

SITUATION ANALYSIS OF MINE/ERW SURVIVORS AND OTHER PEOPLE WITH DISABILITIES

JUBA, CENTRAL EQUATORIA, SOUTH SUDAN

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The following individuals contributed to the field research and analysis undertaken for the Situation Analysis of Mine/ERW Survivors and other People with Disabilities.



Natalie Forcier, Partner
Dr. Rens Twijnstra, Lead Methodologist
Dr. Niketa Williams, Research Manager
Chelsey Buurman, Research Officer
Stanley Gore, Research Officer
Hannah Danzinger, Research Officer
Christopher Abosh, Researcher
Emilia Mario, Junior Researcher
Sunday Peter, Junior Researcher
Riek Bipal, Junior Researcher

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Acronyms

ERW	Explosive Remnants of War
FGD	Focus Group Discussion
GoSS	Government of South Sudan
HI	Handicap International
IDP	Internally Displaced Person
KII	Key Informant Interview
NGO	Non-governmental Organisation
POC	Protection of Civilians
PRRC	Physical Rehabilitation Reference Centre
RDS	Respondent-driven Sampling
SPLM	Sudan People's Liberation Movement
SPLM-IO	Sudan People's Liberation Movement – In Opposition

Map



Executive Summary

Since the 2013 conflict in South Sudan, a vacuum of information on the realities faced by conflict survivors and other people with disabilities has been developed. This assessment provides information on the current situation of conflict survivors and other people with disabilities to inform future advocacy and development efforts. By interviewing members of the community who identified as survivors of the 2013 conflict and other people with disabilities, this situation analysis provides valuable insights in this issue. Specifically, information is provided on the causes and demographics of disability, the impact of disabilities on personal lives, and impact mitigation.

In an effort to trace post-2013 disability, the declared causes of impairment and demographics were mapped. We found that the majority of male respondents were wounded due in direct fighting, while women reported other injuries that lead to their impairment, including injuries and attacks that occurred while escaping violence. Both men and women reported being injured due to landmines/ERW. Following their injuries, men appeared to hold a larger variety of employment statuses, including working as a teacher, farmer or guard. Nevertheless, the majority of respondents was either unemployed or self-employed, making ends meet by selling tea or repairing clothes.

The impact of disability was mapped on two levels: from the perspectives of stakeholders, and from the perspectives of survivors and people with disabilities. We found that the two groups largely share similar concerns, but that stakeholders strongly emphasised the need for government action, policy and reform: issues that were less prioritized by survivors and people with disabilities. We found that stakeholders implemented a holistic approach to service provision, providing services in the area of education, health and employment, which in turn positively affected community inclusion, but that support in livelihood development and economic security could be strengthened with additional programming.

From the perspective of survivors and other people with disabilities, their impairments have affected them both socially and economically. Both in family life and within the community respondents faced negative and unwelcoming attitudes regardless of their gender, and dealt with isolation, social stigma and prejudice. However, respondents also reported positive anecdotes wherein they were welcomed and accepted within their communities. The most significant impact has been the loss of livelihoods and employment. Without a source of income and unable to support their families, respondents reported that their spouses left them, and that they were viewed as a burden to their families. Without livelihoods, respondents indicated feeling useless, being further unable to live a fulfilling life.

In the area of impact mitigation, we analysed the availability and access to services, identified the broader gaps in service delivery, and suggested fitting action points. We found that although services and assistance in the areas of healthcare, education and transport are available, they do not meet the needs and demands of survivors and other people with disabilities, and are usually difficult to access. Respondents also demonstrated a strong dependence on service provision by international actors and NGOs, as government-provided services are practically non-existent. The availability of medical facilities varied strongly, but was generally plagued by long waiting times due to a lack of adequate medical personnel and specialists. The availability of medication and equipment such as crutches and wheelchairs also varied strongly, as well as additional non-food items. Although a smaller number of people also accessed educational services when they were able to, technical support including vocational and computer training, were scarce.

Broader gaps in service delivery exist mainly due to the strong dependence on NGOs as the main service providers. A lack of government action in this area has led to a situation wherein an overwhelming demand is made on extremely limited resources. Considering this, NGOs are usually restricted to offering short-term assistance, and less able to address the long-term economic impact of disabilities. Facilities such as adapted WASH facilities are also extremely rare and difficult to access, as are medical equipment and specialist medical care. The loss of livelihoods and economic independence is by far the area that requires the most attention, as we found financial assistance and housing difficult to access. Additionally, mental health issues, trauma counselling and psychosocial support are insufficiently addressed. Although some positive behavioural change has been achieved within communities, social stigma surrounding mental health issues remains problematic.

Based on these findings, we suggest several action points. First, the South Sudanese government should take a larger role in the service provision for survivors and people with disabilities. This means scaling up advocacy and campaigning efforts in order to ratify international conventions and create a legal framework wherein the rights and needs of survivors and people with disabilities are guaranteed. Eventually, capacity of the local government to act as the primary service provider must be built. Secondly, service provision must go beyond the basics. For example, simply providing prosthetics without proper rehabilitation is ineffective. To go beyond the basics, increased attention for psychosocial counselling and trauma healing is necessary, as social stigma prevents access to services and community inclusion. Providing these services strengthens the coping abilities of survivors and people with disabilities. At the same time, it is important to increase outreach to the most vulnerable groups, in order to enable those in remote communities to access services by providing logistical support. The economic impact of disabilities and impairment must also be addressed, as it not only encourages independence, but is also an important factor in enhancing community and social inclusion. Finally, the social impact of disabilities must be addressed in programmatic activities, and the social impact should not be underestimated. A combination of targeted community outreach and sensitization programmes can mitigate this and improve family and community life.

1 Introduction

Handicap International (HI) is an independent organisation working to empower and provide support services to people with disabilities and other vulnerable populations worldwide. HI is at the forefront of advocacy efforts to ensure equitable rights for those marginalized by their communities or by conflict, particularly in countries where those with disabilities face countless challenges in accessing services.

Handicap International has been working in South Sudan since 2006, when it first deployed an emergency response team. Since then, HI has adapted its activities to respond to the various immediate needs of the internally displaced population, and promotes equal rights and equal access to services for people with disabilities or injuries. Alongside its emergency response projects, HI implements a civic inclusion programme that promotes the inclusion of people with disabilities. It also offers victim assistance by facilitating access to basic rehabilitation services and by training health and social workers, medical professionals, and caregivers. Furthermore, HI actively works on reforming and enhancing the capacity and structure of mental health services in South Sudan.

Handicap International completed a baseline assessment on the situation of survivors and other people with disabilities, who are direct victims of armed violence, and other people with disabilities in 2013 prior to the outbreak of the conflict. Since then, however, the most recent conflict has resulted in a vacuum of information on the realities faced by conflict survivors and other people with disabilities. Handicap International seeks to gather information on the current situation of people with disabilities and the survivors of armed violence including mines, explosive remnants of war (ERW) and other weapons.¹ The results of the assessment will provide updated information for statements, advocacy, planning and development of more appropriate actions for the actors working on disability-inclusive efforts including the Government of South Sudan, as well as those that have not yet mainstreamed disability in their work. The assessment provides information on the situation of survivors from the 2013 conflict and other people with disabilities; because field research was completed prior to the renewed outbreak of conflict in July 2016, survivors of the most recent round of conflict are not included in this assessment.

2 Background

This section provides background information on the conflict, the incidence of bodily harm, and the current state of people with disabilities in South Sudan. It discusses the types of impairments that are most common among survivors of the 2013 conflict and other people with disabilities, and points out the most vulnerable groups living with disabilities in South Sudan.

2.1 Conflict in South Sudan

After decades of civil war in Sudan, South Sudan achieved independence in 2011. Almost two and a half years later, fighting broke out in Juba, the country's new capital. The main warring parties to the

¹ Victims of sexual violence and torture were not explicitly included in this assessment, neither were they explicitly excluded, as potential participants were self-identified persons with disabilities.

conflict were President Salva Kiir's Sudan People's Liberation Movement (SPLM) and Vice President Riek Machar's SPLM-in Opposition (SPLM-iO). Soon after the first clashes in December 2013, violence spread to other parts of the country, plunging South Sudan in a renewed civil war that was largely fought along ethnic lines. Since then, South Sudan has been plagued by on-going violence that seriously hinders the country's development.² A peace agreement was reached in August 2015, which allowed Riek Machar and his forces to return to Juba in April 2016. However, the agreement failed to bring a definitive end to the violence. Regular violent clashes are reported throughout the country, and have resulted in over 2.3 million displaced persons, with an estimated 1.7 million internally displaced persons (IDPs) and 725,000 South Sudanese refugees in neighbouring countries such as Uganda.³

South Sudan's conflict has left a large number of South Sudanese with disabilities, and this number has been further exacerbated by disease and accidents.⁴ In addition to the physical and mental challenges posed by impairment, people with disabilities face significant social and political exclusion. For example, people with disabilities are often excluded from social events in their communities, leading to a secluded and isolated life. 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.⁵ Following independence in 2011, the Government of South Sudan (GoSS) lacked a distinct strategy or policy for addressing the needs of people with disabilities. In addition, official statistics regarding the numbers and situations of people with disabilities did not exist, making lobbying for improved rights and access to services more difficult. Even among local advocacy organisations, a comprehensive definition of disability, including mental impairment, is lacking.⁶ Against this background, Handicap International undertook this assessment to gather information on the current situation of survivors of armed violence and other people with disabilities.

2.2 War as a Cause of Impairment

The recent conflict in South Sudan has not led to an increase in the number of people with disabilities in South Sudan. It has also prevented those with existing impairments from receiving adequate treatment and care, ultimately denying them access to needed resources and services. Armed conflict, poverty, and lack of health care systems have contributed to an increased number of people with disabilities in South Sudan.⁷ Humanitarian response efforts insufficiently include services for children and adults, especially in camps for IDPs, where the number of people with disabilities is estimated to be between 200,000 and 250,000.⁸ Considering the global estimates for people with disabilities range from 10 to 15 per cent of the population, the total number of people with disabilities in South Sudan could be over 1.2 million. As one of society's most vulnerable groups, the needs of people with disabilities often stay

² World Bank. 'Country Overview: South Sudan', last updated on 9 April 2016; accessed on 21 July 2016, <http://www.worldbank.org/en/country/southsudan/overview>.

³ UNICEF. 'South Sudan Humanitarian Situation Report', 16 June 2016, accessed 12 July 2016, <http://reliefweb.int/sites/reliefweb.int/files/resources/UNICEF%20South%20Sudan%20Humanitarian%20SitRep%20%2388%20-%2016%20June%202016.pdf>.

⁴ Government of South Sudan. 'South Sudan National Disability and Inclusion Policy.' 2013. <http://mgcswss.org/wp-content/uploads/South-Sudan-National-Disability-and-Inclusion-Policy.pdf>

⁵ Ibid.

⁶ Sida. 'Disability Rights in Sudan and South Sudan.' December 2014. <http://www.sida.se/globalassets/sida/eng/partners/human-rights-based-approach/disability/rights-of-persons-with-disabilities-sudan-and-south-sudan.pdf>

⁷ Light for the World. 'Crisis in South Sudan: Persons with Disabilities Excluded from Humanitarian Response Efforts.' 12 May 2016. <https://www.light-for-the-world.org/crisis-south-sudan-persons-disabilities-excluded-humanitarian-response-efforts>

⁸ Ibid.

hidden for a wide range of reasons. People with disabilities often face stigma in their communities, some of which is driven by fear or negative stereotypes. In other cases, caregivers lack the skills and capacity of work people with disabilities in times of crisis, and services that could benefit people with disabilities are inaccessible to them.⁹

The conflict in South Sudan has also led to an increase of people with disabilities as a result of mines and ERW. This has resulted in insufficient medical care and rehabilitation of military veterans, civilians, and in particular women and children.¹⁰ The South Sudanese National Disability Assessment estimates that war and conflict is the cause of 21% of people with impairments in South Sudan. This number is likely much higher due to issues of underreporting.¹¹

2.3 People with Disabilities in South Sudan

South Sudan faces major challenges in addressing the needs of people with disabilities. Not only is the awareness among key decision makers and the public low, negative social attitudes and structural discrimination prevail and affect the ability of people with disabilities to access educational services, water, and other essentials. The situation is exacerbated by extreme poverty and low school completion. Women are increasingly acquiring impairments as a result of complications during pregnancy and childbirth, whereas across-the-board new cases of impairment are reported due to widespread violence, mines and sexual abuse.¹²

South Sudan also has limited international legal frameworks in place for people with disabilities, although the constitution dedicates a number of clauses to the rights of people with disabilities.¹³ The Ministry of Gender, Child and Social Welfare has published a National Disability and Inclusion Policy that addresses the various challenges faced by the country and highlights particular issues. For example, it recognizes gender disparity in people with disabilities accessing services. Traditional gender roles prevent women and girls with disabilities from accessing education or finding employment more so than men and boys with disabilities or women and girls without disabilities. This severely limits the livelihood opportunities of women with disabilities and makes them vulnerable and dependent.¹⁴ Despite the intentions and policy objectives set out in the National Disability and Inclusion Policy, lack of government funding and political will have prevented implementation and monitoring of this policy. Although modest improvement has been made in the provision of victim assistance services to mine/ERW survivors and other people with disabilities over the past decade, the majority is provided by international organisations and non-government organisations (NGOs). Victim assistance is still needed in the areas of basic rehabilitation services, psychosocial support, income generating activities, and referral systems.¹⁵

⁹ Sida, 2014.

¹⁰ Light for the World, 2016.

¹¹ Government of South Sudan. 'South Sudan National Disability and Inclusion Policy.' 2013. <http://mgcswss.org/wp-content/uploads/South-Sudan-National-Disability-and-Inclusion-Policy.pdf>

¹² Sida. 'Disability Rights in Sudan and South Sudan.' December 2014. <http://www.sida.se/globalassets/sida/eng/partners/human-rights-based-approach/disability/rights-of-persons-with-disabilities-sudan-and-south-sudan.pdf>

¹³ Government of South Sudan. 'Laws of South Sudan. The Transitional Constitution of the Republic of South Sudan, 2011.' 2011. <http://www.icnl.org/research/library/files/South%20Sudan/SSudan.pdf>

¹⁴ Government of South Sudan. 'South Sudan National Disability and Inclusion Policy.' 2013. <http://mgcswss.org/wp-content/uploads/South-Sudan-National-Disability-and-Inclusion-Policy.pdf>

¹⁵ Landmine & Cluster Munition Monitor. 'South Sudan: Casualties and Victims Assistance.' Last updated: 13 November 2013. Accessed: 21 July 2016. <http://www.the-monitor.org/en-gb/reports/2016/South-Sudan/casualties-and-victim-assistance.aspx>

Service provision related to mental health in South Sudan is especially weak and practically non-existent. The GoSS does not offer accessible mental health services to the general public through the public health care sector. This makes it difficult for mine/ERW survivors, other people with disabilities and victims of recent violent conflict to access these services.¹⁶ In areas of armed conflict, the proportion of the population that suffers from mild or moderate mental disorders, not including post-traumatic stress disorders, ranges between 15 and 20 per cent. An even higher proportion of the population, approximately 41 per cent, specifically exhibits symptoms consistent with post-traumatic stress disorders.¹⁷ Traditional support mechanisms and networks such as neighbours, relatives, friends and church members have dispersed or fallen apart due to conflict and displacement. Services provided by international and national NGOs are insufficient to meet the population's needs. There is almost no support for people suffering from mental health issues as a result of traumatic events that led to their impairment.¹⁸

3 Description of Assessment

HI carried out a baseline assessment of the situation of mine/ERW survivors, victims of recent conflict and other people with disabilities in 2013, prior to the outbreak of conflict. Since then, no comprehensive assessment of the situation has been carried out. This report surveys the needs of survivors and other people with disabilities in South Sudan and informs further programming. Initially, the planned assessment relied on a mixed-method approach, including a quantitative survey, and significant qualitative data collection. During the assessment process, quantitative surveys could not be conducted because of restriction from the authorities. Hence, the report is based on qualitative data.

3.1 Aim of Assessment

The overall aim of this report is to assess the situation of survivors of armed violence—including conventional weapons, small arms, light weapons, mines, bombs, shells, rockets, missiles, cluster munitions / ERW — whose accident occurred during or after the December 2013 conflict in South Sudan¹⁹, as well as that of other people with disabilities. To this end, the assessment focused on survivors of the 2013 conflict who became impaired due to direct violence, as well as people who became impaired due to causes not directly related to the conflict, such as illness (see section 4.1).

In particular, the assessment had the following objectives:

1. **To assess** the perspectives of key international stakeholders in the areas of health, protection and mine action on armed violence, disabilities and future perspectives for survivors and other people with disabilities.

¹⁶ Idem.

¹⁷ Amnesty International. 'Our Hearts Have Gone Dark: The Mental Health Impact of South Sudan's Conflict.' 2016.

¹⁸ Idem.

¹⁹ Excluding sexual violence and torture

2. **To assess** the perspectives of survivors and other people with disabilities of armed violence with regard to the impact current conflict has had on their lives (medical, social, economic elements).
3. **To analyse** the similarities and differences between the two perspectives and propose relevant action in the context of victim assistance.

Evaluation indicators were used as guides in the design of the analytical report. Questions from the qualitative questionnaires yielded relevant data for specific indicators and were assigned to different sections of the report. Relevant axes of comparison, such as gender, age, or disability, were included in each section. In order to address all highlighted indicators and meet evaluation objectives, the Situation Assessment evaluated the following aspects:

- Causes of impairment
- Demographics of disability
- Perspectives of international stakeholders
- Perspectives of survivors and other people with disabilities
- Differing perceptions
- Existing services and service providers
- Suggested action points

3.2 Methodology

Forcier Consulting used qualitative research methods in Juba and in the Protection of Civilians (POC) camps outside of Juba to address the objectives of this assessment. An initial desk review of project documents and relevant literature informed the design of the qualitative tools. The qualitative component of the study consisted of 8 Focus Groups Discussions (FGDs) and 9 Key Informant Interviews (KIIs). All FGDs and KIIs took place in Juba, specifically in Jebel Kujur and Nyakuron West, Juba Town and at UN House. The FGDs included a total of 54 participants – 32 men and 22 women. No FGD was conducted with children or other specific groups.

3.2.1 Desk Review

A comprehensive review of all available documents was conducted prior to commencement of the assessment and informed subsequent analysis and reporting. Documents were reviewed on a continuing basis throughout the project and especially during the analysis phase. Documents included, but were not limited to, HI's Baseline Assessment on the Situation of Survivors and People with Disabilities in December 2013, and HI's Baseline Assessment of Persons with Disabilities and Landmine/ERW Survivors in Yei River County, South Sudan, May 2014.

3.2.2 Field Research

Although a mixed research method deploying quantitative and qualitative tools was originally proposed, an outbreak of violence during the data collection phase meant researchers were unable to

collect quantitative data as planned.²⁰ FGDs were carried out with adult individuals who identified as survivors of the 2013 conflict and who resided in Juba or Juba POC. In this way, researchers were able to assess the perspectives of armed violence survivors from the 2013 conflict regarding the impact of disability on various aspects (medical, social, economic, etc.) of their lives. Key Informant Interviews (KIIs) were employed to assess the perspectives of international stakeholders (health, protection, mine action) regarding armed violence, disability, and outlooks for the future of the survivors after more than two years of enduring the most recent conflict. Note that FGD participants were not recruited from the pool of participants in the 2013 assessment; participants in the FGDs represent a new set of respondents. All selected respondents were adult individuals who identified as survivors of the 2013 conflict and who resided in Juba or Juba POC. The table below provides an overview of research activities conducted by Forcier Consulting.

Methods	Source/ Respondent
Key Informant Interviews (KIIs) (9)	Key Stakeholders providing services and/or support to survivors of the 2013 conflict and other people with disabilities,
Focus Group Discussions (FGDs) (8)	<p>Adult individuals who identified as survivors of the 2013 conflict and who resided in Juba or Juba POC in 8 separate FGDs</p> <p>Juba Protection of Civilian Camps (POCs) (4): Women age 25-35 Women age 35+ Men age 25-35 Men age 35+</p> <p>Juba Area (4): Women age 25-35 Women age 35+ Men age 25-35 Men age 35+</p>

All individuals involved in the management of the survey are bound by corporate research ethics guidelines and ESOMAR standards. This means that the security of interviewers and participants was taken into account at all times, and that researcher took special care when engaging with this particularly vulnerable group. The cooperation of respondents was voluntary, and informed consent of all participants was given. Additionally, the rights of respondents as private individuals were respected at all times, and full confidentiality was guaranteed.

²⁰ A more detailed account can be found in the limitations section.

3.2.1.1 Key Informant Interviews

Forcier Researchers conducted KIIs in the preferred language of each respondent. Organisations and individuals providing support, including medical care, to people with disabilities who are survivors of the recent conflict were contacted for an interview and for help in identifying and mobilising FGD participants. Interviews with organisation representatives were arranged by the researcher at a convenient location and focused on the type and scope of services the organisation provides to survivors of the recent conflict. A total of nine KIIs were conducted. Researchers used a hard copy of the semi-structured interview guides for reference during the interview and took comprehensive notes that were compiled and synthesized at a later time.

Several stakeholders, including NGOs, were interviewed:

- Union for the Physically Disabled (national)
- Protection Cluster (international)
- Operation Save Innocent Lives (national)
- Physical Rehabilitation Reference Centre (national)
- South Sudan Red Cross (international)
- Equatorial State Association for the Deaf and Dumb (national)
- South Sudan Human Rights Commission (national)
- South Sudan NGO Forum (national and international)
- United Nations Mine Action Service (international)

Unfortunately, no interviews were conducted with government representatives, including those from the Ministry of Gender, Child and Social Welfare. Although we recognize the importance of local and national government in the provision of services to people with disabilities, and survivors of the 2013 conflict in particular, we were unable to include a larger number of them in the survey. The KII with the South Sudan Human Rights Commission was conducted with a government representative, and is the only government representative. The majority of relevant government stakeholders were either not in Juba, or were unavailable for interviews. The one government stakeholder that was interviewed was the South Sudan Human Rights Commission.

3.2.1.2 Focus Group Discussions (FGDs)

FGDs were conducted by a Forcier researcher of the same gender as the FGD participants and fluent in the prevailing language of each group of participants. Participants were mobilised and recruited based on gender, age and the presence of a disability that resulted in some way from the 2013 conflict, as was agreed upon in the inception report. FGDs focused on topics such as personal narratives of injury and disability, perceived stigma by family and community, experiences accessing and utilising existing services, and identifying gaps in service provision within the community. FGDs were, on average, between two and three hours in length, and focused on the ways in which impairments affected the respondents' quality of life. The quantitative component was designed to gain more insights into how the impairments sustained in the 2013 conflict affected the respondents' access to services. Because the quantitative survey could not be completed, due to conflict in and around Juba, information regarding access to services has been extracted, to the extent possible, from the available qualitative data.

FGD participants were selected using respondent-driven sampling. Handicap International referred primary respondents or seeds to Forcier, and other eligible participants approached enumerators during fielding. These participants then referred another wave of eligible respondents from within their networks, which was especially easy within the POC and Physical Rehabilitation Reference Centre (PRRC). All respondents in this survey were survivors from the 2013 conflict. Several respondents referred to the enumerators by the PRRC were victims of other conflicts, and as such were not interviewed for this study. Researchers and primary respondents were responsible for the mobilization of respondents. Respondents were not selected based on the kind of disability. Instead, people with all kinds of disabilities were welcomed, however, these were not referred to the survey team during fielding. Thus, HI's involvement was limited to the provision of names of the primary respondents or seeds.

3.2.2 Data Analysis

Data analysis was conducted by analysing the qualitative notes taken during the interviews using a variety of methods, including content analysis (see section 4.1). Due to a lack of quantitative data, only qualitative data was analysed. This severely limited the conclusions that could be drawn from the data, as is discussed further in section 3.3.

3.3 Limitations

Quantitative data collection

As explained in the Description of Assessment, the quantitative data collections has not been conducted as planned²¹. After consultation with Handicap International, basic descriptive statistics were derived from the eight FGDs. This data is not typical, as it is not drawn from a sampling frame or via respondent-driven sampling. It is certainly not representative of people with disabilities or survivors in general in South Sudan, since FGD participants were selected on the basis of age, gender, and the presence of an impairment, and FGDs were conducted exclusively in Juba. However, the data do provide information on the causes of impairment, and occupational status and other demographic characteristics of survivors and other people with disabilities. The non-representative nature of the data must be emphasized; nonetheless, in an environment of extremely scarce data, information derived from the FGDs is still valuable. We recommend that a quantitative survey, with a sample drawn via respondent-driven sampling, be carried out in the future, to provide a representative overview of the demographics of people with disabilities.

4 Tracing Post-2013 Disability

This section assesses the situation of disability in South Sudan after the 2013 conflict. It assesses the causes of impairment by looking at the ways in which the conflict caused disability, and zooms in on individual case studies. It also looks at the demographics of disability and highlights if and why certain

²¹ The original proposal included a quantitative element of 120 observations using respondent-driven sampling (RDS), collected with innovative smartphone technology. These 120 interviews were to be carried out in the Juba Protection of Civilians sites as well as the Juba area

groups, mainly men or women, were more affected than others. However, due to the lack of quantitative data, the lack of a representative sample should be kept in mind. For example, it does not take into account differences between minorities, or respondents of different age groups.

4.1 Declared causes of impairment

Of the women and men interviewed in Juba, the majority of men were wounded in direct fighting due to gunfire or artillery shelling. Women reported a wider range of injuries leading to their impairment, ranging from being attacked by unknown gunmen to being injured while running from violence. Across both groups, individuals reported being injured due to mines.

Figure 1 shows the different causes of impairment reported by the 52 respondents in the FGDs by gender. The men who reported impairment as a result of gunshots were mostly involved in direct violent clashes between warring parties, whilst civilian women reported being shot while fleeing. Those who cited illness, disease and injury as cause of their impairment included cases of untreated minor injuries that resulted in complications and eventually, impairment. It also included accidents leading to bone fractures, injuries stemming from beatings and other incidents indirectly related to the 2013 violence. However, as this is not a properly drawn sample, this figure only serves to illustrate limited descriptive statistics, and does not represent the population in the area. This figure illustrates the limitations of the qualitative sample, due to the selection only of respondents with physical disabilities. Beyond the process by which participants were selected, an additional difficulty in qualitative data analysis arises from the nature of note taking within the FGDs. For instance, among respondents who indicated that they sustained an injury from a mine, it was not clear whether the injury was the result of a landmine or ERW. Based on respondents' stated dates of injury – several of which occurred between 2013 and 2015 – at least some respondents' impairments were the result of an accident with a landmine/ERW.

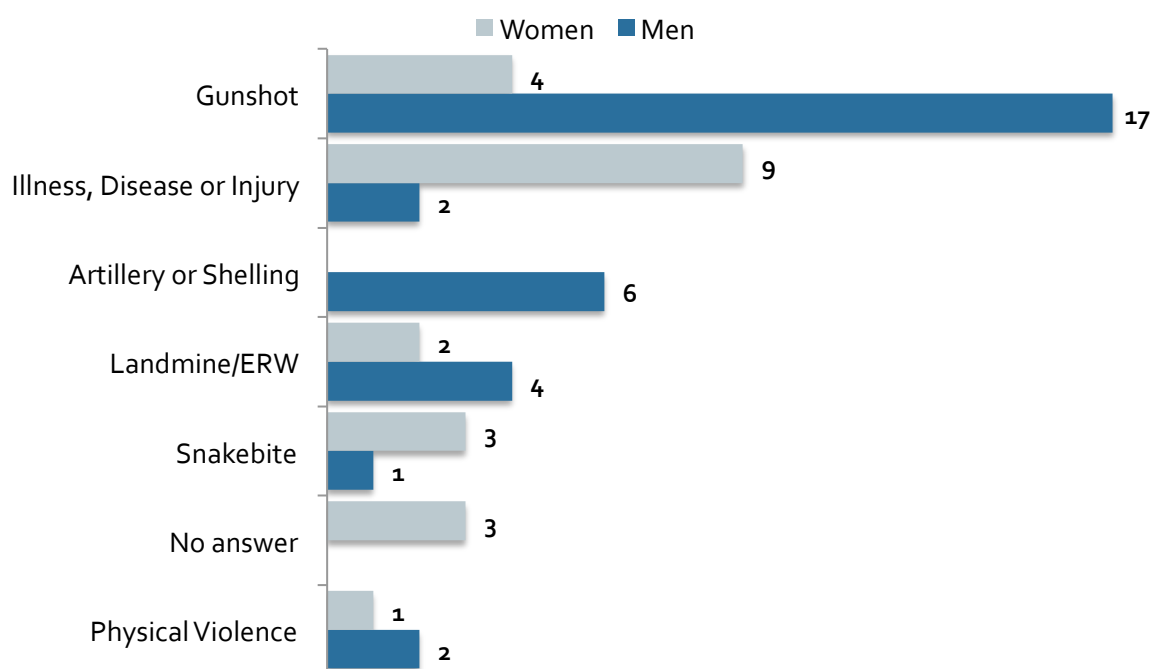


Figure 1 Reported causes for impairment among FGD participants

Female FGD participants reported their disabilities as a result of being shot at by unknown gunmen or stepping on mines.²² Others reported breaking their leg while running, contracting diseases, and blindness.²³ For example, one woman reported being kicked by soldiers in 2013, after which she fell and broke her legs, while another reported falling and breaking her leg while trying to help her child fleeing.²⁴ Snakebites were reported among women who took refuge in the bush or foxholes, and were unable to avoid bites while hiding.²⁵

Although the survey included both male civilians and combatants, the lack of quantitative data prevents any systematic comparison between these two groups, and the attribution of specific characteristics to the two groups. The majority of male respondents reported specific violent incidents during which they were injured. Male combatants were more likely to be disabled as a result of gunshots, artillery or shelling. One government soldier fighting on the offensive stepped on a mine in Athuai in 2014, while another was shot while fighting in Maridi. The Antonov bombing from the Ugandan Defense Forces in Bor in 2014 also led to casualties, as did the fighting between government forces and rebel forces in 2014 in Malakal.²⁶ Male respondents also reported cases of amputation after fighting in Rejaf, Bentiu, Yida and Bor.²⁷ Male civilians reported injuries as a result of fleeing violence, predominantly gunshots to the leg, and associated complications due to lack of treatment. Men reported other incidents, such as being beaten, being burned inside a house, and snakebites, although to a lesser extent than women.²⁸

4.2 Demographics of Disability

Participants in the FGDs were diverse, and included both civilians and combatants, although the qualitative data collection does not allow us to differentiate between civilian and combatant respondents. They came from different ethnicities, speaking many different languages – from Nuer, Dinka, Acholi and Zande to French, Arabic, and Swahili, to mention only a few. Although many of the respondents have never attended school or were only able to attend school for a few years, several male respondents received university-level education. Women reported much lower levels of education in general, with female respondents having either never attended school or only primary school.²⁹ As noted in Section 3.3, the demographic information reported in this section should not be considered representative of the underlying population of people with disabilities; rather, the data is illustrative of the general diversity of people with disabilities.

²² FGD with women 35+, Juba, Munuki, Nyakuron West, 14 June 2016.

²³ FGD with women 25-35+, Juba, Munuki, Nyakuron West, 14 June 2016.

²⁴ FGD with women 35+, Juba, Kator, Jebel Kujur, 14 June 2016.

²⁵ Although several respondents cited impairments resulting from snakebites, it is unclear – based on the available data – the precise impairments which resulted from snakebites. FGD with women 25-35, Juba, Kator, Jebel Kujur, 14 June 2016.

²⁶ FGD with men 35+, Juba, Munuki, Nyakuron West, 14 June 2016.

²⁷ FGD with men 25-35, Juba, Munuki, Nyakuron West, 13 June 2016.

²⁸ FGD with men 25-35, Juba, Kator, Jebel Kujur, 13 June 2016; FGD with men 35+, Juba, Kator, Jebel Kujur, 14 June 2016.

²⁹ Unfortunately, more precise demographic data, including on literacy rates, is not available. The qualitative research tools did not capture literacy of FGD participants.

Figure 2 shows that employment types for women can be divided into two categories: unemployed or self-employed. Men, on the other hand, reported a wider range of employment statuses. Male respondents who reported being self-employed ran, for instance, small businesses like corner stores, while women also ran small businesses, selling goods on the street, or were unemployed. Male respondents included retired soldiers, teachers, farmers, boma chiefs and guards.³⁰

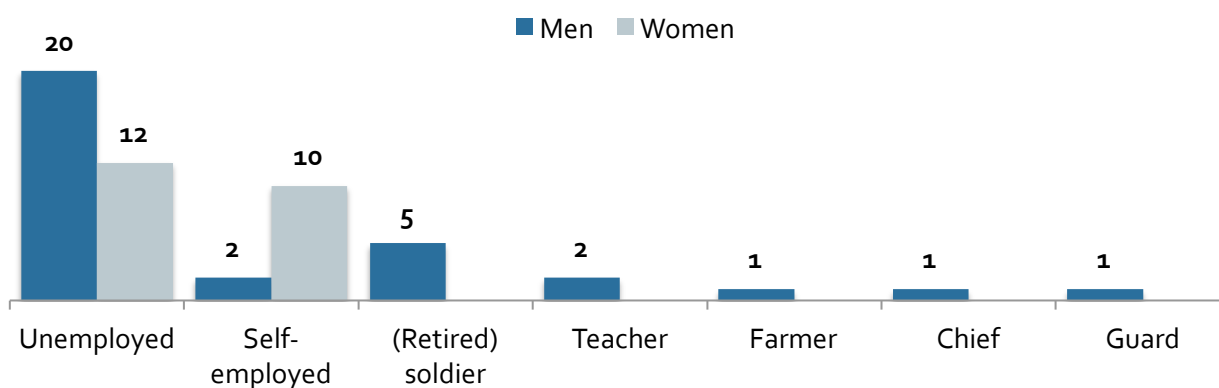


Figure 2 Employment status of FGD participants

5 Impact of Disability

This section provides an overview of the impact that disability has had on the respondents. It analyses the perspectives of international stakeholders and the survivors and other people with disabilities, and points out any discrepancies between the two. While international stakeholders strongly focus on the need for policy action and legal frameworks, survivors and other people with disabilities stress the need for more resources, services and training that will enable them to live a fulfilling life despite their disabilities.

5.1 Perspectives of Stakeholders

This section analyses the perspectives of key stakeholders or national and international organizations providing services for people with disabilities on the impact of impairments resulting from the 2013 conflict. For this section, the qualitative data collected from the nine KIIs was analysed. Interviewees were asked about the programmes and services their organisations offered, the identification of people with disabilities and their inclusion in the community, and the collaboration with other stakeholders, such as government representatives. Stakeholders reported different ways of reaching out to communities and people with disabilities, while also actively engaging with communities to raise awareness and convey the needs and rights of people with disabilities. Also, international stakeholders strongly emphasised the need for government action, predominantly in terms of policy creation and legal frameworks to enable a stable environment to address the needs of people with disabilities. In particular, this includes the implementation and enactment of the National Disability and Inclusion Policy.

³⁰ In South Sudan, a boma refers to a small village.

5.1.1 *Services Provided*

The organisations offered a range of programmes and services across South Sudan for people with disabilities. For example, the Union for the Physically Disabled focuses on raising awareness among communities about the needs of people with disabilities, uniting people with disabilities, advocating on their behalf and providing them with education, including both reading and writing skills and vocational training.³¹ Another provides humanitarian assistance such as water, sanitation and hygiene, protection and education, but specifically focuses on tracking and identification of people with disabilities for the purpose of service provision.³² Another interviewee mentioned that, among humanitarian demining (surveying and mapping mines and ERW, marking and clearing), there are livelihood and peacebuilding activities that their organisation carries out. They developed an inclusion package within their livelihoods programme for people with disabilities that is implemented with other international stakeholders and national government. They also attempt to carry out a baseline survey to map the needs of people with disabilities in South Sudan and assess the needs of people with disabilities in different communities.³³ During the KII, several interviewees elaborated on the services they provided for people with disabilities. This includes the provision of assistive devices like crutches, wheelchairs and prosthetics, as well as social services.³⁴

When asked about the identification of people with disabilities and their needs, organisations operated differently. One organisation relies on people with disabilities to reach out to them following their awareness-raising activities. After assessing their needs, this actor assisted people with disabilities with job placements and livelihoods.³⁵ Another organisation relies on the referral of other NGOs or actors on the ground. People with disabilities are then prioritized based on a medical examination of the type and severity of their impairment.³⁶ A third stakeholder relies on radio campaigns, after which community-based rehabilitation workers reach out to people with disabilities within the community. The field personnel assess the needs through personal observation and by engaging with the people with disabilities and their families.³⁷ The majority of organisations relied on baseline surveys, community outreach in remote areas and liaising with local community entities such as church leaders, chiefs and community leaders and other volunteers. Outreach is also done through seminars and workshops. The needs of people with disabilities are then prioritized based on characteristics such as education level and gender.

5.1.2 *Community Inclusion*

The international stakeholders also indicated specific ways in which they include people with disabilities in the community. The majority of interviewees provide education, health services and employment to people with disabilities, although many challenges are also cited, including “not enough funding and no salary (for service providers),” and that there should be more “(positive) discrimination towards people with disabilities.”³⁸ Another interviewee provides training to internal staff to be more respectful of the needs of people with disabilities, but cited the “lack of partners in victim assistance, lack of resources,

³¹ KII with NGO Staff, Central Equatoria, Juba, Juba, Mobil, 13 June 2016.

³² KII with NGO Staff, Central Equatoria, Juba, Munuki, Tongping, 14 June 2016.

³³ KII with NGO Staff, Central Equatoria, Juba, Munuki, Tongping, 17 June 2016.

³⁴ KII with NGO Staff, Central Equatoria, Juba, Munuki, Nyakuron West, 17 June 2016.

³⁵ KII with NGO Staff, Central Equatoria, Juba, Juba, Mobil, 13 June 2016.

³⁶ KII with NGO Staff, Central Equatoria, Juba, Munuki, Nyakuron West, 17 June 2016.

³⁷ KII with NGO Staff, Central Equatoria, Juba, Juba, Juba, 20 June 2016.

³⁸ KII with NGO Staff, Central Equatoria, Juba, Juba, Mobil, 13 June 2016.

limited access to disabled persons and ignorance” as the largest challenges.³⁹ Although another interviewee addresses the most vulnerable in society by focusing on people with disabilities within gender and diversity mainstreaming activities, they described their main challenge as the high expectations of the communities and the vast needs of people with disabilities.⁴⁰

Overall, the interviewees have all implemented some form of community disability awareness raising activities to enhance the inclusion of people with disabilities in the community, although more should be done for non-specialist NGOs and local government. One interviewee said that the challenges they faced were multiple:

“We face inadequate funding, and South Sudan has no legal framework to protect the rights of persons with disabilities. There is not enough knowledge of an inclusive education system.”⁴¹

Another interviewee raised the issue that although they had developed a tool to assess the capacity of their partners to successfully address the needs of people with disabilities; they had difficulty convincing their partners to subscribe to it.⁴²

The KII also inquired about the ways in which international stakeholders identify national partners such as local NGOs, government officials and community leaders, and if and how they cooperate with the government. Stakeholders are identified on the ground and through grassroots assessments, and the interviewees mentioned collaboration with a broad range of humanitarian actors including UN agencies, civil society organisations and many other international NGOs. Collaboration with the GoSS is fairly limited. There is great need for formal policy and legal frameworks, and, in particular, for the ratification of the UN Convention on the Rights of Persons with Disabilities. One employee from an NGO stated:

“I don’t think the government has any vision. The government hasn’t prioritised the victims of war or people with disabilities.”⁴³

Another NGO employee said, “We need policy that can guide the rights of persons with disabilities. The government needs to sign and ratify the UN Convention on the Rights of Persons with Disabilities.”⁴⁴ Besides the UN Convention, stakeholders also emphasised the need to:

“Sign and ratify the National Disability and Inclusion Policy, so that these two instruments can provide and deliver services to persons with disabilities. People with disabilities must also be represented at all levels of government, and the government must provide funding for programmes addressing the needs of people with disabilities.”⁴⁵

³⁹ KII with NGO Staff, Central Equatoria, Juba, Munuki, Tongping, 17 June 2016.

⁴⁰ Idem.

⁴¹ KII with NGO Staff, Central Equatoria, Juba, Juba, Juba, 20 June 2016.

⁴² Unfortunately, no additional information is available on the tool or the interviewee’s attempts. KII with NGO Staff, Central Equatoria, Juba, Juba, Juba Town, 24 June 2016.

⁴³ KII with NGO Staff, Central Equatoria, Juba, Munuki, Nyakuron West, 17 June 2016

⁴⁴ KII with NGO Staff, Central Equatoria, Juba, Munuki, Tongping, 17 June 2016

⁴⁵ KII with NGO Staff, Central Equatoria, Juba, Juba, Juba, 20 June 2016.

The need for policy development was stressed on multiple occasions, as “the government needs to put in place laws that create an enabling environment for people with disabilities. It should also invest in institutions that provide services to people with disabilities.”⁴⁶

The interviews with international stakeholders highlight the ways in which the different types, severity and number of disabilities they encounter has changed since the 2013 crisis, and how this has impacted their service delivery. The conflict has led to an overall increase in people with disabilities who need special assistance. There is a lack of social service provision such as (trauma) counselling, rehabilitation, community integration and reintegration, as well as medical supplies, which means that “the GoSS and NGOs need to put much more effort into the rehabilitation of people with disabilities,” despite the deterioration of security, political instability and insufficient funding.⁴⁷ The conflict has also increased the number of vulnerable people, which now includes young girls who are increasingly forced into marriage and theft. The 2013 conflict led to an explosive increase in the demand for basic services for people with disabilities, such as food, water and clothing - as well as social support such as counselling, medication, life support and mobility aids such as crutches, prostheses, and wheelchairs.⁴⁸ The scale of overall need increased so rapidly that it has been extremely difficult for existing organisations to keep up. Stakeholders are struggling to relocate funding for the construction of facilities and the provision of services.

5.2 Perspectives of Survivors and other People with Disabilities

The following section analyses survivors’ perceptions of the social and economic impacts of their impairment, including stigma and access to services. The FGDs included questions in two sections relevant to the perceived impact of the impairment on respondents’ personal lives: the perception of people with disabilities in society and community as per their personal experience. Survivors were often confronted with negative perceptions in their communities, sometimes even among their own families, which led to social isolation and loneliness. Overall, survivors struggled with the impact of their impairment on their place in society, especially in terms of their capacity to care for their families and their economic independence.

5.2.1 Family Life

Respondents reported a range of different, although overwhelmingly negative experiences within their families and communities regarding their disabilities. Survivors and other people with disabilities reported both negative and positive perceptions of people with disabilities among their families and communities. Disabilities are often viewed with superstition or explained with religious motives.

When respondents were asked about what sorts of perceptions members of their household had about people with disabilities, God and witchcraft arose as common themes: suggesting that a person’s impairment might be “God’s will or making” or that “disability is a result of bad omens and bad deeds, that I had done witchcraft.” As another participant reported:

⁴⁶ KII with NGO Staff, Central Equatoria, Juba, Juba, Juba Town, 24 June 2016.

⁴⁷ KII with NGO Staff, Central Equatoria, Juba, Munuki, Tongping, 17 June 2016.

⁴⁸ KII with NGO Staff, Central Equatoria, Juba, Munuki, Nyakuron West, 17 June 2016.

"They think that people with disabilities might be involved in wrongdoings like witchcraft or theft that led to their disabilities, or maybe the disabled are witches."⁴⁹

The lack of quantitative data makes it difficult to look for possible correlations between respondents that reported these negative experiences involving witchcraft and divine intervention, and the types of impairment they face. While some respondents mentioned this, others reported being welcomed by their families, who reportedly said sympathetic things like: "people with disabilities shouldn't be neglected, but looked after," and "they pity and have mercy for people with disabilities, and are sometimes helpful."⁵⁰

Women appear to note more positive receptions than men, suggesting, that their families do not have any problems with people with disabilities: "my family considers me a human being like them and any other, and people with disability are important to them."⁵¹

Some said "they have positive perceptions and consider it as something normal about persons with disability." Female respondents generally reported that they were respected by their family, saying "they respect people with disabilities because they understand that it is an accident," "they always encourage people with disabilities," and "my household and family members respect me."⁵²

Respondents who did face negative responses by their family members often blamed negative perceptions on ignorance and a lack of understanding of the people around them. They described feeling worthless, and described feelings of being a burden on their families since they were unable to contribute to the household. Some said: "they look at me as a person with no benefit," and "they don't bother with people with disabilities, they think it is a burden for them."⁵³

These perceptions also impact their interactions with others; people with disabilities often feel embarrassed and have difficulty interacting with people around them. However, there were also exceptions. Some reported not being embarrassed since they did not blame themselves for their disabilities.⁵⁴

5.2.2 Community Perceptions

Respondents also reported that their impairments led to a lower social status within their communities. They reported not being taken seriously in their communities or being considered to be contributing less than others: "they look at me as a useless person due to my disability," and "they ignore my ideas in family issues mostly because of my disability."⁵⁵ Others reportedly faced isolation and active insult, as "people usually insult me and isolate me so I can't associate with them,"⁵⁶ while another said:

⁴⁹ FGD with men 35+, Central Equatoria, Juba, Munuki, Nyakuron West, 14 June 2016.

⁵⁰ FGD with men 25-35, Central Equatoria, Juba, Munuki, Nyakuron West, 14 June 2016.

⁵¹ FGD with women 35+, Central Equatoria, Juba, Munuki, Nyakuron West, 13 June 2016; FGD with women 25-35, Central Equatoria, Juba, Munuki, Nyakuron West, 14 June 2016.

⁵² FGD with women 35+, Central Equatoria, Juba, Munuki, Nyakuron West, 13 June 2016; FGD with women 25-35, Central Equatoria, Juba, Munuki, Nyakuron West, 14 June 2016.

⁵³ FGD with men 35+, Central Equatoria, Juba, Kator, Jebel Kujur, 14 June 2016.

⁵⁴ FGD with men 35+, Central Equatoria, Juba, Kator, Jebel Kujur, 14 June 2016.

⁵⁵ FGD with men 25-35, Central Equatoria, Juba, Kator, Jebel Kujur, 13 June 2016.

⁵⁶ FGD with women 25-35, Central Equatoria, Juba, Kator, Jebel Kujur, 13 June 2016.

"Sometimes people feel exhausted when they interact with me because they think I am disturbing them when I ask for help."⁵⁷

Respondents also shared their most significant experiences living with their disabilities, which were predominantly negative. They described instances in which they were insulted, laughed at, hurt by children throwing stones at them while queuing for food relief, publicly discriminated against, gossiped about, suspected of theft, abused by people who knew they were unable to defend themselves, and abused by spouses and neighbours. In only one case was a respondent's most significant experience positive, when he reported that:

"One time when I was in a taxi, I tried to pay, and one passenger told me not to pay, and he paid for me."⁵⁸

As such, the data suggests that although it is predominantly negative, there are some other experiences. Further quantitative research would allow investigating whether there are significant differences in these experiences across people with different disabilities, or across men and women of different ages and income groups.

5.2.3 Livelihoods

People with disabilities have also experienced significant economic impacts on their lives due to their impairments. FGD participants were asked about the ways in which their lives have been affected by their impairment, and all agreed that their lives were better prior to becoming disabled. The most significant impact has been the loss of livelihoods and employment. Many respondents manage to make a small income doing a variety of jobs, and use this to support their children and extended families.

Male respondents reported that their disabilities impacted their ability to care for spouses and family members, which has led to their wives leaving them and "economically you resort to begging for money as you can't work on your own," and "amputation has made me unable to perform my old job as a mechanic."⁵⁹ The disabilities have left them without sources of income, as they are unable to walk or run as they used to, often are unable to drive, and cannot afford money for transportation. Women reported similar economic impacts due to their impairment, being jobless without any way to earn money. Women lost the small ways they had to make a living, which included selling tea in the market, working as a household worker, or working as a tailor.

Living with disabilities has also impacted the respondents' social and daily lives. They report being confined to their homes, unable to participate in community and social events and instead sitting at home, performing small household chores such as taking the children to school, cooking, washing clothes and fetching water, and passing time by listening to the radio, going to church, and in some cases, attending adult school. Both male and female respondents described losing many friends, as

⁵⁷ FGD with women 25-35, Central Equatoria, Juba, Kator, Jebel Kujur, 13 June 2016.

⁵⁸ FGD with men 35+, Central Equatoria, Juba, Munuki, Nyakuron West, 14 June 2016.

⁵⁹ FGD with men 35+, Central Equatoria, Juba, Munuki, Nyakuron West, 14 June 2016.

they cannot go out and play football, or attend parties. One man said, "I cannot dance at the cultural day anymore like before."⁶⁰ While most respondents report a sense of idleness, one woman said:

*"No one is taking good care of me. I am just living my life by God's grace until my death."*⁶¹

This particular quote illustrates the need for not only programming geared towards creating livelihoods for people with disabilities, but also for psycho-social counselling and community sensitization so that people with disabilities can be reintegrated into their communities.

5.3 Differing Perceptions

This section provides a comparison of the perceptions of national and international organisation, and that of survivors and other people with disabilities in terms of the perceived impacts of disability, and the way NGOs address them. Although they largely overlap, there are some noteworthy differences, primarily in the area of emphasizing the importance of policy and legal frameworks.

Table 1: Comparison of perceptions of survivors and other people with disabilities and interviewed stakeholders

Topics	Survivors and other people with disabilities	Stakeholders
Main Impact	The main impact is economic . Loss of source of income and livelihoods is the most significant impact	Address economic impact with job placement and employment programming, including trainings
Awareness	Negative community perceptions hinder the inclusion of people with disabilities	Focus on community outreach to inform communities about the needs and rights and people with disabilities and address stigma
Policy	This is not considered a priority by the respondents	Focus strongly on advocacy and lobbying with local and national governments

There is a strong-shared understanding that the main impact of disabilities is the disappearance of a source of income and the loss of livelihoods. Survivors and other people with disabilities repeatedly mentioned the loss of their ability to make a living and support their families as the main economic impact, while national and international stakeholders have included job placement, employment and training schemes in their programming. However, very few respondents mentioned attending these schemes or adult education as a part of their daily lives, which suggests that increased outreach in this area is necessary.

Both international and national stakeholders and survivors and other people with disabilities emphasize the need for raising the awareness of the community on issues related to disability. The negative perceptions that dominate the community are obstacles to the inclusion of people with disabilities in their communities, and require substantial outreach efforts. Informing communities of the needs of

⁶⁰ FGD with men 25-35, Central Equatoria, Juba, Kator, Jebel Kujur, 13 June 2016.

⁶¹ FGD with women 35+, Central Equatoria, Juba, Munuki, Nyakuron West, 13 June 2016.

people with disabilities and addressing the stigma surrounding disabilities is essential to advance the inclusion of people with disabilities and survivors who became impaired as a result of the 2013 conflict.

A noticeable difference between the (inter)national stakeholders and survivors and other people with disabilities is the emphasis put on policies and legal frameworks by international stakeholders and NGOs, which is not a prominent issue for survivors and other people with disabilities. Instead, the latter focus on the services and support to which they have access (see Section 6). However, they were not explicitly asked about the assistance they receive from the GoSS or local authorities.

6 Impact Mitigation

This section discusses the different ways in which the impact of disabilities on peoples' daily lives is mitigated. Specifically, it looks at the existing assistance provided by different stakeholders, the gaps in that assistance, and where currently the greatest needs are. Based on the findings in this section, we suggest actionable recommendations to inform future programming.

6.1 Services – Availability and Access

This section describes the existing services and programmes to which people with disabilities have access, for the purposes of mitigating the impact of impairments on their daily lives.⁶² In addition to the information provided by international stakeholders and NGOs in the KIIs and synthesised in section 5.1, FGD participants were also asked about their access to services. Overall, assistance is available in the areas of healthcare, education and transport, but in most cases it is insufficient, as it does not meet all the needs of survivors and other people with disabilities. This assistance is also generally difficult for them to access. People with disabilities are confronted with challenges when attempting to access these services, which often include not having transportation to reach the hospital or clinic, long waiting times once they arrive there, and inability to afford medication. Considering the limitations of this study, further research is advisable to more comprehensively map the current availability of assistance and services.

FGD participants were asked about their access to health facilities and responded that they have access to a broad range of different hospitals. These included hospitals in POC sites; military sites such as Giada Military Hospital; and hospitals run by NGOs such as the International Medical Corps, MAGNA, Norwegian People's Aid hospital in Yei, the Médecins Sans Frontières hospital, and UNICEF hospitals in Ajuongtok and Yida.

Although and other people with disabilities survivors can access medical facilities, they face significant challenges related to the services received in hospitals and clinics. The challenges include a lack of adequate medical personnel, especially the limited number of specialists who can treat certain disabilities; the shortage of medications available in hospitals; long lines and queues in the hospitals; and not having enough money to purchase medication.

⁶² Importantly, this section does not provide a comprehensive overview of all available services that people with disabilities might theoretically access. Rather, it provides FGD participants' perceptions of the availability of, and their access to, services.

FGD participants were also asked about what kinds of services and assistance were difficult to access or not available. Both male and female respondents describe having access to medical equipment such as crutches, wheelchairs, and bandages. However, the availability of prosthetics, particularly artificial arms and legs, varied strongly. Participants pressed the fact that access to medication also varied.

Respondents reported accessing medical care in hospitals more often than education services. Those who do report accessing education services do so at adult schools in POC sites and schools run by NGOs, such as the Society of Daughters of Mary Immaculate and Collaborators and other church organisations. Technical support, such as vocational and computer training, was described as difficult to access or obtain.

FGD participants were asked about the transportation challenges they faced in accessing health and education services. Interviewed survivors and other people with disabilities reported that the most frequently used modes of transportation were by foot, public or UN transport and, in a few cases, with the assistance of relatives. Poor infrastructure, such as unhardened roads into Juba, makes it difficult to access services--especially during the rainy season. Transportation fees were described as expensive, and too expensive when combined with medication costs.

Respondents were provided with non-food items (such as clothes, mosquito nets, furniture, torches, radios, jerry cans, blankets, plastic sheets and tents) but access to services which provide basic needs items was described as insufficient. One respondent said, "Only some basic needs items are available to us, such as some soap and some medication, but it is not enough."⁶³ A lack of nutritious food and milk was also highlighted. Although people with disabilities were provided with water and food assistance, this was often found to be insufficient to meet their needs.

The following section provides a more in-depth overview of the kind of support that respondents feel they need, but which they are currently lacking.

6.2 Broader Gaps in Service Delivery

This section analyses the remaining gaps in terms of impact mitigation, and discusses challenges that both people with disabilities and service providers face. It discusses issues such as access to services or barriers to socio-economic advancement. The existing gaps in assistance are mainly due to an overwhelming demand on very limited resources, while the supply side is unable to keep up and meet all the needs. Service delivery is challenged as a result of on-going insecurity and political instability, and a lack of government action. NGOs remain the primary service providers, with few encouraging signs from the GoSS that they are prepared to take over that role in the near future. As such, NGOs also face operational challenges including a lack of funding. However, considering the substantial limitations of this report due to the lack of quantitative observations, more concise and in-depth mapping of the needs of people with disabilities and related services is advisable.

During the FGDs, participants stressed the need for programming to address the economic impact of their disabilities, as these often led to a complete loss of livelihoods and economic independence. They also highlighted other specific gaps in services, mentioning services they needed but were unable to

⁶³ FGD with women 25-35, Central Equatoria, Juba, Munuki, Jebel Kujur, 14 June 2016.

access, or which were not available to them. Some participants also mentioned language barriers that prevented or impeded access to services.

Assistance that was considered difficult to access or sometimes unavailable included financial assistance and housing, as “housing is difficult to find since rent is becoming too expensive in Juba, it is difficult to access money and it is hard to get a job.”⁶⁴ However, monetary assistance is considered by far the most difficult to access. While limited access to education is also cited, others mentioned the lack of WASH facilities like adapted latrines and toilets, or appliances and tools to be able to run small businesses, like sewing machines and wheelbarrows. However, smaller things that could be easily addressed by improving coordination with humanitarian actors on the ground were also mentioned. For example, respondents highlighted a lack of nutritious food and milk.

Although NGO staff provide a range of services to survivors and other people with disabilities, including livelihoods, education and rehabilitation, there are several noticeable gaps in service provision and numerous obstacles that prevent offering these in an accessible manner. Throughout South Sudan, mental health issues remain stigmatised. Although trauma counselling has proven to be very helpful, some stakeholders indicated a need for more psychosocial support. Although community-wide sensitisation has been helpful in changing the attitude of people towards people with disabilities, the impact is limited due to the lack of lobbying and advocacy at the most local levels. Stakeholders have therefore suggested including these efforts at the boma level, such as forming local governance committees in the communities where people with disabilities are included. Accessing the most vulnerable people in remote places is – unsurprisingly – difficult, considering the insecure areas service providers must travel through or work in. People in rural areas are difficult to reach, meaning they are a vulnerable sub-group who must be reached with additional outreach efforts.

In the FGDs, participants were also asked about what kind of support they feel that people with disabilities should receive, and who the best people or organisations would be to provide this support. They were also asked which types of support they would ideally want to have, and why this is important to them as a group and as an individual. When asked: “What kind of support do you feel that persons with disabilities should have/need?” financial and monetary assistance was mentioned most often, closely followed by medical equipment including crutches, prostheses, and wheelchairs. Other frequently mentioned support included basic needs such as food, soap, mosquito nets and bed sheets, alongside technical support and vocational or educational training.

Participants were then asked which people or organisations they felt would best provide that support. UN agencies such as UNICEF, UNHCR, WFP and WHO were mentioned most frequently, while Handicap International was the NGO mentioned most often. Other NGOs included Oxfam and World Vision. The national government was mentioned only a few times. Further research into this could possibly explain the low levels of confidence that people with disabilities have in the GoSS.

This assistance and support is important to people with disabilities for a number of reasons such as being able to care for children and family, and being able to do things alone so that they can live their daily lives in a meaningful manner. Participants also expect that this kind of support will give them full rights as people with disabilities and become less dependent on others.

⁶⁴ FGD with men 25-35

Overall, the gaps in existing assistance stem from two sources. First, South Sudan faces overwhelming demand for assistance to survivors and other people with disabilities. Even prior to the 2013 conflict, the GoSS was unable to adequately respond to the needs of survivors and other people with disabilities. As a result of the 2013 conflict, there has been a huge increase in the number of people with disabilities in South Sudan, exacerbating the government's shortcomings in support. Second, the sector providing services to people with disabilities is run almost entirely by international stakeholders and NGOs, on which people with disabilities are completely dependent for basic services. As a result, NGOs are often able to provide only the bare minimum or focus on a narrow programme such as rural outreach or job placement, instead of establishing a holistic approach. For example, this means that while an NGO might be able to provide prosthetics such as artificial limbs, they are less able to provide long-term follow-up such as rehabilitation services and physical therapy.

6.3 Suggested Action Points

This section provides practical recommendations to mitigate the impact of disabilities on people's lives in future programming. Action points in the area of policy, programming and assistance have been suggested on the basis of qualitative data collected in June 2016. Our recommendations are tempered by the lack of quantitative data, preventing us from providing extremely tailored recommendations that might have been possible with richer data. For instance, quantitative data would have allowed us to assess differences in access to services across demographic groups, provided additional insight into what specific services or assistive devices were missing, and where respondents were currently receiving services.

The GoSS should take a larger role in providing services for survivors and people with disabilities.

International stakeholders have all emphasised the need for a larger role, political will and commitment from the GoSS. This goes beyond the GoSS acting as the primary service provider – a gap that is likely to remain to be filled by NGOs and other non-governmental actors, considering the very limited capacity and resources of the GoSS. Actionable steps that the GoSS can take are in the area of signing, ratifying and enacting international conventions on the rights of people with disabilities, and creating national legal frameworks to give people with disabilities a designated space in national policies. To achieve this, more coordinated and structured lobbying and advocacy is necessary, starting at the boma level. Considering the stalemate on the national level on these issues, advocacy on the community level is likely to be most helpful. As such, advocacy at this level, including bomas and payams, is most likely to affect change, particularly if attention is focused on areas with particularly high numbers of people with disabilities. In the long-term, a handover of service provision from NGOs to the GoSS is envisioned. To this end, HI could – in the long-term – focus future programming on advocacy efforts on the national level, as well as lobbying on the very local. It could also target broader capacity building and infrastructure enhancing efforts within the public health care sector so that an eventual handover in the future may be expected.

Service provision must go beyond the basics. For example, the provision of prostheses should go hand in hand with broader rehabilitation services such as physical therapy. Considering the substantial logistical challenges that people with disabilities face in accessing these services, they should be combined with some kind of transport initiative since facilities remain difficult to reach, especially in the rainy season.

A greater focus on psycho-social counselling and trauma healing. The stigma surrounding mental health issues in South Sudan remains substantial. The limited mental health support that has been provided has proved to be very helpful in changing the coping ability of survivors and people with disabilities who sustained their impairment as a result of a traumatic injury or a disabling disease. Considering the social stigma and isolation of people with disabilities in their communities, attention to mental health should remain high on the agenda and is currently insufficiently prioritised.

Increased outreach to the most vulnerable groups. Poor infrastructure and the rainy seasons make remote communities in rural areas among the most vulnerable groups in South Sudan. They often lack the resources to access facilities in the closest large town where specialised services for people with disabilities are provided. As such, it is advised that future programming includes logistical support in outreach efforts. For example, transportation assistance could be provided in coordination with other humanitarian actors, or clinics and hospitals frequented by program beneficiaries, survivors and other people with disabilities. Other possibilities include community-based rehabilitation and mobile clinics.

Prioritise addressing the economic impact of disabilities. Future programming should be geared towards addressing the economic needs of survivors and other people with disabilities – beyond direct monetary assistance. The majority of interviewees reported feeling frustrated and useless due to their inability to contribute in an economically meaningful way to their households and families. They not only requested education and vocational training, but also suggested small tools and instruments that would allow them to become economically independent. For example, multiple FGD participants described their need for sewing machines so they could work as independent tailors. Not only would this address the concrete and real need for livelihoods, but this would also be valuable in restoring self-value and social standing within communities.

The social impact of disabilities must be addressed in programmatic activities. Disabilities have a tremendous impact on the social lives of people with disabilities in their communities. This can be addressed by including specific action points in community outreach and sensitization programmes. For example, forming community-level committees with designated seats for representatives from the population of people with disabilities is an active way of including people with disabilities at the local level. Social stigma preventing social inclusion can be addressed by informational campaigns. These campaigns can remove social stigma in communities and can have large impacts at a small cost. Some NGO stakeholders already broadcast radio programs as part of their community outreach, but if HI or other organisations focusing on people with disabilities partner with other actors on this topic, awareness-raising activities regarding disabilities can be included in their existing programs at a low cost. This could also be in the form of inclusive sports, leisure and cultural activities.

7 Conclusions

The 2013 conflict in South Sudan led to an increase in the number of survivors of violent conflict and other people with disabilities, especially those dealing with impairments resulting from a range of sources, including mines, direct violence, and other injuries. This has not only resulted in physical challenges in their daily lives, but also mental trauma, and social isolation as survivors and other people with disabilities and their needs are regularly ignored in society. More speculatively, political exclusion appears to represent an additional challenge for survivors and other people with disabilities. This

situation assessment is a first step in the direction of comprehensively mapping and addressing the needs of people with disabilities in South Sudan. By tracing post-2013 disability, the impact of disability and impact mitigation, the report assessed the situation and provided recommendations for future programming.

Considering the lack of quantitative information, descriptive statistics were inferred from the 52 male and female FGD participants. The majority of men in the sample reported being injured as a result of gunshots, usually due to involvement in direct fire and violence as a soldier. Women reported their impairments were caused by other reasons, including (but not limited to) untreated illness and disease contracted while fleeing and that eventually led to disability. Both men and women reported impairments resulting from mines. The majority of respondents did not receive high levels of education, although men reported to have completed more years of education than women. Women also reported being unemployed or being self-employed as business owners, while men reported professions including teachers, business owners and farmers. As such, men with disabilities are likely to be economically more independent than women with disabilities, making the women more vulnerable.

A comparison of the perspectives of international stakeholders and survivors and other people with disabilities allowed for an assessment of the impact mitigation. Both survivors and other people with disabilities and stakeholders emphasize the economic impact of their impairments, as this often led to a loss of income and livelihoods. Survivors and other people with disabilities also shared how negative community perceptions proved to be obstacles to their social inclusion, which stakeholders also address with community awareness raising programs. The two groups differed most on the importance placed on policy and legal frameworks. While this was not a priority for survivors and other people with disabilities, stakeholders focused strongly on this. The assessment found that although international stakeholders provided a wide range of services to fill the service gap, many elements were missing. KIs highlighted the specific activities NGOs undertook to address the needs of people with disabilities, which ranged from providing medical equipment to community outreach and awareness-raising activities, and from training to improve livelihoods to tracking and identifying people with disabilities. However, their assistance was often hindered by the lack of partners in this area, limited access and ignorance. Most importantly, South Sudan lacks policies and a legal framework to protect the rights of people with disabilities. With limited cooperation with the GoSS, there is a heavy dependency on international stakeholders to fulfil the needs of people with disabilities.

Survivors and other people with disabilities emphasized the social and economic impact the impairment has had on their lives. They faced negative perceptions in their communities and families, rendering them unable to participate in social events, which often resulted in extreme loneliness and isolation. The inability to provide and take care of their families was seen as especially painful, as were the assumptions that disabilities resulted from witchcraft or divine punishment. In very few cases, respondents reported positive experiences while living with disabilities, as their community recognized that the disability often resulted from an accident.⁶⁵ Survivors and other people with disabilities did not mention the lack of policies and legal frameworks in South Sudan – an issue that was prominent in discussions with international stakeholders.

Although healthcare, education and transport assistance was available to survivors and other people with disabilities, it was considered insufficient and constricted. People with disabilities predominantly

⁶⁵ Unfortunately, the small and non-random sample of FGD participants does not allow us to draw conclusions about variation in community reactions or individual experiences living with a disability across types of impairments.

accessed military hospitals and hospitals and schools run by NGOS. When accessing them, people with disabilities faced challenges such as long waiting times and insufficient medication – issues that arose from the overwhelming demand for specialized care but limited supply. Although most basic needs items were available, the most difficult to access services were financial support and technical and vocational training, both which are needed to develop economic independence and livelihoods.

Overall, service delivery was challenged by the on-going insecurity and political instability in South Sudan as well as funding issues for NGOs. Social stigma is still dominant in many areas, despite widespread activities that raise awareness about disability. Psycho-social and trauma counselling remain the most difficult to access service while survivors and other people with disabilities believe that the main gaps in assistance are financial, followed by medical equipment. Due to the previously mentioned issues, NGOs are usually only able to provide life-saving and immediate assistance, and less able to provide long-term specialist care for people with disabilities.

To mitigate the impact of disabilities in the future, several strategic action points were recommended. First, the GoSS should take a larger, more pro-active role in service-delivery for people with disabilities, while service provision overall must go beyond the basics, including a greater focus on psych-social counselling and trauma healing. Secondly, international stakeholders and the government should systematically address the economic impact of disabilities, as this is closely linked to the social impact of disabilities. Addressing this will allow survivors and other people with disabilities to become more independent, regain confidence and allow for community inclusion and participation. Lastly, it is recommended that, considering the lack of quantitative data for this report, a quantitative survey is conducted to more precisely inform future programming.

Forcier

Forcier is a development research firm that operates in challenging post-conflict environments. Established in 2011 in South Sudan, Forcier has invested in developing methodologies and approaches to research that are contextually appropriate and feasible, whilst adhering to international standards for social science research and utilising the latest data collection technology available. Our core services include population and social science research, project evaluations, market assessments for livelihoods and vocational trainings, private sector and market research for feasibility studies, strategic planning and representation, and training and capacity building workshops.



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