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Barriers and Facilitators to Providing Assistive Technologies to Children with Disabilities in South Sudan

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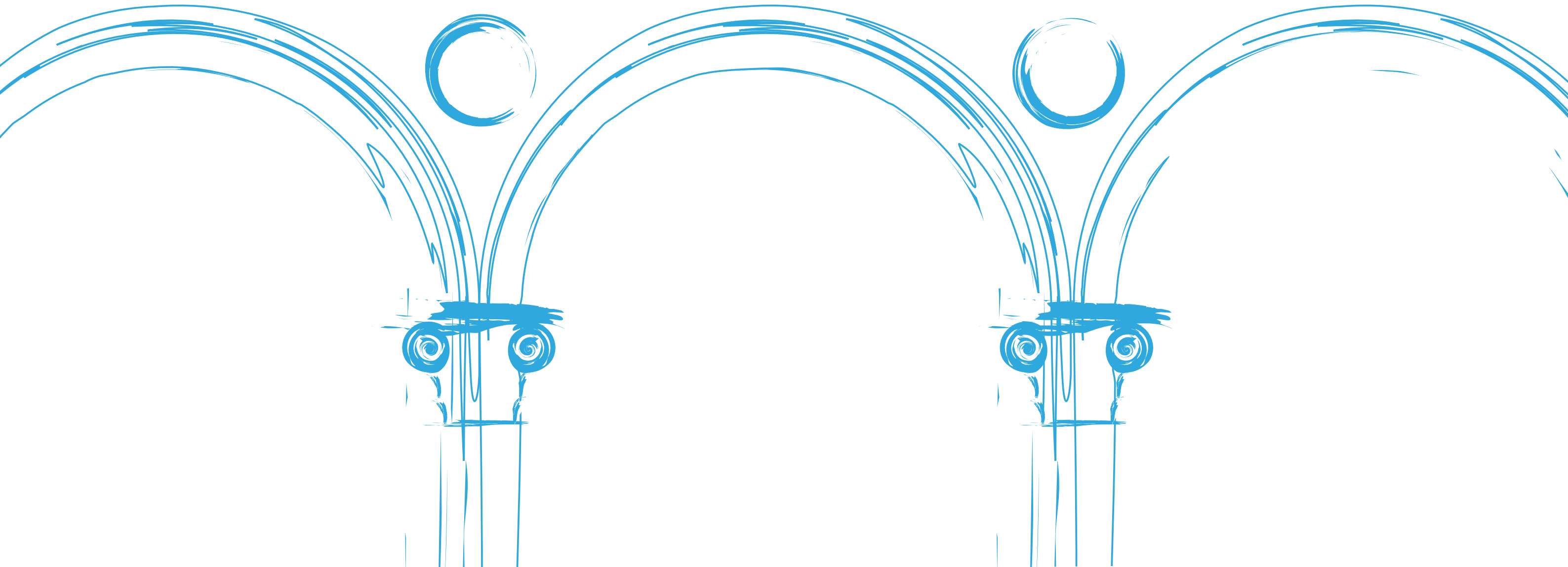

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BARRIERS AND FACILITATORS TO PROVIDING ASSISTIVE TECHNOLOGIES TO CHILDREN WITH DISABILITIES IN SOUTH SUDAN

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Overview

South Sudan is in a protracted crisis, in which 4 million people have been displaced and many have been left living with high levels of injury, poverty and food insecurity. The impact of the crisis on children – who make up over 29 per cent of the population – is particularly high, and a large number are at risk of being born with or acquiring a disability. Assistive technologies (AT) – the systems, services and products that enhance the functioning of people with impairments – are likely to be required by many children in South Sudan with disabilities. There is no reliable data available on disability prevalence or AT needs in South Sudan, though estimates suggest a range between 10 and 15 per cent of the population. This work aims to understand the landscape of AT provision and the barriers and facilitators to provision and provides recommendations for priority actions.

Approach

We first conducted a review of the global literature to understand what is known about the nature and scale of AT provision in humanitarian settings, and best practice in AT delivery. This review identified several knowledge gaps, with a key question being whether the paucity of academic literature reflects the scale of provision. We aimed to fill the evidence gaps by conducting an in-depth examination of field-level provision in two protracted crises – Afghanistan and South Sudan (see separate report) – which offer contrasting examples of humanitarian response. We conducted a review of the literature describing AT provision in South Sudan and identified the relevant organizations and key informants to participate in the research.

As there was good evidence regarding the barriers to AT **access** for children with disabilities, a key objective of the case study was to focus instead on explaining the (low) levels of AT **provision** in South Sudan. As such, the focus of our research was on providers rather than recipients of AT services. Informants included programme managers; implementation staff; policy leads; health, education and child protection advisers; advocacy leads and other experts with a role in the provision of programmes for children with disabilities. We conducted semi-structured interviews to build on the evidence in the literature to understand the factors affecting the provision of AT in South Sudan. Due to the ongoing COVID-19 pandemic, interviews were conducted remotely. Pandemic restrictions limited the scope of research (as implementers' projects could not be visited) but may have also led to more informants being accessible to researchers, due to the relative ease of online meetings in comparison to arranging in-person discussions.

Findings

Almost all AT provision in South Sudan is led by a small number of non-governmental organizations. We only found five organizations currently distributing assistive devices systematically. Most of the free-at-point-of-use provision is of mobility devices, though even this provision is likely to fall well below the levels required. We found few examples of AT provision for visual, hearing, communicative or cognitive impairments beyond a single eye hospital, which cannot meet the needs of the whole population. It is highly likely that most children with such impairments do not have access to the devices they need. Key barriers to access include high levels of stigma against children with disabilities, constraining demand, and the lack of provision, particularly for those living in remote and insecure locations.

The lack of AT provision is driven by a variety of interrelated factors. These include the absence of data on AT needs; the failure of the government and humanitarian agencies to prioritize targeted support for children with disabilities; the failure of the government to sign the Convention on the Rights of Persons with Disabilities (CRPD); low technical capacity by responsible actors to instigate, maintain and expand quality AT services; and the denial of humanitarian access by parties to the conflict.

Goal

Organizations with a responsibility for the humanitarian response in South Sudan – including the government, donors, multilateral agencies, NGOs and civil society – have a responsibility to coordinate provision of AT for all children who need it. It will not be enough to scale up existing provision of devices. This work aims to engage all responsible actors to coordinate their activities, prioritizing the following actions:

- Developing a roadmap towards ratification of the CRPD;
- Making the needs of children with disabilities a priority of the humanitarian and development agenda including, but **going beyond** 'inclusion', to provide targeted support to children with disabilities;
- Mapping AT services, needs and gaps, both geographically and by impairments;
- Establishing a monitoring mechanism and timeframe for meeting the CRPD commitments;
- Establish funding mechanisms to capacitate and scale up existing provision based on evidence, ensuring that provision reaches beyond state capitals and is accompanied by the necessary long-term services and awareness-raising to tackle stigma.

Audience

Organizations with a responsibility for the humanitarian response in South Sudan – including the government, donors, multilateral agencies, NGOs and civil society.

Case study: Assistive technology access and provision for children and adolescents with disabilities in South Sudan

Summary of findings

- We found no reliable data related to disability prevalence or AT needs in South Sudan. Disability prevalence estimates by WHO and HI range between 10–15 per cent, though disability prevalence may be higher among some population groups, such as PoC camp residents. We found no reliable estimates of child disability rates, or children's AT needs.
- The largest-scale provision of assistive devices for which we found evidence in South Sudan was via international NGOs, in particular the International Committee of the Red Cross (ICRC), Organismo di Volontariato per la Cooperazione Internazionale (OVCI) and Christian Blind Mission (CBM); these services included provision to children. Mobility-related devices, in particular prosthetics, are likely to have the highest free-of-charge distribution relative to other devices due to the specialisms of the dominant organizations providing assistive devices. However, even this provision is likely to fall well below the levels required. The only child-specific provision we found evidence of was via OVCI.
- We found evidence of Protection of Civilians (PoC) camp-based AT provision by Humanity and Inclusion and Light for the World.
- Barriers to access included the lack of provision and evidence from ICRC suggests that as provision has become more available and publicised, demand for devices has grown.
- The legislative and policy environment does not incentivise humanitarian organizations to focus on meeting gaps in AT provision. South Sudan has not yet ratified the CRPD. There is little evidence of government capacity or will to respond to AT needs. Basic unmet needs among the population – for food, water and shelter – are so high that the rights of people with disabilities to have their specific needs met receives little attention.
- Similarly, there is little evidence that wider international humanitarian organizations in South Sudan consider the **specialized** needs of people with disabilities. While there is consideration of people with disabilities in many humanitarian actors' programme and guidance documentation, the response is almost exclusively framed as requiring 'mainstreaming' solutions: i.e., ensuring people with disabilities can access the same services as people without disabilities.
- There is evidence of some manufacturing capacity for assistive devices in South Sudan: organizations including ICRC, CBM and OVCI report that they manufacture devices themselves or through partners.
- We also found evidence of civil society actors advocating for disability issues: these organizations are becoming more visible, as evidenced by the 2020 launch of the South Sudan Union of Persons with Disabilities Organization.
- Key barriers to AT provision by humanitarian actors are likely to depend on the type of organization. Multilateral organizations experienced little 'push' from donors (or other advocates) to respond to AT needs and were able to satisfy internal and external requirements for disability inclusivity through efforts to make their mainstream services accessible to people with disabilities. This is despite that fact that the lack of assistive devices has been found to be a barrier to the participation of people with disabilities in community participation (47).
- For smaller NGOs, the lack of funding or specialized grants to apply for the provision of AT was reported to be a barrier. Of existing providers, their ability to scale up is limited by insecurity, weak infrastructure, and geography, which prevents organizations from reaching mostly rural populations. Other key barriers include the lack of local expertise or trained providers to sustainably provide and continue services.
- Recommendations are provided, covering operational approaches, policy and advocacy needs and research needs.

Objectives of case study

We conducted a literature review on the barriers and facilitators of assistive technology (AT) provision in humanitarian settings globally. The review found several gaps in the literature including those related to:

- The nature and scale of AT provision in crises beyond the acute phase;
- Evidence of the comparative effectiveness of models of AT provision and coordination in crises;
- The impact of any interventions with the objective of improving or scaling up AT access in a crisis;
- The rate of child and adolescent-specific AT needs;
- How to alleviate barriers to provision and access;
- The nature of coordination and provision in protracted crises, particularly camp settings and settings where international agencies have a large mandate and capacity.

This case study on AT in South Sudan is intended to provide a ‘deep dive’ that explores the extent to which these gaps are understood in South Sudan. The same case study approach was repeated in Afghanistan and similarly in the State of Palestine and reported separately. In summary, this case study aims to:

- Describe what is known about the AT needs of children in South Sudan;
- Map the AT providers and services available in South Sudan;
- Understand the barriers and enablers of AT provision and access in South Sudan.

Methodology

Rationale

The objectives above required the research team to gain an understanding of the motives and perspectives of potential and actual providers of AT in humanitarian settings, and other humanitarian (and development) actors involved in the provision of services and goods for people with disabilities. Qualitative approaches can be an effective way of meeting these objectives, as they can offer explanatory tools to get an in-depth view of a phenomenon – in this case, the phenomenon of limited and poor-quality provision of AT. The case study approach is a qualitative research methodology that can elicit evidence relevant to decision making in the areas of both policy and professional practice. This approach involves examining a phenomenon in its context using multiple sources of data in order to build a holistic picture of the phenomenon (1). Case studies are particularly useful for research questions concerned with the 'how' and 'why' of a phenomenon, where the context is central to the phenomenon being studied (2). These characteristics make the case study approach appropriate for exploring barriers and enablers to assistive technology provision for children in humanitarian contexts.

Key informant interviews are an affordable qualitative approach that draw on the knowledge of experts in a field to gain an understanding of the motives and perspectives of actors involved in a phenomenon. They are a valuable tool in filling knowledge gaps regarding complex behaviours, and can bring to light issues which researchers have not previously considered (3). As they involve small sample sizes, key informant interviews may be limited in their ability to show the validity of findings (4). However, in this study we were trying to understand why so **few** organizations were involved in AT provision in South Sudan, and the factors effecting the nature and scale of provision. As a result, the small size of the sample was to some extent inherent to the issue being studied.

Further, we saw strong and consistent agreement between a range of respondents in different organizations regarding the main barriers to provision. The interviews both corroborated the findings of the academic literature and helped us identify new issues which were not emphasized or found in the literature prior. This supports our confidence that this research both adds to the evidence base on the state of AT provision in South Sudan, and in the validity of the findings.

Grey literature review

We began by conducting a literature search in order to establish the documented evidence base. We found 152 items in the grey literature discussing disability and rehabilitation services in South Sudan since 2010.[1] Items of grey literature included web pages; government reports; conference proceedings; theses; research reports; and press releases. A minority of these (approximately 50) made mention of assistive devices (some refer to assistive devices generally, and some to specific services such as mobility products, braille or prosthetics and orthotics services). These documents were mostly from the same three international response organizations: ICRC, Light for the World, and Humanity and Inclusion. Two reviewers independently chose which articles should be excluded based on the criteria above.
The team will use the grey literature to provide an overview of the evidence base on:

- The status of disability;
- The policy and legal landscape of assistive technology provision;
- AT provision at national and local levels;
- The role of NGOs and multilaterals in the provision of AT services and products;
- Coordination mechanisms for AT provision.

This evidence was recorded in this report and built on through the key informant interviews.

Sample

Based on the grey literature, we identified all organizations that currently play a role in the provision of assistive technologies in South Sudan, including advocacy organizations. We aimed to ensure representation from government; donors; multilateral organizations; international and local NGOs; and civil society. The primary focus of our research was to understand barriers to provision (as opposed to barriers to access), as this is a key gap in the literature. As a result, we chose to interview key informants within organizations that had a current or potential role in AT provision, to understand their experiences and views.

We used two techniques for identifying the interview sample: key informant sampling (where we targeted those we knew would be knowledgeable, based on the findings of the grey literature review), and snowball sampling (asking key informants for recommendations for who else they considered experts). In conducting key informant sampling, we approached each contact point

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[1] The items prior to 2013 were less relevant to our understanding of the situation in South Sudan, given that the beginning of the conflict in 2013 caused many changes to the landscape of provision. However, we retained these documents as context.

identified three times to seek an interview – if there was no response after three attempts, the team did not pursue the organization or individual further.

Methodological caveats

We aimed to follow best-practice guidelines for conducting interview-based research (3). However, we anticipated challenges related to collecting data for this research through informant interviews. These included challenges related to seeking a representative sample of informants. We were aware that there was a risk we could collect a biased sample by using researchers' own contact points in organizations where we were not able to find information in the public domain. As such, we sought to formally make contact with organizations wherever possible, even were we had access to our own contacts. We worked with organizations' public contact points to identify who would be experts in the topic of our research by accompanying introductory emails with a written briefing on the research objectives. We explained our desire to speak with a range of experts in each organization, if possible.

We were also aware of the risk that organizations might have an incentive to provide us with contacts who had a public-facing communications role, as opposed to being experts in the topic, in order to share a more formal or sanitized perspective on their work. In seeking key informants in consultation with contact points, we explicitly communicated that we sought to maximize the representation of all staff, considering the representation of:

- local staff
- international staff
- staff at different levels of seniority
- staff in different roles (e.g., policy, implementation, HQ-based, field-based).

The use of snowball sampling also helped to mitigate against the risk of only identifying contact points in larger or more well-resourced organizations which we were already aware of or which had a bigger public presence. While the population size was unknown, there was agreement within both the grey literature and among informants whom we interviewed that the number of organizations with a role in AT was small, and we therefore had a high level of confidence that we were able to contact the majority of organizations with such a role. However, we are aware that smaller, local organizations that were unknown to our participants (the majority of whom were based in state capitals) may have been unwittingly excluded.

We conducted semi-structured interviews, using the flow chart in Annex A, ensuring consistency and some comparability of themes across interviews, while allowing us to follow up on issues and concepts introduced by the respondents. Each interview took between 1 and 2.5 hours, depending on interviewee availability. We were aware of the risk of response bias, particularly as respondents knew that UNICEF Innocenti funded this research. Respondents might exaggerate the levels of need, or their organizational capacity or achievements, in pursuit of future funding or partnership. However, we saw broad agreement across different types of organizations regarding their responses on the types and levels of need, including from international organizations that were unlikely to be interested in seeking funding from UNICEF, which improved the reliability of our data. We also provided written and oral briefings on the purpose of the research, to ensure clarity that this research was not related to any potential or actual funding. Where possible, we interviewed multiple representatives from each organization and where possible, conducted interviews separately to allow respondents to freely express opinions without being consciously or unconsciously influenced by colleagues.

Our methodological approach was also influenced by the ongoing COVID-19 pandemic. National travel restrictions prevented researchers from country-based fieldwork which would have allowed for additional data-gathering (such as in-person visits to sites of provision), or more independent approaches to identifying key informants (for example, based on first-hand observations of implementation). However, there may have been advantages to these restrictions. For example, many agencies have adapted to remote – and therefore more accessible – online working approaches following pandemic restrictions. This may have allowed us to schedule interviews with more informants thanks to the efficiencies realized through remote working.

We sought informed consent from participants by providing them with a written pre-briefing on the aims of the research, how the information they shared with us would be used, and by seeking signed consents from all participants. This consent form assured participants that their responses would be anonymized in the write-up and that data would be stored securely. We recorded the interviews through typed notes, which we sent to each participant after interviews to seek their assurance that the record accurately reflected the conversation and to also allow them to make any corrections they deemed necessary.

We interviewed 21 individuals working for 12 organizations, all based in South Sudan:

- Two individuals working in donor and multilateral agencies;
- Seven individuals working in international NGOs;
- Twelve individuals working in local NGOs and civil society organizations.

We also received responses from four organizations and individuals (including two donor organizations) who declined to be interviewed. One limitation of our study is related to the difficulty of seeking participation from donor organizations who have lower incentives for participation (or who may be disincentivized to participate) due to higher pressures to reflect their headquarters' policies in their responses. In addition, one of our findings was that there was very little evidence of bilateral donor-funded AT provision or specialist provision of services for people with disabilities, and this may have led to those organizations feeling that they had no expertise to share in this research.

We summarized the findings in this case study, integrating the findings from the grey literature and interviews to meet our objectives. In Annex B we provide a summary of our sources of data to demonstrate points of agreement between the grey literature and interviews, and to identify where interviews provided additional information not found in the literature.

Context

South Sudan is the world's newest independent nation, having seceded from Sudan in July 2011. Hopes that South Sudan would transition to a peaceful and stable country were quickly shattered in 2013, when an internal armed conflict broke out between the Sudan People's Liberation Movement/Army in Opposition and the Government of South Sudan. In the course of this conflict, both sides were involved in human rights violations, such as looting civilians' homes and businesses and attacking humanitarian assets (5). This led to countless deaths, high levels of injury, displacements within and outside South Sudan's borders and high levels of poverty and food insecurity (5). South Sudan is now in a protracted crisis. To date, 4 million people have been displaced (6) and 2.2 million have found refuge in neighbouring countries including Kenya, Uganda, Ethiopia and Sudan, while 2 million have been internally displaced (6).

The conflict in South Sudan is likely to have contributed to increased rates of disability (7). People with disabilities in the country experience neglect and are likely to be disproportionally affected by conflict's effects as they are less able to escape it (7). WHO estimates that there are over 1.2 million people in South Sudan with a disability (8), and 250,000 people with disabilities live in PoC sites (8). The ICRC has reported that approximately 60 per cent of patients to its rehabilitation centre in Juba have gunshot-related injuries, and many are children (9).

The impact of the crisis on children has been particularly high. Children make up over 29 per cent of the population(10). In 2015 it was reported that 68 per cent of South Sudanese refugees were under the age of 18 (11) and by 2017 this had risen to 70 per cent (12). More than 270,000 children in South Sudan are likely to be suffering from severe acute malnutrition (12). A large number of these children and adolescents have been separated from their families and are unaccompanied. Children have experienced enormous suffering as a result of the conflict, and levels of psychosocial distress and trauma among children are high. Children with disabilities are likely to be particularly vulnerable to protection risks in PoC sites as a result of overcrowding (13).

Children in South Sudan report experiencing different forms of violence to adults, including higher levels of sexual abuse and exploitation, with girls bearing the brunt of this abuse (11). Since the start of the conflict, many thousands of children have been recruited as child soldiers – UNICEF estimates 19,000 are associated with armed groups (6) and many child soldiers are recruited from the refugee population (11). South Sudanese refugee children (both within South Sudan and those displaced in neighbouring countries) are also particularly vulnerable to being recruited to work (11). All of these vulnerabilities, compounded by the fact that more than 6 million people in South Sudan face huge shortages of water, food and healthcare (6), make South Sudanese children highly susceptible to acquiring a disabling impairment or for children with disabilities to acquire co-morbidities.

Sources of data: AT needs and disability prevalence

There is no centralized system to monitor the extent to which children's rights and protection needs are realized in South Sudan, and data on children with disabilities is considered a major gap (14). Available information on disability prevalence is from international organizations' estimates and surveys of specific sites, for example PoC camps. As far as we are aware, no survey of AT needs has been carried out in South Sudan outside of camp settings.

WHO (2017) has estimated that there are at least 250,000 people with disabilities living in PoC sites (8), and over 1.2 million people in South Sudan (approximately 10 per cent) with a disability (8). The 2020 South Sudan Humanitarian Response Plan states that 13 per cent of its target beneficiaries will be people with disabilities (15). HI uses global estimates to suggest that 15 per cent of the population lives with a disability (16). An HI survey in Wau PoC found that 14.4 per cent of respondents were people with a disability (17). The majority of those had difficulties with mobility or vision. Seventy per cent of those with disabilities surveyed in Wau PoC site reported a need for AT. In Wau PoC, even the most low-cost devices, such as canes, were lacking: 50 per cent of those needing a cane did not have access to one (17).

The Ministry of General Education and Instruction (MoGEI) reported in 2015 that 18,000 primary school students had an impairment (8), i.e., less than 0.5 per cent of the child population.[2] Estimates of disability prevalence among the child population cannot be extrapolated from these figures. MoGEI data on students with disabilities are derived from annual school census data. The school census is unlikely to capture all children with disabilities as it does not employ a clear definition of disability and is particularly likely to fail to count children who have disabilities that are not physical or visible (8). Few children with disabilities are likely to be able to access education. High levels of stigma against children with disabilities in South Sudan are likely to contribute to the underreporting of numbers of children with disabilities by authorities, and the invisibility of those children to authorities when parents choose not to disclose their child's disability (8).

Coordination mechanisms

According to South Sudan's Humanitarian Response Plan, the Health Cluster has lead responsibility for providing assistance to people with disabilities (18). Interview respondents reported that there is a disability technical working group, which is a coordination group sitting under the Health Cluster.

Provision by international humanitarian and development donors

We examined the documentation of the major donors with bilateral funding in South Sudan. USAID, DFID, Global Affairs Canada and SIDA have no bilateral programming in South Sudan with an AT provision component. However, we found several examples of programmes with a broader disability-related focus. For example:

- DFID funds the Humanitarian and Resilience in South Sudan (HARISS) – Mental Health and Inclusive Humanitarian Response project, which does not provide assistive devices but does provide mental health rehabilitation in Juba, Yei, Torit and Yambio (16);
- The DFID-funded Girls Education South Sudan (GESS) programme includes Capitation Grant funding for schools to improve the learning environment, and schools are encouraged to use this to improve accessibility for children with disabilities – but this use of funds is not mandated (19).

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[2] The 2018 UNESCO Out of School Study found that the school age population of South Sudan was 3.5 million. The total population was estimated at 12.3 million.

Government

Policy environment

The Ministry of Gender, Culture and Social Welfare is responsible for disability issues (20). Local Government is responsible for keeping a register of children with disabilities and assisting them to 'develop their potential for self-reliance' (14).

South Sudan has not signed the Convention on the Rights of Persons with Disabilities (CRPD). However, South Sudan is a party to the Convention on the Rights of the Child (CRC), which mandates the rights of children to the "highest attainable standard of health".

As of 2020, the Disability Inclusion and Promotion Policy and the Inclusive Education Policy had not yet passed into law or been signed by the President, though they had both been drafted (7). Relevant national laws include the Southern Sudan War Disabled, Widows and Orphans Commission Act 2011 and the Southern Sudan War Disabled, Widows and Orphans Commission Revised Policy 2010–2014. This Act and Policy merely establish the Commission and commit to the intention of the Commission to improve people with disabilities' rights to services. We found no further evidence of specific legislation related to the rights of people with disabilities in South Sudan, which is supported by historical reviews of the literature (21)(22).

Government-led provision

There is evidence of very small-scale, government-led provision of assistive devices in at least some South Sudanese states before the conflict began. For example, a strategic plan for Central Equatoria State in 2012/13 aimed to provide assistive devices to a small number of people with mobility impairments: 50 tricycles, 50 wheelchairs, 100–200 leprosy sandals and 6,000 crutches annually. There is no evidence of whether these targets were met, but it is notable that the need for these devices was acknowledged by the local government (23).

There is a South Sudan Safety Net Project which will provide cash transfers to 430,000 people, including grants to people with disabilities who are not able to work. This is the only currently running government-funded project we found that targeted people with disabilities with assistance directly (24). South Sudan has no other national social protection system for people with a disability, and there is no national disability registry, universal disability benefit scheme, or other national support services for people with disabilities.

Technically, Juba's Physical Rehabilitation Reference Centre is overseen by the Ministry of Gender, Child, and Social Welfare, but it is managed by the ICRC with international funding (25). The Centre was established by ICRC and is supported through its Physical Rehabilitation Programme (PRP). As this is delivered primarily via ICRC resources, this is discussed further under the section 'NGO-led provision'. NGOs which manage other government-overseen services for people with disabilities – such as South Sudan's main eye hospital – report that government contributions are small or only nominal. This is discussed further in the section on barriers to provision.

Education services

The 2018 UNESCO Out-of-School Children Study highlights children with disabilities as a group particularly at risk of being out of school. Mainstream schools are inaccessible to most children with disabilities in South Sudan due to a range of factors including the difficulty of travelling to distant schools, the cost of school, and the stigma they face (8)(37). A study evaluating Global Partnership for Education (GPE) support to South Sudan between 2012 and 2018 found there continued to be high barriers for children with disabilities in accessing education, and that "few significant or large-scale measures" were taken to meet the educational needs of children with special needs (26). Materials such as Braille and audio recordings are rare, and only available in urban schools and in secondary and higher levels of education (8).

The General Education Strategic Plan 2017–2022 states that assistive materials for the inclusion of children with disabilities in learning will be prioritized (37). The plan states a goal of increasing the percentage of learners with disabilities who are enrolled in primary education from 1.7 per cent to 17 per cent (37). To date, the only government-led activity targeted at improving education access and quality for children with disabilities that we identified is the development of campaigns and teaching and learning materials for pupils with special needs in 2016 (26). However, the relevant guides and textbooks for children with disabilities were as yet unprinted as at 2018 and there is no evidence they ever have been printed (8).

Provision by civil society

Interview respondents reported the existence of local disability advocacy organizations that, in some cases, conduct small-scale activities to support disability inclusion. For example, the South Sudan Association of the Visually Impaired has, through a small grant, purchased computers with screen readers to provide training for teachers of the visually impaired.

Most disability-related civil society advocacy takes place in Juba (27). There is some discussion, via advocacy groups, of the articles of the CRPD via radio and other media (27). We found the following local DPOs or NGOs focused on disability-related advocacy, and some played a role in AT provision or referral:

- National Union of Physically Disabled (established September 2020);
- South Sudan Association of the Visually Impaired (SSAVI);
- South Sudan Women with Disabilities Network;
- Equatoria States Union of the Visually Impaired (ESUVI);
- Central Equatoria State Union of the Physically Disabled (UPD)
- Equatoria States Association of the Deaf and Dumb (ESADD)
- There are two organizations specifically advocating for young people with disabilities: Young Voices and Hidden Ability Melody. Both are awareness-raising organizations and we found no evidence that they were involved in AT provision (27).

Provision by NGOs and multilateral agencies

A 2016 report on behalf of a coalition of South Sudanese NGOs reported that partnerships between international disability-focused NGOs and local DPOs and civil society organizations was still nascent (27).

We found evidence of at least three organizations providing AT services at scale: the Italian NGO Organismo di Volontariato per la Cooperazione Internazionale (OVCI), International Committee of the Red Cross (ICRC) and CBM (formerly the Christian Blind Mission). Confirming the findings of previous reviews, we found that ICRC was the main international organization providing rehabilitation and AT services (28).

Figure 1: Physiotherapy department at the Physical Rehabilitation Reference Centre in Juba

ICRC's Physical Rehabilitation Programme (PRP) and rehabilitation centres

- ICRC manages three working rehabilitation centres in South Sudan: The Physical Rehabilitation Reference Centre (PRRC) in Juba, the Rumbek Rehabilitation Centre (RRC) in the Lakes state and the Wau satellite centre. The PRRC is overseen by the Ministry of Gender, Child, and Social Welfare but is managed with support from ICRC (25). The PRRC is also a referral centre for nationwide needs. The Wau centre includes a wheelchair specialist, an ortho-prosthetist and a physiotherapist (22). Since 2016, the Wau centre has been expanded into a production site. A new satellite centre has also been established in Waat, which distributes assistive devices produced by the Juba PRRC (29).

- The PRP programme reports a constantly growing demand for its services. Based on ICRC annual reporting, there appears to have been a year-on-year increase in patients served since ICRC took over the centre from Medical Care Development International in 2013 (30). In its 2019 annual report, the ICRC stated that its centres had seen an increase in the number of beneficiaries referred by PRRC and arriving in Juba on ICRC flights from former opposition-held areas (31).

- ICRC recognizes the need for a gradual transfer of responsibilities to its government partner, the Ministry of Gender, Child and Social Welfare (MoGCSW) (29). ICRC pays a performance fee to prevent the flight of qualified and trained professional personnel from South Sudan's rehabilitation centres (29). ICRC believes that these bonuses have made an important contribution to retaining and maintaining the motivation of local staff (31). Upon handover to the government, it is unknown whether ICRC rehabilitation centres will be able to continue such provision, given the financial limitations the country faces (29).

- ICRC also develops the capacity of local staff by sending personnel from all three rehabilitation centres to courses on providing wheelchair services, and supports local ICRC personnel to attend the three-year prosthetic and orthotics course at the Department of Prosthetics and Orthotics (32).

- ICRC uses planes and helicopters to transfer patients to rehabilitation centres due to Sudan's poor road transport infrastructure (9).

- Following an increase in violence in July 2016, the PRP programme was (temporarily) extended to both PoC sites and to hospitals supported by other international teams, despite acute care (short-term treatment) not being part of its programme mandate (29).

- OVCI was the only organization we found that specialized in providing assistive technologies to children and adolescents with disabilities.

- The summary table below provides an overview of all programmes for which we found evidence via the literature and interviews.

Table 1: Assistive technology provision programmes in South Sudan

Implementer	Summary of known AT provision
International Committee of the Red Cross (ICRC)	Manages a physical rehabilitation programme based in its three rehabilitation centres (In Juba, Rumbek and Wau). ICRC reached 4,961 people with assistive technology in 2019. Children represented 8 per cent of those reached via the PRP programme in 2016 – more recent breakdowns are not available. ICRC manufactures prosthetic and orthotic devices.
Usratuna Sudanese Association for Disabled Children (funded by OVCI)	A centre providing rehabilitation, healthcare and education services for children with disabilities in Juba. In a 2012 interview, an Usratuna staff member describes the centre's caseload as made up of children with "cerebral palsy, delay in development, hydrocephalus, [and children who are] deaf" (33). In addition, OVCI has partnered with the ICRC Physical Rehabilitation Programme to expand rehabilitation services in underserved regions not reached by ICRC's centres. Under this agreement, OVCI delivers services in five southern provinces of South Sudan, and ICRC monitors those services and supports OVCI to build its capacity further (29). OVCI also partners with other disability-focused organizations such as CBM to deliver rehabilitation services.
Light for the World (LFTW)	Launched the first South Sudanese sign language dictionary in 2016 (34). In partnership with Sudan Evangelical Mission (SEM) and other local NGOs, LFTW implements a community-based rehabilitation programme which includes the manufacture of assistive devices made from local materials in SEM's carpentry workshop (35). Interview respondents reported providing wheelchairs, white canes, prosthetics, chairs, and crutches. They also provide software for blind students who use computers.
Humanity and Inclusion (HI)	Established a rehabilitation room at Bor Hospital providing mobility devices. Also provides support to staff working in the psychiatric unit of the Juba Teaching Hospital and Juba prison, to support people with mental disabilities. There is evidence of HI providing devices in PoC camps.
Christian Blind Mission (CBM)	Provides eyeglasses, white canes and other assistive devices through its programming, particularly in Buluk Eye Hospital.
UNMAS (historical, no evidence since 2012)	A 2012 report states that UNMAS supported 1,800 people with disabilities with AT (including prostheses, crutches, wheelchairs and white canes). However, there is no evidence of UNMAS' provision of AT beyond this report (36).
Motivation UK (historical, now closed)	In 2013, ICRC collaborated with Motivation UK to implement the Appropriate Assistive Devices Project in South Sudan. Motivation UK provided the products, and ICRC led associated distribution and provided training for AT-related staff (22). This programme aimed to sustainably scale up and improve the quality of mobility and seating device provision. Products were requirements of the WHO Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings.

The General Education Strategic Plan 2017–2022 states that UNHCR will provide mobility and assistive devices to refugee children with disabilities.

We also found examples of specialist schools for people with particular impairments; for example, the Norwegian Association of the Blind and Partially Sighted (NABP) has established a special school for the visually impaired in Juba (27), although this was planned at the time of writing to become a research centre under the Ministry of Gender, Child and Social Welfare (35). However, those with intellectual impairments or other impairments, including visual impairments, are unlikely to have access to these schools.

Camp-based provision

As of 2019 it was estimated that nearly 200,000 civilians were residents of PoC sites – UN peacekeeping bases. South Sudan is the first country in which UN bases have been used as long-term camps for internally displaced people. An influx of displaced people housed in camps can cause a humanitarian response that is disproportionately 'site-centric' and that can exclude people with disabilities due to their being unable to access those sites (38). A comment recorded in one agency's report, from a girl with a hearing impairment based in a camp, explains vividly why children with disabilities risk 'slipping through the cracks' if humanitarian response focuses too narrowly on camp-based provision:

> *"I was sitting in a room in my home. I couldn't hear what was happening. When the fighting reached my village, everyone tried to save their lives, but I still sat there, in that room, unaware of the imminent threat. I was lucky the militants didn't find me. Somehow, I made it to camp Mahad. Why was I left behind? Our community should love one another."* – A girl with hearing impairment living in the Mahad IDP camp *(39)*.

Although humanitarian actors have been criticized for focusing on camp provision, assistive devices in camps have been described as 'rare'(17). One interview respondent told us that "the situation is much worse for people with disabilities in IDP camps" (40). Nevertheless, we found examples of programming in camps that considered the AT needs of South Sudanese people with disabilities:

- A Light for the World bulletin describes community-based rehabilitation programming serving PoC sites which includes programmes aimed at children with disabilities, and the provision of mobility devices, Braille and sign language services (41). However, no programme evaluation or details of the programme's results were publicly available.

- Light for the World also provides training to camp management teams to support them in understanding effective disability inclusion mechanisms. However, we found no evidence that this includes education on how to provide AT, or education on the levels of need for AT (42). There is evidence that Light for the World has provided assistive devices in the Mahad, Lologo and Gumbo IDP camps (42)(43). This is through collaboration with OVCI to extend a CBR programme to IDPs in Juba.

- Humanity and Inclusion (HI) have reported establishing a disability and vulnerability focal point (DVFP) in a camp in Juba. HI reports challenges in securing supplies but were able to transport assistive devices from one of its bases to the Juba camp. These devices include crutches, walking frames and canes. In 2019, HI reported providing functional rehabilitation and assistive devices to 2,719 people, in Juba, Yei and other locations.

- There is evidence that even early in the establishment of IDP/PoC sites there was a consideration of the needs of people with disabilities, resulting in efforts for some level of inclusive design of camp resources. For example, an Oxfam camp-based programme for delivering water and sanitation included the construction of six 'disabled-access' latrines (44).

- In the Kakuma camps in 2014, 270 people with disabilities were given access to accessible latrine facilities (45).

- HI have partnered with GDI Hub to pilot a digital manufacturing approach to provide orthotic devices in three refugee camps in Uganda serving South Sudanese people with disabilities. The aim of this pilot is to test whether it is feasible to establish digital manufacturing hubs across the East African region to serve the prosthetic and orthotic needs of refugees (46). Digital manufacturing involves the use of 3D scanning and printing to make customized prosthetics and orthotics.

- A report on PoC sites in South Sudan describes how a protection organization worked with sanitation specialists to design accessible toilets for people with disabilities (38).

- Though there is evidence of relatively high emphasis from donors and NGOs on needs in camps, children with disabilities in camps are likely to remain underserved. For example, HI assessments of the experience of people with disabilities in Bentiu and Wau camps indicated high levels of unmet AT needs (17)(47).

Private sector

We found no evidence of the availability of assistive devices in the private sector in the grey literature. However, interview respondents told us that:

> "Hearing aids are not accessible at all: not in the market and not through health services. Glasses are available, hearing aids are not. Glasses shops source their products from India, Pakistan, Uganda." (48)

> "People will normally seek support/devices? from NGOs, because devices are not available in the market. You cannot find the devices. The crutches – when their rubber is worn down, the users do not have enough income to buy rubber from market. So there is a lot of dependency on NGOs."(49)

> "There are private hospitals that provide this, but they are crazy expensive and ordinary people can't afford them, so we have to fill the gap."(50)

Gaps in provision

A survey of people with disabilities in Wau PoC camp found that the most requested solution was the provision of free-at-point-of-use services (17).

Interviews with organizations working on disability issues corroborated the view that supply of provision was far outstripped by need.

> "The need for AT is huge, and it's [an] unmet need…"(48)

> "There are not many partners working on disability – [there's a] huge capacity gap in South Sudan; [it's] difficult to find agencies doing disability work." (48)

However, interviews particularly highlighted an issue regarding the location of services: several respondents emphasized the lack of services outside Juba and in rural and remote areas:

> "Services not being in all parts of the country... There could be referrals, but because of poverty, it's very hard for people to reach the eyecare centre... Needs are overwhelming for all devices." (50)

Further, interviews supported findings from both the global and local literature that provision of services for some impairments were overlooked, with mobility impairments being better served than others. One respondent gave the following assessment of relative provision for different needs:

> "Yes, some impairments receive more attention than others, but I think that's the nature of impairment. If someone can manage with crutches, then they can access education more easily than someone who needs Braille. For people who are wounded as a result of war, they tend to receive some more kind of attention. I think that is the only difference. But in South Sudan there's low attention for all types if impairment. When it comes to attitudes it's all the same."(51)

Barriers to access and provision

The **unaffordability and danger of travel** by beneficiaries to rehabilitation centres was a barrier discussed both in the literature and by interviewees. The majority of South Sudan's population live in rural areas (16). Respondents to a 2014 assessment of the needs of people with disabilities in IDP camps reported a fear of travelling to the only primary health care clinic due to security concerns (43). Travel restrictions can also be caused by adverse weather conditions as South Sudan is susceptible to annual flooding (52). In a public address, an NGO representative stated that a key barrier to accessing services for the hearing impaired was the fact that services were only available in Juba (53).

Just as travel restrictions are a barrier to accessing AT for children and families in need, these restrictions also inhibit humanitarian actors from travelling to reach those with AT needs (52). **Transport logistics are hindered by continuing violence, crime, lack of transport infrastructure *and poverty*** (29). One provider explained: "there is a big issue in access, because most of the country is inaccessible. We have long waiting lists, and we can't bring many people to the centre because the only way to bring people is by plane ... [What is restricting our capacity is] mostly transport – bringing people into the centres. (48)

Apart from Light for the World's work in Yei, and ICRC's centres in Rumbek and Wau, all other disability-related activities appear confined to large cities, and in particular Juba city (27). This reflects observations from a previous literature review in 2018 suggesting that there had been little progress since (21). **Security restrictions** are cited by humanitarian actors as a barrier to expansion of disability-related services to hard-to-reach populations with high levels of need (33). A respondent told us: "We would have loved to provide outreach services but there is conflict, violence, ambushes in the road which are an impediment to reaching populations in need."(50)

Insecurity reduces the ability of humanitarian actors to respond to the needs of people with disabilities. When violence erupts, the international organizations involved in rehabilitation often leave the country, if only temporarily, disrupting operations (29).

Lack of basic infrastructure outside city centres also hinders AT providers' ability to establish new sites of provision where they are needed. One AT provider explained: "We can't build centres just anywhere – centres need electricity, etc." (48)

> "[There are] difficulties of moving within the country (in this period, due to the COVID pandemic, transport prices have risen considerably) and this creates discomfort [for] the families in bringing children for the treatments that are not short but the result of a rehabilitative process." (54)

Relatedly, the literature suggests that **denial of humanitarian access** by parties to the conflict in South Sudan may be a barrier to humanitarian actors reaching children with disabilities (55). One provider told us: "There is a government controlled area and an opposition controlled area. Bringing people from the opposition held area was a particular challenge so that is why we built a centre in Jonglei – but it didn't work out." (56)

Conflict also makes any valuable assets, such as assistive devices and AT equipment, particularly vulnerable to theft. The same respondent went on to explain that a temporary rehabilitation centre was looted by participants in the conflict.

High levels of **stigma** continue to be a barrier to both access and provision of AT (57). People in South Sudan most commonly view disability through a medical model, which contributes to stigmatization as this model conceptualises disability as deficit within the person rather than the environment. People with disabilities are viewed as non-contributing members of society and associated with begging and therefore, their voices are rarely heard (27). Interviewees also raised discrimination as an issue:

> "… Mothers are often abandoned by their husbands when a disabled child emerges, blaming them and leaving them alone and without money." (54)

> "Mainly it's a problem of discrimination. People with disabilities are overlooked." (40)

> "Stigma is a major barrier." (58)

> "I was having visits in IDP camps and people with disabilities there lack devices. Some of the parents of CWD are not aware of how to support their children; they may have the wrong concept about disability. They may believe disability is punishment for their parents doing something wrong." (40)

Interviewees also suggested that widespread discriminatory attitudes rooted in this stigma influenced institutional de-prioritization of disability:

> "The issue is that disability inclusion in general has not been taken seriously by the government and even other agencies. When you read the Constitution, it says beautiful things about everyone, including people with disabilities. But it is a matter of priority. That comes down to how people

> perceive disability. There are a lot of issues about lack of commitment but also, I think, attitudes around disability … Disability is not seen as something that is important." (51)

There is limited evidence that, with efforts by humanitarian actors to expand provision of services to people with disabilities, demand for services is growing and this may be associated with a lessened level of stigma. For example, a staff member at the Juba Usratuna rehabilitation centre describes changing attitudes and the presence of many children on the waiting list for Usratuna's services, suggesting that parents' expectations for their children with disabilities have increased (33).

Limited information on the services available in accessible formats has also been cited as a barrier to access (47). It should be noted that in South Sudan, most people with disabilities are likely to be unable to read or write and so, even where information is available, if it is not provided accessibly, it will not be understood.

Humanitarian actors have historically **prioritized needs in PoC camps and IDP camps** at the expense of the levels of need of children with disabilities outside camps. However, PoC sites may not house the most marginalized, including those with disabilities, because they are less likely to be able to flee crisis-affected areas (38). As a result, the prioritization of provision in camps may act to further exclude people with disabilities from priority humanitarian provision.

NGOs may be reluctant to provide AT services because of the **sustainability challenges** related to delivering relatively expensive resources that require upkeep and replacement. For example, a Norwegian Refugee Council programme that included the construction of accessible toilets and classrooms for children with disabilities reported a lack of capacity by local authorities and the community to maintain the services provided. In this case, even broken doors were not repaired (59). This failure to sustain services may be an expected (if undesirable) aspect of humanitarian programming, but it is particularly likely to be the case for the provision of AT, which can be both particularly expensive and complex (depending on the device) and requiring ongoing upkeep (the case for most devices).

Relatedly, organizations providing AT in partnership with government suggested that government had limited capacity and made only nominal and infrequent resource contributions, reducing programme sustainability. The AT system, limited though it is, is heavily reliant on NGOs for salary payments and other upkeep, even where staff are ostensibly on the government payroll:

> "The government contributes $500 every quarter [to the health centre] – but this is intermittent, it does not come regularly. You can imagine for us to pay salaries… it is expensive; we are paying some $6,000 a quarter. In contrast, the salary contribution that the government makes ranges between $5 and $15 on monthly basis per staff member. So the contribution that the NGOs are making is what's significant. If it is delayed, the staff are really affected, because it's what they depend on. If [our institution] withdraws tomorrow, the centre will deteriorate so much." (50)

> "There is an issue with sustainability – the government needs to be willing to take it over because it's an expensive centre." (48)

A further barrier may be **international organizations' weak accountability systems**. For example, an evaluation of Norwegian Church Aid's Emergency Preparedness and Response Programme in South Sudan found that data collected across their programmes were never disaggregated by type of disability, which limited the organization's ability to understand the needs and required response (60). At a higher level, cluster coordination similarly has not held its partner organizations accountable for the delivery of their own internal or collective commitments to people with disabilities – though this has changed recently with greater inclusion of disability in IASC guidance. One representative of an international agency said:

> "None [of the members of the education cluster] are asking for disability-related indicators ... Indicators encourage partners, of course ... If the [disability] data is not there, it is very difficult for us to act on that. We have to prioritize the indicators that are there... There are so many indicators, we have to prioritize." (48)

The **lack of disability data**, and the weakness of existing data is a key barrier in advocating for the rights of people with disabilities (27). Service providers report having insufficient information on the needs of people with disabilities, and do not know how to identify people with disabilities or communicate with them (47). Interview respondents said:

> "There are more children [with disabilities] than reported in the Education Management Information System ... There was data, but it was insufficient. It was difficult for us to trust [government data] that only 2,000 or 3,000 children out of 1.9 million children had disabilities. So we were not comfortable to move forward."(48)

> "There need to be some investment geared towards collecting information on people with disabilities. There is no clear data on the number of people with disabilities in South Sudan. People are working on the basis of global estimates." (50)

> "We need data collection. We need disability data. Once you have data, we also need information on who is providing what services." (56)

These reports suggest that to date, some organizations with a role in the provision of AT or of disability advocacy have failed to act on IASC guidance to apply a 15 per cent estimate of disability prevalence, based on global estimates, where data is weak or unavailable (61).

There may also be **limited government understanding of the scale and nature of the needs** of people with disabilities (at central and local levels) (53). There may be limited **political will** or no sense of urgency regarding AT needs, as implied by the fact that the draft National Disability and Inclusion Policy has remained in draft for over seven years and the CRPD remains unsigned. One respondent from a multilateral agency said one reason international actors were not responding to the gap in AT provision was the lack of government will and policymaking:

> "If there is no policy from the Ministry of Education, partners cannot target this, because they do not know what the Ministry wants." (48)

Other respondents similarly expressed their view that the government should have a role in the provision of services and goods to people with disabilities:

> "The other challenge is also for government to recognize that eye health should be part of their priorities. For example, in the health information system, there are no indicators to report on eye health." (50)

> "We also need to push the government to take more and more responsibility. South Sudan has not yet ratified the UN convention [CRPD]. Local organizations are lobbying, but big organizations need to push to make this faster… There's not even a disability law in South Sudan." (56)

Several organizations believe the government's failure to ratify the CRPD is both a symptom and a cause of the low prioritization of disability issues:

> "We believe that if the CRPD is signed by the President there are a lot of rights indicated there. But the challenge is, SS has not yet ratified the CRPD. South Sudan is not putting the issue of disability as a priority, because CRPD is not ratified. That is why there is no manufacture. It should be possible to find resources for low-technology and low-cost manufacture." (40)

However, respondents also recognized that there was low government capacity to provide funding for disability provision:

> "We know for at least five years the government won't be able to provide money for this sector." (56)

The grey literature suggests that government and humanitarian actors have not seen the provision of services for people with disabilities as a priority until very recently (57). The approach to provision evidenced in planning documents, such as the IASC Humanitarian Response Plan, is for inclusion of people with disabilities in mainstream provision, as opposed to responses to the specific needs of people with disabilities (such as AT) (15). Interview respondents agreed that **humanitarian agencies, including donors and multilaterals, did not prioritize disability issues**. A symptom of this low prioritization may be evidenced in the lack of internal disability expertise in humanitarian agencies. For example, in an HI survey of services in Bentiu PoC, only three out of nine providers reported having access to a disability focal point (47). In the same survey, both people with disabilities and service providers reported that the needs of people with disabilities was not a priority (47). Like government, donors and other agencies are faced with many competing priorities which they may perceive as more urgent than disability services. For example, one respondent in a multilateral agency explained how donor priorities in a resource-constrained environment had a direct impact on children's experiences:

> "Of course, there are financial issues. In South Sudan primary education is a priority for the donors, so there is a lot of investment here, but little going for secondary education. Vocational and secondary education are no priority for donors, so children often drop out after primary." (48)

Organizations remarked that there was no funding available from these institutions for disability-related provision. For example, respondents said:

> "I just received a request from Rumbek – Rumbek Hospital would like to revitalize its eyecare services. Similarly, Juba Teaching Hospital. But the funding we have does not allow us to do that." (50)

> "Provision of devices has not been a focus because funding is limited." (62)

> “[Among donors] there’s a bit of a piecemeal approach. A systematic approach has not been there from the donors to my knowledge. I've seen sporadic efforts that fizzle out. I think DFID has definitely been focusing on disability and they did a report which we used previously. But now, with the restructuring of system in UK [merger of FCO and DFID], I don't know how that will go.” (62)

However, one respondent said that low government and international agency investment in disability issues was not necessarily a matter of “bad will” but rather reflected the difficulty of ensuring “continued pressure” to respond to this neglected area (62). Another respondent reported good working relationships between government ministries and themselves as providers of AT:

> “The Ministry [of Gender, Child and Social welfare] does not provide funding or finances to assistive technology, but they help us by building relationships with schools or the Ministry of Education – or help us with staff who can be seconded here.” (58)

Perhaps resulting from low donor and government prioritization of disability, several organizations suggested that **weak coordination mechanisms** were a barrier to provision. These coordination mechanisms include DPO coordination through the newly-established Union of Physically Disabled (which intends to represent all DPOs, and the Disability Working Group), which sits under the Health Cluster.

> “I don't think coordination is happening in the best way. It seems project-based … There is DPO coordination … The problem with the committee [the Union of Physically Disabled] is, it’s very Juba-based and doesn't have representation from the rest of the country. Other types of impairments (e.g., cognitive) are not represented.” (51)

> “There is a disability working group […] so that stakeholders can identify gaps and needs. It started in 2018/19. But WHO was always cancelling the meeting and never taking it forward [and] stakeholders were constantly pushing. We suggested they include DPOs to improve coordination and access, but nothing happened.” (Health Cluster member) (56)

Limited trained local human resource are a related barrier. There are insufficient specialist healthcare providers, including physiotherapists, prosthetic and orthotic technicians and audiologists (63). The few healthcare workers who are available are not sufficiently aware of or able to respond to the needs of people with disabilities (43). Teachers similarly have little knowledge of how to meet the particular needs of children with disabilities, or even how to recognize them and their needs, and there are no adapted learning materials to support them (43). Some organizations, such as SEM, are using community-based approaches to train teachers to include children with disabilities in mainstream classes, including through Braille and sign language (35). PoC camps report that responding to AT needs is hindered by the lack of trained staff, lack of resources and lack of workshops to make the necessary devices (46). The literature reports an ICRC health coordinator remarking that “patients cannot be referred to other health structures or specialists in the country so our teams need to be able to diagnose and treat, on-site, all sort[s] of pathologies, with limited means” (52). Interviewees in our study made similar comments:

> "We do not have many eyecare professionals in the country… So we would be constrained by capacity in terms of staffing, even if we had funding." (50)

> "Funding is not the issue. The issue is human resources and finding appropriate places where we could build a centre." (56)

Several organizations pointed out **procurement challenges and the need to import** many materials and some devices, given the low manufacturing base in South Sudan:

> "South Sudan doesn't have a company that can provide assistive devices. We are not like neighbouring countries, like Kenya and Uganda where you can find devices. We are still a little bit far from this." (40)

Effects of COVID-19 pandemic

The pandemic has placed an enormous burden on South Sudan's already very weak health system. Humanity and Inclusion reports that pandemic-related trade restrictions have prevented imports of assistive devices (57)(64). HI also reports that people with disabilities – already deprioritized before the crisis – face being denied access to COVID treatment because it is assumed they are less likely to survive than people without disabilities. Given the inaccessibility of WASH facilities for people with disabilities, they may also be more susceptible to contracting the COVID virus (57). Interview respondents corroborated the findings of the literature on the impact of the pandemic:

> "[We] don't have the staff or the time to travel [to provide services outside Juba]. We're supposed to start this year but because of COVID, had to stop." (58)

> "We had a plan to conduct a proper mapping of actors in South Sudan, looking at a more local level… This was delayed because of COVID." (62)

> "Our waiting list has increased because of COVID. We have lower capacity because of COVID, as we have reduced the number of spaces to allow for social distancing." (56)

> "A group of people came from Jonglei after recent flooding; 68 had needs and the majority needed white canes. [We] couldn't get white canes for them due to COVID restrictions." (50)

Discussion

Absence of provision

The overwhelming impression left by the literature and interview responses is one of long-term neglect of disability issues on the part of all humanitarian and development actors, including donors, multilaterals and government. The lack of disability-specific programming (and related indicators) in organizational strategies or country-level planning (such as the IASC Humanitarian Response Plan) is likely to be both the cause and result of this inattention. Similarly, the absence of reliable disability data is the result of a failure to consider and monitor disability issues by humanitarian actors, and the lack of data is likely to prolong this inattention. The lack of prioritization of children with disability is a cyclical problem, in which low levels of provision begets continued inattention.

We noted in evidence that there was an imbalance in donors' and NGOs' investment in the two 'tracks' of the twin-track approach (65) of mainstreaming versus targeted support for people with disabilities. Global guidance states that both mainstreaming and targeted support are needed alongside one another for the needs of people with disabilities to be met (65). However, mainstreaming approaches, particularly in education, are overrepresented compared with disability-specific programming such as the provision of assistive devices. For example, the 2020 South Sudan Humanitarian Response Plan only refers to the needs of people with disabilities in the context of their inclusion in mainstream programming (15).

While humanitarian actors' awareness of the importance of mainstreaming is positive, it may have come at the expense of targeting support (e.g., with AT) to the particular needs of people with disabilities. The paucity of examples of AT provision that we found in our search of the grey literature, and confirmed by interviews, demonstrates the relative lack of specialist support to people with disabilities in South Sudan.

Support for the literature

Responses from key informant interviews support many of the barriers to AT access and provision found in the literature review conducted in the earlier phase of this project. In particular, respondents spontaneously raised issues found in the literature related to the challenges of provision to remote and rural populations; the limited data on disability; and the high levels of stigma and discrimination experienced by all people with disabilities, including children who are particularly vulnerable. Respondents also pointed to poor coordination mechanisms for the provision of assistive technology, with the relevant working group (in South Sudan) being underutilised.

Barriers specific to the context

The key informant interviews helped to identify a number of issues in the South Sudanese context which were not explicitly encountered through our review of the global academic literature. These were:

- The absence of an enabling policy environment, in reference to the CRPD being unsigned. Respondents emphasized that this constrained their ability to lobby government to take responsibility for the provision of AT.
- The lack of funding available for AT from donors (and government) and the lack of donor and government prioritization of disability-related issues.
- Humanitarian actors' focus on the inclusion of people with disabilities at the expense of providing resources to meet the specific needs of people with disabilities. This imbalance in focus is exemplified by the most recent Humanitarian Response Plan which does not discuss the need for specific provisions, such as AT.
- Political and security restrictions hindering providers' ability to access those in need and limiting the capacity of even well-established AT providers to expand their provision.

Other lessons

Areas for further research

The perception of many local and international NGOs is that the lack of resources dedicated to AT is due to the poor prioritization of donors, government and multilateral agencies. It is also clear that insecurity is a barrier to provision for many organizations currently implementing AT programming and therefore, may also prevent other organizations from entering the space. However, we were unable to interview organizations with no current role in AT provision/disability-specific provision (i.e., those yet to 'enter this space') to confirm these perceptions and assumptions. Organizations not working in the field of AT provision may find it a challenge to discuss why that is the case (and may perceive criticism in the question). Future research would benefit from expanding the work done here to understand the barriers to funding and provision by interviewing staff in organizations with no role in AT provision, which could help confirm the findings of this work.

Recommendations

Operational

- Donors, NGOs and multilaterals in South Sudan should conduct audits or evaluations of their support to people with disabilities. This would be an important first step in identifying contributions and gaps, in order to engage with coordination through the disability technical working group.
- Donors, NGOs and multilaterals should collectively agree to apply the 15 per cent estimate of disability prevalence, based on IASC guidelines, in the absence of reliable data. The lack of data should not continue to be used as a reason to fund programming as the gap between need and provision is clearly large, based on these estimates.
- Donors and multilaterals can strengthen existing systems and platforms for AT provision; for example, further capacitating existing assistive device workshops. This could include building the capacity of local personnel to make devices using locally available materials and supporting local agencies with procurement. Further funding through ringfenced, AT-specific grants, which prioritise national providers, could help expand provision to cover more areas of need.

Policy/advocacy

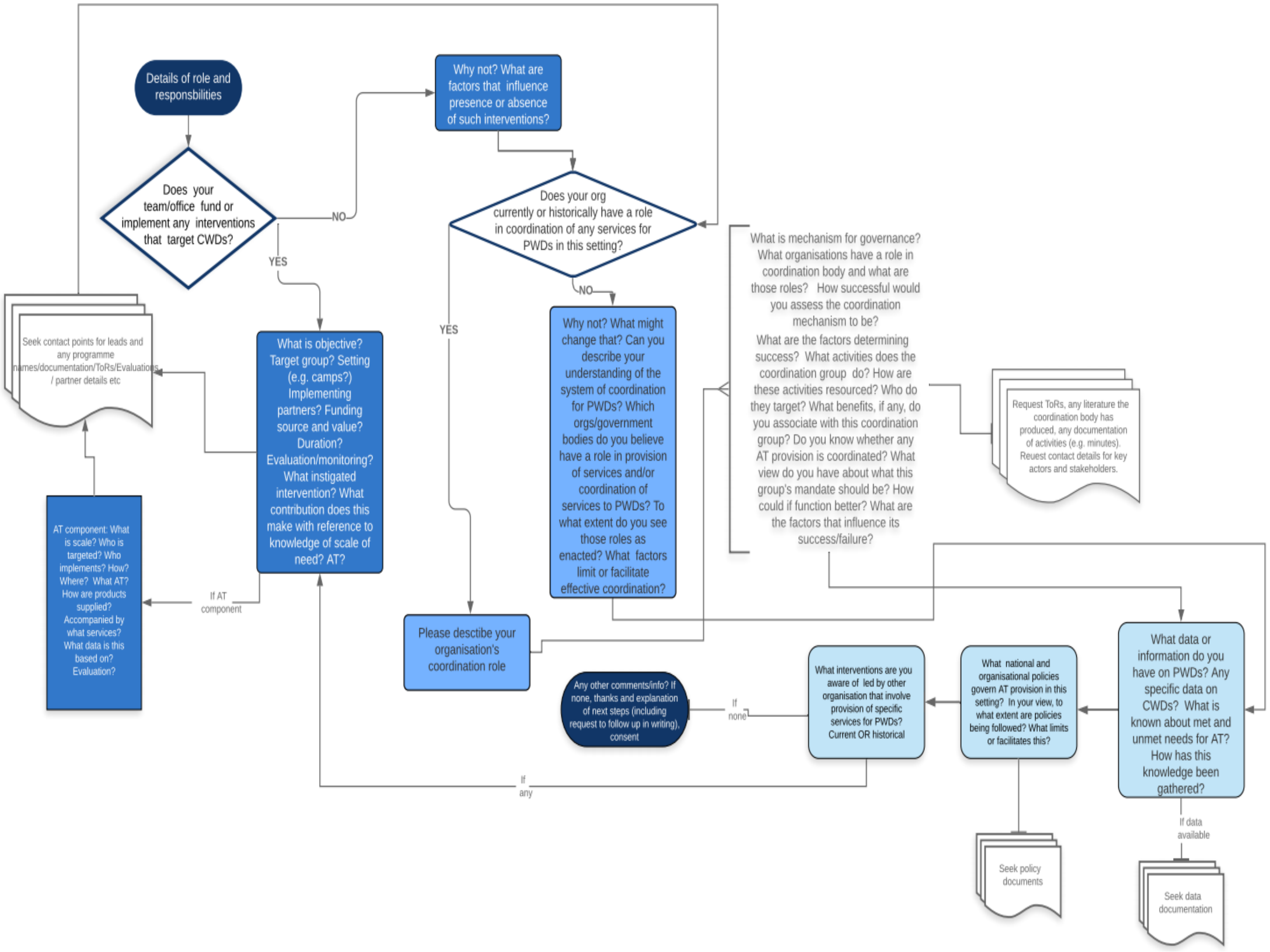
- Engagement in the disability technical working group (which currently sits under the Health Cluster) should be a priority for all agencies with a role in AT provision. However, this will require engagement of relevant actors in cross-cutting sectors, such as child protection and education, to ensure coordination of activities. This requires well-resourced and renewed leadership (ideally through funding of a part-time chair), to instigate regular meetings and the tracking of an agenda based on the existing ToRs. Priorities should include:
    - Mapping AT services, needs and resultant gaps, both geographically and by device needs (see research below); there is the opportunity to leverage and support NCA's recent commissioning of a mapping on disability.

  - Documenting steps to be taken towards achieving government signature and ratification of the CRPD.
  - Instigating the development of a unifying strategy for AT provision in South Sudan, to mobilize all humanitarian actors, including government.
  - Coordinating pooled travel resources, where possible, to meet needs. For example, when WHO charters a plane for a field trip, it should alert ICRC to identify any spaces offering opportunities for AT provision outreach in remote areas.
- The National Union of Physically Disabled, as the newly-established umbrella coordinating body for civil society organizations, should be supported by international NGOs and multilaterals to advocate for government to ratify the CRPD. This would be a significant step towards incentivizing the prioritization of disability in South Sudan.

Research

- Disability data is severely lacking in South Sudan, hindering the ability of humanitarian actors at all levels to advocate for, or instigate, AT provision. An urgent first step is to conduct a disability survey, which includes AT needs assessment, using the Washington Group questions alongside the WHO Assistive Technology Needs Assessment tools which are currently being piloted in several countries.
- While we found evidence that there are AT services in South Sudan, as detailed in this report, we found no independent process or impact evaluations of these activities to inform future programming. As such, the evidence base on 'what works' to improve and scale up AT provision in South Sudan remains very weak. NGOs currently providing AT services should earmark funds for monitoring and evaluating their activities, to build the evidence base on how assistive devices can best be procured, manufactured, coordinated and delivered to meet gaps in provision. If new funds are introduced to the sector, this evidence base can be used to access grants and incentivise further donor prioritization of AT provision.

Annex A: Interview guide



Annex B: Summary of available provision of and barriers to AT in South Sudan

Key
Green – Global literature
Purple – Grey literature on South Sudan
Blue – Interview outcomes

Scope	Findings
AT provision in South Sudan	• Insufficient provision to meet needs. • ICRC manages a Physical Rehabilitation Programme (PRP) based in its four rehabilitation centres. Reached 4,961 people with assistive technology in 2019. Children represented 8 per cent of those reached via the PRP programme in 2016 (67). • OVCI Ustratuna has a centre in Juba providing rehabilitation, healthcare and education services for children with disabilities. OVCI has also partnered with others to expand rehabilitation via outreach (29)(33). • Light for the World launched the first South Sudanese sign language dictionary in 2016 (34). In partnership with Sudan Evangelical Mission (SEM) and other local NGOs, LFTW implements a community-based rehabilitation programme which includes the manufacture of assistive devices made from local materials in SEM's carpentry workshop (35). LFTW also has provided devices in camps (42)(43). • Humanity and Inclusion established a rehabilitation room at Bor Hospital providing mobility devices and has other outreach programmes for rehabilitation. • Christian Blind Mission provides eyeglasses, white canes and other assistive devices through its programming (50). •
Barriers within the pre-existing context	• Centralized services are difficult to access for remote and rural populations (16)(56) (68)(69)(70)(71) (72)(73)(74). • Limited existing health infrastructure, including trained personnel (75)(76)(70)(77)(78)(79)(80)(81) (82)(83)(84)(50). • Limited existing AT market/manufacturing base/supply (85)(78)(86)(40). • Stigma and limited awareness of benefits by beneficiaries and their families (86)(87)(69)(88)(83)(89)(90,91)(27)(54)(40)(58)(40). • Limited data on met and unmet needs, and limited knowledge of best practice in conducting needs assessment (same point applies within the crisis) (69)(79)(78)(92)(93)(94)(84)(95) (27)(48)(50). • Poverty and prohibitively high healthcare access costs (96)(93)(69) (29) (50). • Unsupportive policy environment (CRPD unsigned). •
Barriers resulting from crisis	• Worsened infrastructure, including health and transport infrastructure (72)(97)(15)(80)(99)(100)(84)(98)(52)(29). • Inaccessibility of affected populations due to political or security restrictions (43)(50)(56). •
Barriers resulting from crisis response	• Limited information on the services available (47). • Shortage of funds available for AT from donors and government (51)(62), resulting from lack of government (48)(50)(40) and donor prioritization of disability issues (48)(62). • Prioritization of needs in PoCs and IDP camps over general population (38). • Lack of expertise, capacity, technical knowledge and awareness on AT needs among government and NGOs (both local and national), including knowledge of how to gather disability data (101)(102)(103)(104)(82)(105)(60)(47).

	• Low government capacity to take over and sustain services established by NGOs (105). • Poor coordination/leadership of AT provision and disability-related provision, and weak accountability systems (106)(84)(107)(51)(48). • Ineffective models of provision (e.g., NGO-led donations from HICs) (108)(106). • Prioritization of acute care over early rehabilitation, and mismatch between volume and types of needs and provision (109)(110)(111)(112) (106) (93). •
AT provision challenges	• Cost (110)(110)(113)(50). • Heterogeneity of AT products (114)(114). • Cost (time and financial) to tailor AT to setting and user (115)(77)(85)(116)(115)(77)(115)(77)(85)(58). • Need for ongoing services and provision limits capacity of agencies to provide, due to ongoing costs(117)(71)(51).

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