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Disability in South Sudan

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Question

What are the experiences of people with disabilities living in South Sudan (covering their prevalence, attitudes towards them, the barriers and challenges they face, and their responses to these challenges)? Where possible identify evidence gaps.

Contents

1. Overview
2. Prevalence
3. Life for people with disabilities in South Sudan
4. References

1. Overview

Decades of conflict in South Sudan, pre and post-independence in 2011, poverty and poor access to services have increased the rate of disability and rendered people with disabilities more marginalised and excluded as a result of the numerous attitudinal, environmental, and institutional barriers they face, and the lack of concerted efforts to include them. This rapid review identifies the available evidence on the experiences of people with disabilities living in South Sudan. There are still numerous evidence gaps in relation to the experiences of people with disabilities living in South Sudan as very little research has looked at disability in South Sudan and the available evidence base is extremely limited. Much of the available information focuses on Juba rather than the rest of the country. Further research with people with different types of disabilities, and in different areas of South Sudan is needed to more fully understand the experiences of people with disabilities living on South Sudan, the barriers and challenges they face, and how they and their families have responded to them.

The main findings include:

- **Prevalence:** Statistics or comprehensive information on the number and situation of people with disabilities in South Sudan is lacking. However most estimates suggest that it is likely to be at least as high as the global estimate of 15% and a few household surveys have found similar percentages of people with disabilities within households. Studies suggest that the prevalence of post-traumatic stress disorder (PTSD) is very high (41-53%).
- Lack of data on disability in South Sudan has made lobbying for improved rights and access to services difficult.
- **Capacity to meet needs**: South Sudanese authorities have had limited capacity to respond to the needs of people with disabilities and the support provided by national and international organisations is not enough to meet the immediate and long term needs of people with disabilities.
- **Legislation and policies:** There is no specific legislation relating to the rights of persons with disabilities and South Sudan has not ratified the UN Convention on the Rights of Persons with Disabilities. The draft 2011 constitution refers to people with disabilities and special needs and National Disability and Inclusion Policy and the Inclusive Education Policy have been developed but lack of political will and government funding mean the policies have not been implemented.
- **Attitudes:** Disability is often stigmatised in South Sudan and as a result children and adults with disabilities are hidden and isolated. Such negative attitudes contribute to discrimination against people with disabilities in South Sudan. Community based rehabilitation is reported to have helped to change attitudes towards disability in some communities.
- **Abuse:** Adults and children with disabilities in South Sudan have been subject to various forms of verbal, physical and sexual abuse by their families and the wider community.
- **Age and gender:** Children with disabilities face many barriers to inclusion including a lack of specialised services; difficulties accessing mainstream education, health and other services; and stigma. Traditional gender roles limit women and girls with disabilities access to education and employment making them more vulnerable and dependent. Women with disabilities also experience higher levels of physical, psychological and sexual violence.

- **Education:** Children with disabilities have very limited access to any educational opportunities, especially outside Juba, and if they are girls or if they have intellectual, psychosocial and multiple impairments.
- Barriers to education for children with disabilities include the schools location and accessibility, negative attitudes and lack of teacher experience. Efforts are being made by the government and other actors to foster inclusive education.
- **Infrastructure, communications, and transport**: Poor transport infrastructure and the cost of transport make it harder for people with disabilities to access services. Service and social infrastructure and communications are often inaccessible, contributing to the social exclusion of people with disabilities.
- **Healthcare:** People with disabilities struggle to access and afford healthcare, including assistive devices, and are among those most vulnerable to malnutrition.
- **Livelihoods:** Most people with disabilities are unemployed and there are almost no social safety nets and food security schemes for persons with disabilities. Barriers to employment include the accessibility of the working environment and the attitudes of employers and colleagues.
- **Political participation:** People with disabilities tend to be underrepresented in political processes, although disabled people's organisations have pushed for their involvement.
- **Mental health:** South Sudan has critical levels of mental health issues as a result of the conflict but mental health services are extremely limited and people with mental health conditions have been locked in prison even if they haven't committed a crime.
- **Conflict**: People with disabilities face greater risks of being caught in fighting and have been left behind when communities have fled attacks. Numerous abuses against them have been documented. Conflict also increased the severity of disability by preventing people with disabilities accessing services and medicines they need.
- **Humanitarian assistance:** People with disabilities have limited access to humanitarian assistance, especially if they are not in protection of civilian sites, although a lot of the mainstream support provided in these camps is also inaccessible.
- **Disabled peoples organisations (DPOs):** The disability movement in South Sudan is mainly focused around Juba and engages in rights advocacy, awareness raising, and programmes aimed at socio-economic and political empowerment of people with disabilities.
- DPOs face challenges as a result of lack of government support and lack of income to keep programmes running.

2. Prevalence[1]

Persons with disabilities include 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UNCRPD, 2006; MoGCSWHADM, 2013,

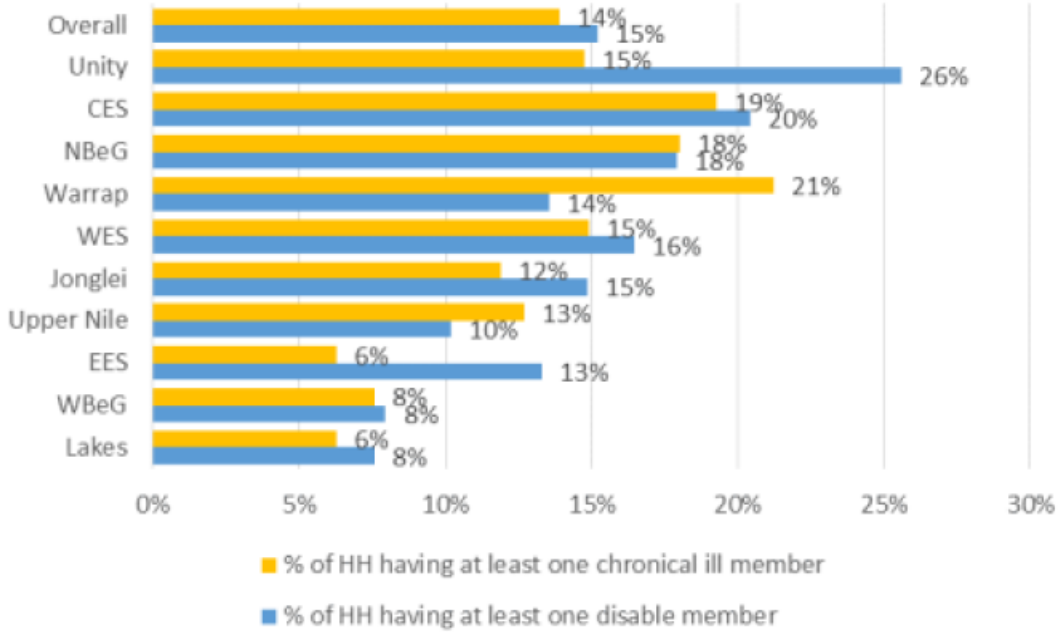
[1] For more information on the issues related to disability prevalence more generally, including issues with disability measurement, please see Thompson S. (2017). *Disability prevalence and trends*. K4D Helpdesk Report. Brighton, UK: Institute of Development Studies. http://www.gsdrc.org/publications/disability-prevalence-and-trends/

p. 8). Despite decades of conflict and its impact on poverty and services, leaving many South Sudanese with different types of disabilities, there are no official statistics in relation to disability prevalence.

According to a national census carried out in 2008, before the 2011 independence of South Sudan, persons with disabilities accounted for 5.1% of the population, although the census is controversial and the number of disabled people believed to be an underestimate (Legge, 2016, p. 1; Anyang, 2016, p. 4; Sida, 2014, p. 1). This is due to both issues with how disability was defined and the likelihood that stigma prevented people from identifying themselves as being a person with disabilities (Legge, 2016, p. 1).

Based on global estimates of 15% of the world's population living with disabilities, South Sudan is estimated to have more than 1.2 million people with disabilities (HRW, 2017; Forcier et al, 2016, p. 4). A 2016 household survey[2] carried out by the Food Security and Livelihood Cluster in South Sudan also found that around 15% of households has at least one disabled family member (WFP, 2017, p. 6). Figure 1 shows the percentages for each state.

Figure 1: Households with disabled or chronically ill member(s)



Source: WFP (2017, p. 6)

A 2014 baseline survey[3] found that 16.7% of households had people with disabilities in them (SSH4A, 2014, p. 2). Richer households were found to have more people with disabilities than poorer households although no reason was given for why this might be (SSH4A, 2014, p. 25).

[2] In December 2016, a total of 5,175 households from across the country were surveyed in the nineteenth round of the Food Security and Nutrition Monitoring Report (FSNMS).

[3] Undertaken in June 2014 in the two counties of Aweil East and Magwi, involving data collection at the household level, as well as focus group discussions. A total of 2137 households were surveyed.

A study[4] of four Greater Bahr el Ghazal States using the Washington Group Short Measurement Set on Disability found the estimated prevalence of disability (with severe difficulty) was 3.6% and 13.4% for disability with moderate difficulties (Ayazi et al, 2013, p. 1).

While there are no official statistics on mental health, 'the Director of the Ministry of Health's Department of Mental Health acknowledged that there has been an increase in the number of patients with mental health conditions since the start of the conflict', which is also reinforced by independent research (AI, 2016, p. 8). A 2015 study found that 41% of 1,525 respondents across six states and Abyei exhibited symptoms consistent with a diagnosis of PTSD (AI, 2016, p. 8). A different 2015 study in Malakal PoC site found that 53% of respondents exhibited symptoms consistent with a diagnosis of PTSD (AI, 2016, p. 8).

The 2008 census and a 2011 disability assessment report show a range of impairment types, including physical impairments (35-52%); vision impairments (20-33%); hearing impairments (12-15%); intellectual impairments and mental illness (10-17% - intellectual 1.6%, mental illness 8.3%); and speech impairments (4-7%) (MoGCSWHADM, 2013, p. 8-9). A 2011 study in Yei (Central Equatoria) and Mundri (Western Equatoria) counties found of the 700 children with disabilities, the most significant impairments in the sample were epilepsy (39.4%), physical impairment (18.3%), hearing impairment (12.9%) and nodding syndrome (10.6%) (MoEST, 2014, p. 19).

The lack of official statistics has made lobbying for improved rights and access to services more difficult (Forcier et al, 2016, p. 4; Legge, 2016, p. 1).

Causes of impairments

Armed conflict, poverty and lack of health services contribute to increased numbers of persons with disability (Sida, 2014, p. 1). The current civil war and South Sudan's previous history of conflict have 'caused disabilities among large numbers of civilians, with maiming and amputations, damaged or destroyed sight and hearing, or other impairments' (HRW, 2017; Forcier et al, 2016, p. 4; CARE, 2016, p. 15). For example, more than 70% of amputations performed by the International Committee of the Red Cross (ICRC) in South Sudan result from conflict-related wounds (HRW, 2017). Conflict is estimated by the South Sudanese National Disability Assessment to be the cause of 21% of impairments in South Sudan, with the number likely to be higher due to issues around underreporting (Forcier et al, 2016, p. 5). A qualitative assessment[5] carried out in Juba on behalf of Handicap International (HI)[6] looking at people with acquired disabilities after the conflict in 2013 but before the renewed outbreak of conflict in 2016 found that 'the majority of male respondents were wounded in direct fighting, while women reported other injuries that lead to their impairment, including injuries and attacks that occurred while escaping violence', although they warn that the sample is not representative (Forcier et al, 2016, p. 1, 11-12). Sida (2014, p. 1) found that new cases of disability during the conflict were as a result of landmines, widespread violence, sexual abuse and displacement. Treacherous conditions in the bushes or swamps as people flee to safety have led to injuries or diseases

[4] 1200 participants

[5] 8 focus group discussions (54 participants) and 9 key informant interviews.

[6] In January 2018 Handicap International changed their name to Humanity & Inclusion.

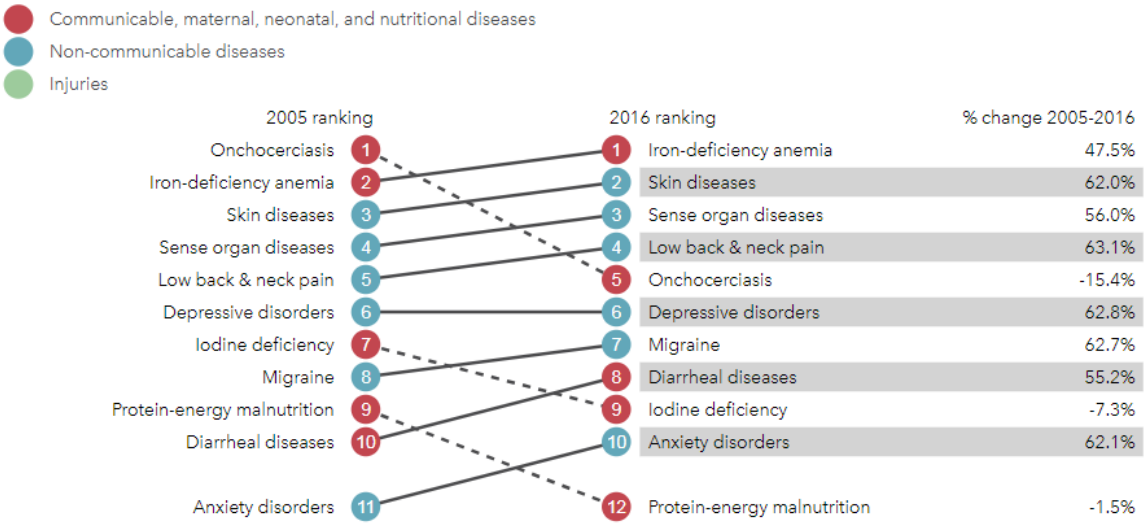
leading to disabilities (HRW, 2017; Forcier et al, 2016, p. 12). Ayazi et al (2013, p. 10) found that disabled participants in their study had a significantly higher rate of exposure to traumatic events compared to nondisabled individuals. The conflicts and displacement have also contributed to traumatising thousands, resulting in increased mental health conditions (HRW, 2017; AI, 2016).

The large number of South Sudanese with disabilities as a result of the conflict is further exacerbated by disease and accidents (Forcier et al, 2016, p. 4; MoGCSWHADM, 2013, p. 6). 'Chronic underdevelopment and lack of medical services have contributed to the emergence of physical and sensory disabilities linked to preventable or untreated conditions, such as polio, tuberculosis, cataracts, or other tropical diseases' (HRW, 2017). Complications during pregnancy and childbirth have also contributed to increasing numbers of impairments (Forcier et al, 2016, p. 5; UNICEF, 2015, p. 66; GoSS, 2015, p. 21 Sida, 2014, p. 1).

A partial National Disability Assessment in 2012 carried out on behalf of the government found that that the main self-reported causes of impairment among the surveyed population with severe disability were: eye disease (23.5%), war/conflict (21%), poliomyelitis (21%), mental illness (14.1%), acquired at birth (12.2%), road accident (10.6%), animal/snake bite (10%), physical violence and abuse (8.8%), burns (6.7%), hypertension (3.8%) and HIV/AIDS (0.9%) (MoEST, 2014, p. 21; MoGCSWHADM, 2013, p. 9).

The Institute for Health Metrics and Evaluation's Global Burden of Disease country profile for South Sudan presents what it has found to be the health problems that cause the most disability in 2016 in Figure 2.

Figure 2: What health problems cause the most disability in South Sudan?

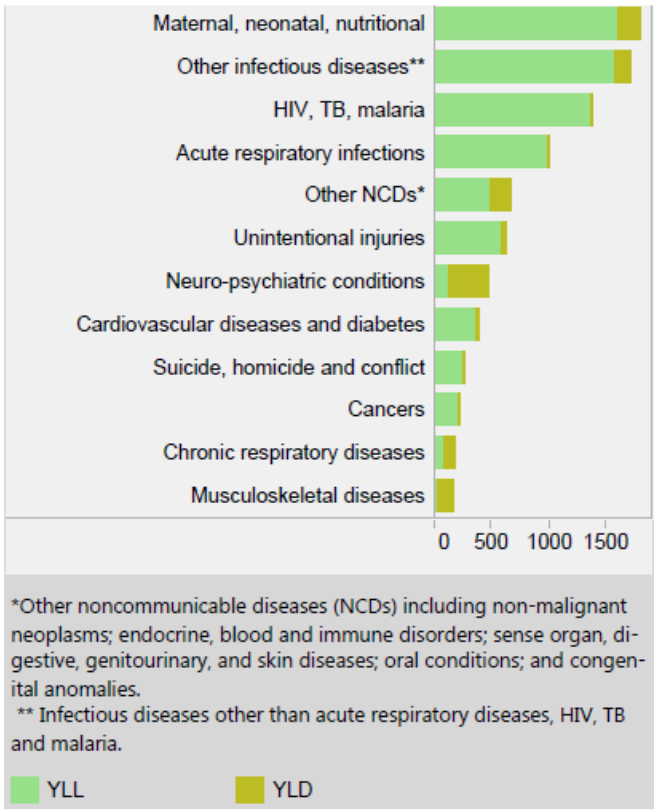


Source: Institute for Health Metrics and Evaluation[7]

The WHO calculated disability adjusted life years for South Sudan in 2012, shown in Figure 3. Disability-adjusted life years (DALYs) are the sum of years of life lost due to premature mortality (YLL) and years of healthy life lost due to disability (YLD) (WHO, 2015, p. 3).

[7] http://www.healthdata.org/south-sudan accessed 15/3/18

Figure 3: DALYs, YLL and YLD (thousands) by broad cause group



Source: WHO (2015, p. 3)

3. Life for people with disabilities in South Sudan

People with disabilities in South Sudan face significant social and political exclusion and are among the most marginalised in society (Forcier et al, 2016, p. 4; Legge, 2017, p. 1). Awareness of disability issues among key decision makers and the public is low, negative social attitudes and structural discrimination prevail, and people with disabilities have limited access to essential services and employment (Forcier et al, 2016, p. 5; CARE, 2016, p. 15; Rieser, 2014, p. 3; MoGCSWHADM, 2013, p. 6; MoGCSWHADM, 2013, p. 18). They are more likely to be illiterate, unemployed and unproductive than their peers without disabilities due to widespread exclusion (Legge, 2016, p. 1).

South Sudanese authorities have had limited capacity to respond to the medical, educational and mobility needs of people with disabilities, both before and after the country's independence in 2011, and there has been little pressure on them to respond to their needs (HRW, 2017; Forcier et al, 2016, p. 20; McNeish, 2013). Research found that 'the majority of local authority and services providers expressed a lack of knowledge and experience to provide services and enable equal participation of people with disabilities' (Rieser, 2014, p. 3; MoGCSWHADM, 2013, p. 9). A number of international and national organisations[8] provide some services and support for

[8] Including but not limited to: ICRC, Humanity & Inclusion (formerly Handicap International), Light for the World, Sightsavers, OVCI, The Leprosy Mission, Sudan Evangelical Mission (SEM), UNICEF, WFP, The Scottish Catholic International Aid Fund

services, including health and rehabilitation, inclusive education and livelihoods, although this is not enough to meet the immediate and long term needs of people with disabilities, especially as a result in the increase in need due to the conflict (Forcier et al, 2016, p. 14, 16, 20; McNeish, 2013).

People with disabilities are generally invisible in development programming in South Sudan and are not considered part of the target population which has had a negative impact on the quality of life and participation of persons with disabilities, their families, and the socio-economic development of South Sudan (Rieser, 2014, p. 3; MoGCSWHADM, 2013, p. 9).

Rights and legal frameworks

There is no specific legislation relating to the rights of persons with disabilities in South Sudan (Legge, 2016, p. 3; Sida, 2014, p. 2). The country has not signed or ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD), although the transitional constitution[9] has a number of clauses which refer to the rights of people with disabilities and people with special needs (Legge, 2016, p. 2; Sida, 2014, p. 2). However, 'article 30 does not explicitly guarantee equal protection against discrimination and abuse to persons with disabilities' (Legge, 2016, p. 2). This is despite efforts by DPOs to ensure there were better provisions for persons with disabilities in the Constitution (Legge, 2016, p. 3). The concern for war veterans has been a driving force in recognising the rights of persons with disabilities (Sida, 2014, p. 1). The Government's national action plan on UNSCR 1325 on women, peace and security, does however reference women with disabilities, as do a number of other pieces of legislation (GoSS, 2015; MoGCSWHADM, 2013, p. 13-14). However enforcement of the legal provisions for the promotion and protection of the rights of people with disabilities is lacking (MoGCSWHADM, 2013, p. 24).

The Ministry of Gender, Child and Social Welfare and the Ministry of Health are responsible for issues concerning disability (Sida, 2014, p. 3). The Ministry of Gender and Social Welfare is mandated to safeguard the rights and welfare of people with disabilities (Anyang, 2016, p. 3; UNICEF, 2015, p. 57; MoGCSWHADM, 2013). DPOs have been working with them to try and develop the 2013 National Disability and Inclusion Policy and the Inclusive Education Policy (Anyang, 2016, p. 3; MoGCSWHADM, 2013, p. 6). The National Disability and Inclusion Policy is guided by principles of non-discrimination and a rights based approach; affirmative action; diversity and inclusiveness, recognising that people with disabilities are not a homogenous group; disability mainstreaming; and participation (MoGCSWHADM, 2013, p. 15-16). However, lack of both political will and government funding means that the policies have not been implemented (Forcier et al, 2016, p. 5). There is no separate budget line for people with disabilities (Gilbert, 2016).

Sida (2014, p. 3) also reports that a separate independent commission was appointed, named the Southern Sudan National Commission for War Disabled, Widows and Orphans. The commission existed to improve the rights, participation, and accessibility of services for war disabled, widows, and orphans (Sida, 2014, p. 3).

[9] https://www.ilo.org/dyn/natlex/docs/monograph/90704/116697/f

Attitudes towards disabilities

Most people in South Sudan view disability within the medical model, i.e. 'they view disability as a limitation of a body function rather than a combination of impairments and barriers as the social model of disability enshrines' (Legge, 2016, p. 1).

There is also stigma around disability in South Sudan and disabilities are often viewed with superstition or explained with religious motives (Forcier et al, 2016, p. 5, 16; Gilbert, 2016). In many communities in South Sudan children born with disabilities are thought to be a sign that the family is being punished by God (CARE, 2016, p. 15; McNeish, 2013). Families have hidden children born with disabilities from public view as they are seen as a source of shame (Jørgensen, 2018; CARE, 2016, p. 15; UNICEF, 2015, p. 153; McNeish, 2013). There are even some reports that in some ethnic groups children born with disabilities are killed (MoGCSWHADM, 2013, p. 11). Sometime fathers abandon families when children with disabilities are born (Faehnders, 2018). People with disabilities have been given poorer quality food than the rest of the family (Jørgensen, 2018). Disabled people have reported that they had a lower social status within their communities and were not taken as seriously (Forcier et al, 2016, p. 17). People are reluctant to marry people with disabilities, even if they get them pregnant (McNeish, 2013). People with disabilities are often excluded from social events in their communities, leading to isolation (Forcier et al, 2016, p. 4, 18). In addition people with disabilities report being insulted, laughed at, had stones thrown at them, being publically discriminated against, gossiped about, suspected of theft, and abused by family, neighbours and strangers (Forcier et al, 2016, p. 18; Gilbert, 2016). Disabled people are often believed to be beggars and there are low expectations as to what they can achieve and contribute (Anyang, 2016, p. 5; Legge, 2016, p. 1; MoGCSWHADM, 2013, p. 18).

DPOs and others have identified negative attitudes and misconceptions of disability resulting from curses or witchcraft and viewing disability solely as a medical condition as the main reasons for discrimination against people with disabilities in South Sudan and barriers to their equal participation in social and economic life and access to services (Anyang, 2016, p. 2; Rieser, 2014, p. 3; MoGCSWHADM, 2013, p. 9). Such attitudes lead to some people with disabilities to feel worthless, a burden on their families, and embarrassed to interact with others (Forcier et al, 2016, p. 17; McNeish, 2013; Gilbert, 2016). However, some respondents to an assessment for HI mentioned that their family had a positive attitude towards them (Forcier et al, 2016, p. 17).

There are reports that people with disabilities acquired as a result of the conflict discriminate against people born with an impairment or those who have acquired their impairment as a result of a health condition (CARE, 2016, p. 15-16; McNeish, 2013).

There are reports that community based rehabilitation (CRB) efforts have helped to shift attitudes towards people with disabilities in communities where they are being implemented and making a positive change to their lives (Jørgensen, 2018). Children with disabilities are now playing outside with other children and people with disabilities are being consulted by community leaders to find ways the community can help them and they can help the community (Jørgensen, 2018).

Abuse

People with disabilities have experienced varying degrees of physical and verbal violence based on disability prejudice (Rieser, 2014, p. 3; MoGCSWHADM, 2013, p. 9). For example, HRW (2017) found examples of abuse of people with disabilities by their families and the wider

community, with people with disabilities being beaten or having their food and possessions forcibly removed. The 2011 national disability assessment found that '82% of persons with disabilities experience daily incidents of nervousness and anxiety and 12% experience physical violence' (MoGCSWHADM, 2013, p. 11). CARE (2016, p. 16) also warn that 'people with disabilities, in particular girls, generally have an increased risk to sexual violence being perpetrated against them'. The neglect of children and adults with intellectual disabilities or mental health problems increases the risk that they are abused or mistreated (MoGCSWHADM, 2013, p. 11).

Lack of accessible communication and discrimination within the justice system makes getting justice for abuses against people with disabilities very challenging (Gilbert, 2016).

Age and gender

UNICEF (2015, p. 2) finds that children with disabilities are especially disadvantaged as they 'have to contend with a lack of specialised services; difficulties accessing mainstream education, health and other services; and stigma within families and in society'. However, they also find that 'little research has been done on the challenges they face and the extent that they are integrated into society (UNICEF, 2015, p. 153).

Traditional gender roles restrict women and girls with disabilities from accessing education or vocational training or finding employment in comparison to men and boys with disabilities or women and girls without disabilities (Forcier et al, 2016, p. 5; Rieser, 2014, p. 3; MoGCSWHADM, 2013, p. 11). 'This severely limits the livelihood opportunities of women with disabilities and makes them vulnerable and dependent' (Forcier et al, 2016, p. 5).

The Government of South Sudan (2015, p. 10) recognised that women and girls with disabilities are particularly vulnerable during armed conflict due to the combined risk factors of gender and disability. This is as a result of a combination of factors including facing high risks of violence, harassment, neglect, exploitation and psychological trauma, and being less likely to have access to critical safety information and to be able to protect themselves or seek protection from imminent danger (GoSS, 2015, p. 10). Women with disabilities also generally experience higher levels of physical, psychological and sexual violence (MoGCSWHADM, 2013, p. 11).

Education

Despite article 29 of the transitional constitution obliging the government to provide access to education for all, including children with disabilities, in practice this has not been fully realised (Legge, 2016, p. 3; MoGCSWHADM, 2013, p. 10). Most children with disabilities don't go to school in South Sudan because special schools are scarce and mainstream schools are often inaccessible and do not have teachers trained in inclusive education (Faehnders, 2018; Jørgensen, 2018; Legge, 2016, p. 4). According to the 2015 education management information system (EMIS), approximately 21,300 of primary pupils had an impairment, representing 1.7% of all enrolled primary pupils (UNESCO, 2017, p. 67). Other studies find that the percentage of children with special needs in school varies from 0.7 to 2.7%, depending on the region (Faehnders, 2018; MoEST, 2014, p. 18-19). Earlier estimates from 2011 had much higher figures, where school attendance of children with disabilities ranged from 21.9-24.3%, with a dropout ratio of 48% (MoGCSWHADM, 2013, p. 10).

'Girls with disabilities are less likely to access education than their peers without disabilities as well as than boys with disabilities' (Legge, 2016, p. 4; Rieser, 2014, p. 3; MoGCSWHADM, 2013, p. 10). Special schools mean that children with visual, hearing, speech and physical impairments from the capital have some possibilities to access education (Legge, 2016, p. 4). However, children with intellectual, psychosocial and multiple impairments have far fewer opportunities to attend school (Legge, 2016, p. 4). Children with disabilities who are enrolled in schools tend to be older than their peers without disabilities (Legge, 2016, p. 4).

Legge (2016, p. 4) suggests that access to education depends on factors such as 'the type and/or degree of impairment, socio-economic status of a family, physical accessibility of schools, distance, and attitudes'. The 2014 Draft National Inclusive Education Policy finds that the three main barriers preventing people with disabilities from accessing education are:

(i) long distances to school (84% of cases),

(ii) negative attitudes (52%), and

(iii) lack of teacher experience (42%)[10] (UNESCO, 2017, p. 21; MoEST, 2014, p. 23).

Teasing and bullying was also a problem for 24% of respondents (UNESCO, 2017, p. 21). Other barriers to accessing education include the lack of inclusive education institutional policy and processes, the impact of poverty, existing insecurity in some areas, lack of assistive devices, lack of accessibility to the roads and streets, inaccessible school facilities and infrastructures (ramps, toilets for persons with disabilities), as well as the overall challenges facing the education sector (Legge, 2016, p. 4; UNICEF, 2015, p. 7; MoEST, 2014, p. 21; Rieser, 2014, p. 4; MoGCSWHADM, 2013, p.10-11). Stigma around disability can also reduce parents' desire to send their children to school and many communities are unaware that children with disabilities can also participate in mainstream education (UNICEF, 2015, p. 7, 113; MoEST, 2014, p. 24; Gilbert, 2016).

Oxfam[11] (2017, p. 10, 30) reports that no children with disabilities were able to access schools in Protection of Civilians (PoCs) sites[12] and there were no facilities to take care of pupils with special needs in the camps (see also HRW, 2017). HRW (2017) found that schools were not accessible and people with disabilities experienced bullying and stigma from their peers and teachers.

Izizinga (2017, p. 16) reports that South Sudan has recently approved a Special Educational Needs policy, as well as a new national strategy relating to disability and education. The 'National Inclusive Education Policy' proposes a vision for inclusive education, providing the necessary supports of children with disabilities in regular classroom settings (MoEST, 2014, p. 9-10). Schools in communities with CRB programmes have been supported to be inclusive of children with disabilities and children have been provided with mobility aids to help them to get

[10] Based on interviews and focus groups in 54 schools across 6 states and 9 counties.

[11] Oxfam carried out a gender analysis field study in May–June 2016 in Wau State, Jonglei State and Juba State, targeting 490 internally displaced persons (IDPs) in these areas. In each location, the study team also conducted key informant interviews (KIIs) and focus group discussions (FGDs) among women, men, boys and girls and in some cases reached out to host community members.

[12] Protection of Civilian (PoC) sites refer to situations where civilians seek protection and refuge at existing United Nations bases when fighting starts (Lilly, 2014).

there (Jørgensen, 2018). The Education Sector Strategic Plan 2017-22 pledges to 'seek to increase access to learning for children with special education needs', with more accessible classrooms and WASH facilities and training on inclusive education (MoGEI, 2017, p. 61). To encourage this there are plans to set up a model government school for inclusive education in each payam (MoGEI, 2017, p. 61). There are also plans to set up social clubs within schools to advocate formally and informally for children with disabilities (MoGEI, 2017, p. 61). Izizinga (2017, p. 16) suggests that disabled people's organisations in South Sudan are not engaged in advocacy and capacity building around inclusive education.

Children with disabilities who have managed to get an education and reach high school or university struggle as a result of inaccessible environments and a lack of assistive devices (Legge, 2016, p. 4).

Infrastructure, communications, and transport

Environmental barriers such as poor transport infrastructure make it harder for people with disabilities to access services (Forcier et al, 2016, p. 21). The majority of education, health and sports facilities, places of work, election/ polling centres, courts, information and other physical infrastructure are also inaccessible, with a lack of ramps and lifts and accessible communication (MoGCSWHADM, 2013, p. 12). Transportation costs can also be prohibitively expensive (Forcier et al, 2016, p. 21). Most electronic and print media is not available in accessible formats meaning people with disabilities struggle to access information (MoGCSWHADM, 2013, p. 12). This limited accessibility has contributed to the social exclusion of people with disabilities (MoGCSWHADM, 2013, p. 12).

Healthcare and nutrition

Despite article 31 of the transitional constitution entitling them to equal access to health, people with disabilities struggle to access and afford healthcare, including assistive devices (Forcier et al, 2016, p. 20-21; MoGCSWHADM, 2013, p. 9-10). HRW (2017) found that many of the people they interviewed had never or rarely seen a doctor. Some healthcare and rehabilitation services for people with disabilities are provided by international organisations such as HI, including in conflict affected areas (Lordet, 2017, p. 2, 4; MoGCSWHADM, 2013, p. 10, 21-22). UNICEF (2018) intends to strengthen the integration of disability programming in maternal newborn child health and nutrition services in South Sudan.

People with disabilities struggle to access healthcare due to the long distances and poor road networks; the lack of ambulance services, inadequate drugs supply in the health centres; negative attitude towards people with disabilities by health workers; inadequate and in accessible health information and knowledge (lack of sign language, Braille and easy to read information); and inaccessible health physical infrastructure (MoGCSWHADM, 2013, p. 10)..

Oxfam (2017, p. 23) found that internally displaced persons (IDPs) with disabilities were amongst those most vulnerable to malnutrition (see also HRW, 2017). The World Food Programme has included people with disabilities as specific targets in it new strategy for South Sudan (WFP, 2017b, p. 7).

Livelihoods

People with disabilities are heavily represented among the poorest and unemployed in South Sudan (Legge, 2016, p. 5; MoGCSWHADM, 2013, p. 11-12). The 2011 National Disability Assessment indicated that 89.3% of respondents with disabilities were unemployed and there are almost no social safety nets and food security schemes for persons with disabilities (Legge, 2016, p. 5; MoGCSWHADM, 2013, p. 12; McNeish, 2013). Those that exist have focused on disabled veterans, although they are still inadequate for their needs (McNeish, 2013). People with intellectual or psychosocial impairments were least likely to be employed and most likely to be exploited if working (MoGCSWHADM, 2013, p. 12; Legge, 2015, p. 5). Social protection schemes 'mainly protect persons whose impairments result from the armed conflict' (Legge, 2016, p. 6).

HRW (2017) found that IDPs with disabilities living in camps struggled to make a living as they has they had less opportunities than others to cultivate, fetch wood, or trade outside of the sites. The assessment carried out for HI found that most respondents were unemployed but men with disabilities who were employed had a much wider variety of employment options than women with disabilities (Forcier et al, 2016, p. 13). People with acquired disabilities reported losses of livelihoods and employment as a result of their new disability which impacted on their ability to care for their families (Forcier et al, 2016, p. 18).

Legge (2016, p. 5) suggests that education is vital for people with disabilities to access decent employment, with most people with disabilities needing a university degree or certificate in order to get a decent job. Barriers to employment include the accessibility of the working environment, discrimination, and the attitudes of employers and colleagues, while barriers to self-employment include the lack of access to banking and credit facilities (Legge, 2016, p. 5; MoGCSWHADM, 2013, p. 12; Gilbert, 2016). A few skills development and self-employment support programmes are inclusive of people with disabilities, although most mainstream livelihoods programmes are inaccessible to people with disabilities (MoGCSWHADM, 2013, p. 12).

Political participation

Forcier et al (2016, p. 4) note that 'people with disabilities and their needs are often underrepresented or not represented at all in the political process, which makes it difficult for them to be heard'. Their lack of voice means their 'issues are barely taken into consideration in decision-making processes' (Legge, 2016, p. 1). However, efforts were made during the referendum on independence, for example, to ensure the accessibility of voting for people with disabilities (Sida, 2014, p. 1). DPOs have pushed for a 5% representation of people with disabilities in decision making bodies to be included in the constitution (Sida, 2014, p. 4). People with disabilities have also been involved in forums feeding into the South Sudan National Dialogue[13].

[13] http://www.ss.undp.org/content/south_sudan/en/home/presscenter/articles/2017/09/30/in-second-forum-people-with-disabilities-and-minority-groups-call-for-representation-in-the-national-dialogue.html Accessed 16/3/18

Psychosocial disabilities/mental health

Conditions within South Sudan contribute to critical levels of mental health issues and decades of conflict have left a legacy of psychological distress (HI, 2018, p. 2; AI, 2016, p. 7). Research[14] by Amnesty International found that the armed conflict in South Sudan and the torture, arbitrary detention, sexual violence, killing, and forced displacement experienced as a result of it has had a 'serious and significant mental health impact' (AI, 2016, p. 7). IDPs 'described experiencing a range of symptoms commonly associated with mental health disorders such as PTSD and depression—having nightmares, getting angry easily, feeling unable to concentrate, and considering suicide. Many spoke of headaches, stomach pains, backaches, and heart palpitations— common physical manifestations of psychological stress. They also told of feeling unable to work, study, carry out basic daily tasks, care for children, or maintain relationships with friends and family' (AI, 2016, p. 7).

According to the World Health Organisation, in 2014, South Sudan has the 13th highest suicide rate in the world[15]. People with mental health problems experience social stigma and family members generally have limited awareness about mental health and trauma or what constitutes appropriate care and treatment (AI, 2016, p. 8). For example, people with psychosocial disabilities are often chained up in order to 'protect' them (CARE, 2016, p. 15). People with mental health conditions are also routinely arbitrarily incarcerated in prisons, even if they haven't committed a crime, where they receive insufficient medical care and live in poor conditions (AI, 2016, p. 8, 38; HRW, 2012, p. 10, 56-64). In some cases their families hand them over, not believing that mental disabilities are treatable (HRW, 2012, p. 57).

Mental health services are extremely limited and many people are unaware of the opportunities and benefits of psychosocial support (HRW, 2017; HI, 2018, p. 2; Forcier et al, 2016, p. 6; AI, 2016, p. 8; HRW, 2012, p. 56). There are only 12 public beds available in Juba Teaching Hospital's psychiatric ward and the availability of psychotropic drugs is inconsistent and limited (AI, 2016, p. 8). In 2016 there were only two practising psychiatrists in the country (AI, 2016, p. 8). 'Mental health services have not been integrated into the primary health care system, and there is no dedicated mental health policy, strategy, or legislation' despite the government recognising the need for improved mental health services (AI, 2016, p. 8). The available public mental health services are not accessible which makes it harder for mine/explosive remnants of war survivors and other people with disabilities to access these services (Forcier et al, 2016, p. 6). Some mental health care is provided by international and national organisations such as HI but it is insufficient to meet the population's needs (HRW, 2017; Lordet, 2017, p. 3; Forcier et al, 2016, p. 3, 6; AI, 2016, p. 8). Conflict and displacement have resulted in traditional support mechanisms and networks such as neighbours, relatives, friends and church mechanisms dispersing or falling apart (Forcier et al, 2016, p. 6; AI, 2016, p. 8).

[14] Based on interviews with 161 internally displaced people living in United Nations Mission in South Sudan (UNMISS) Protection of Civilians (PoC) sites in Juba, Malakal and Bentiu and in an informal settlement at Mahad School in Juba, and with government and UN officials, donors, representatives of non-governmental organizations (NGOs), and international and South Sudanese mental health professionals—including psychiatrists, psychologists and psychosocial workers.

[15] http://www.eyeradio.org/south-sudan-highest-suicide-rates/ accessed 15/3/18

Conflict

Research by Human Rights Watch[16] found that people with disabilities face greater risks of being caught in fighting as they are often find it hard to flee ahead of attacks or are left behind by their families (HRW, 2017; HI, 2018, p. 2; Anyang, 2016, p. 4; CARE, 2016, p. 15). Light for the World found that the 'percentage of children with disabilities is very high in the group of children who got lost during forced migration in South Sudan' (Faehnders, 2018). Those who helped people with disabilities to flee were also more vulnerable as they carried or guided them to safety (HRW, 2017).

Numerous cases of people with disabilities and older people being shot, hacked to death, or burned alive in their houses or in PoC sites by government and opposition forces have been documented (HRW, 2017; CARE, 2016, p. 15; OHCHR, 2016, p. 44). OHCHR (2016, p. 38) found cases of women with disabilities being victims and survivors of sexual violence by armed forces. HRW (2017) also found some cases where soldiers spared the lives of a number of people with disabilities and older people who had been left behind at the orders of their commander and provided them with food and water. Conflict has also prevented people with disabilities accessing services and medicines they need, which may increase the severity of their disability (Forcier et al, 2016, p. 4; CARE, 2016, p. 16).

Access to humanitarian assistance

Research by a variety of organisations in South Sudan has shown that people with disabilities are amongst those who have been hit hardest by the crisis (Faehnders, 2018). People with disabilities access to humanitarian services, such as food distributions, WASH facilities, and education and health care, is limited (HRW, 2017; Oxfam, 2017, p. 60; HI, 2018, p. 2; Faehnders, 2018). Lack of mobility devices and challenging and unfamiliar environments in sites of displacement, for example, make it hard for people with disabilities to access aid services (HRW, 2017). HRW (2017) found that 'displaced people with disabilities and older people who have sought refuge in the remote bushes of Western Bahr el-Ghazal, Upper Nile, Jonglei, and the Equatorias or on islands in the Sudd, are more likely to encounter difficulties getting aid than those who found their way to the PoC sites inside UN bases'. However, even in these sites people with disabilities have problems accessing services, with conditions differing depending on the service providers at the site (HRW, 2017). An estimated 250,000 people with disabilities live in displacement camps in South Sudan, according to Light for the World (Faehnders, 2018; HRW, 2017).

Some organisations such as Humanity & Inclusion and Light for the World are providing services to people with disabilities in IDP sites, including through community based rehabilitation (CBR) focusing on education, health, social inclusion, empowerment and livelihoods (HI, 2018, p. 3; Lordet, 2017, p. 5; Faehnders, 2018; Forcier et al, 2016, p. 3, 14).

[16] In February and March 2017, Human Rights Watch interviewed more than 45 people with disabilities and older people in displacement sites in Juba and Malakal, as well as in Panyijar county in the former Unity state. Human Rights Watch also met with aid organisations and the South Sudan Human Rights Commission.

Advocacy and disabled people's organisations

A number of disabled people's organisations[17] exist in South Sudan who engage in rights advocacy, awareness raising, and programmes aimed at socio-economic and political empowerment (Anyang, 2016; Forcier et al, 2016, p. 14; Legge, 2016, p. 3). Most awareness raising campaigns on disability rights are concentrated in the capital Juba, where DPOs are fairly strong and popular (Legge, 2016, p. 2). For example, radio programmes running since 2010 have helped raise awareness of disability in Juba (Legge, 2016, p. 2). People with disabilities and their organisations have also used arts and sports to challenge stereotypes in society about people with disabilities (Legge, 2016, p. 2).

Sign language was only recently introduced to South Sudan and its use is mainly concentrated in Juba (Legge, 2016, p. 4). The Deaf association in Juba has developed a national sign language dictionary[18] (Legge, 2016, p. 4).

DPOs face challenges as a result of lack of government support and lack of income to keep programmes running (Anyang, 2016, p. 4). Engagement and partnerships between DPOs in Juba and mainstream national and international civil society organisations, including international organisations working in the field of disability, has only started recently and only a few of the DPOs have engaged in partnership with mainstream international NGOs (Legge, 2016, p. 2).

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