest in capacity-building and empowerment, remove barriers and enhance participation of person with disabilities. These measures have delivered concrete results. Persons with disabilities are now included in the Humanitarian Needs Overviews, the Food Security and Nutrition Monitoring Survey and the Multi-Sector Needs Assessment. UN agencies and NGOs have dedicated focal points that monitor progress on inclusion, set up and work with community groups to consult with persons with disabilities, establish services and distribution points in areas that are accessible for persons with physical impairments, and reach out to inclusion-focused organizations for guidance, training and other support.

Nevertheless, humanitarians struggle with access constraints, tight deadlines and communication barriers, and most importantly, the inability and incapacity to implement inclusive humanitarian action in such a challenging context. Hence, many gaps in the inclusion of persons with disabilities in South Sudan remain. Undoubtedly, the interviews with humanitarian staff carried out for this article reveal that awareness of the needs of, and protection gaps for, persons with disabilities is high, and many humanitarians are familiar with the IASC Guidelines, Humanitarian Disability Charter and internal organizational policies on inclusive humanitarian action. However, they lack the skills and knowledge to apply these tools in what they perceive as an extremely complex operational environment.

More investment into capacity-building and coordination at all levels of the humanitarian response is therefore called for. Through inclusion experts with and without disabilities, organizations can acquire the necessary skills and knowledge on how to overcome operational challenges in the field – for example, on how to

collect data on disability in hard-to-reach areas or reduce communication barriers. Donors play a key role and need to provide dedicated funding for reasonable accommodation, training, coaching and coordination. Over time, this will give humanitarians the skills and confidence to implement inclusive programmes and promote the human rights of persons with disabilities across the whole country. Humanitarian organizations should therefore indicate these additional costs in their project proposals.

Yet, in order to reduce gross human rights violations in South Sudan and enable persons with disabilities to live their lives in safety and dignity, the national government needs to take immediate steps to implement the peace accords and ratify crucial human rights instruments, including the CRPD. The more progress is made with the peace process, the easier humanitarian action and inclusion will become.