



# THE **FORGOTTEN**

AN INFORMATION ECOSYSTEM  
ASSESSMENT FOR PEOPLE WITH  
DISABILITIES IN SOUTH SUDAN



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# LIST OF ACRONYMS

<b>ADRA</b>	Adventist Development and Relief Agency
<b>AYR</b>	Advance Youth Radio
<b>CEN</b>	Community Engagement Network
<b>CES</b>	Central Equatoria State
<b>CPA</b>	Comprehensive Peace Agreement
<b>CPJ</b>	Commission for the Protection of Journalists
<b>HI</b>	Humanity and Inclusion
<b>FGDs</b>	Focus Group Discussions
<b>ICAP</b>	International Centre for AIDS Care and Treatment Programs
<b>IEA</b>	Information Ecosystem Assessment
<b>KIIs</b>	Key Informant Interviews
<b>MOH</b>	Ministry of Health
<b>NSS</b>	National Security Services
<b>OPD</b>	Organisations of People with Disabilities
<b>RSF</b>	Reporters Sans Frontiers

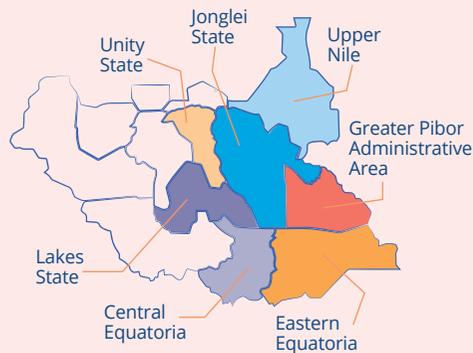
<b>RiT</b>	Rooted in Trust Phase
<b>SSBC</b>	South Sudan Broadcasting Corporation
<b>SSNA</b>	South Sudan News Agency
<b>SSTV</b>	South Sudan Television
<b>TRC</b>	The Radio Community
<b>TV</b>	Television
<b>UJOSS</b>	Union of Journalists of South Sudan
<b>UN</b>	United Nations
<b>UNCPRD</b>	United Nations Convention on the Rights of Persons with Disabilities
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>UNICEF</b>	United Nations International Children's Emergency Fund
<b>UNS</b>	Upper Nile State
<b>USAID</b>	United States Agency for International Development
<b>WHO</b>	World Health Organisation

# 1. EXECUTIVE SUMMARY

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 because of the many attitudinal, environmental, and institutional barriers they face. The situation is worsened by lack of concerted efforts- at a policy level- to include them in socio-economic and political processes. There is a paucity of information detailing the experiences of People with Disabilities living in South Sudan as truly little research has looked at disability in the country. Despite their unique needs and specific vulnerabilities, these are often submerged under the category of 'most vulnerable'. Organisations working with and representing People with Disabilities are often absent from humanitarian programming and the needs of People with Disabilities are thus not included in response action. To ensure that Internews' Rooted in Trust 2.0 (RiT 2.0) Information Ecosystem Assessments (IEAs) are inclusive of People with Disabilities, this study assessed access to information and information flows among People with Disabilities in Central Equatoria and Northern Bahr El-Ghazal states in South Sudan.

The study utilised the IEA approach, which explores both the supply side and the demand side of the information ecosystem. The principles of the IEA methodology employed in this mini-IEA included a human-centred research design and a participatory approach. A qualitative approach was used to explore personal and social experiences, meanings, and practices of People with Disabilities in Central Equatoria and Northern Bahr El-Ghazal states in South Sudan. The IEA was conducted through purposive sampling comprising 13 key informant interviews (KIIs), six focus group discussions (FGDs), and desk research. Desk research was conducted between November 2022 and December 2022. Data from KIIs and FGDs was collected from December 2022 to January 2023 in Central Equatoria and Northern Bahr El-Ghazal states in South Sudan. The data was transcribed and analysed thematically. The themes studied focused on information consumption, habits, health, and preferences, as well as beliefs about the reliability of information from diverse sources.

South Sudan Rooted in Trust 2.0 Project Areas



## KEY FINDINGS

Regarding information supply, the study found that radio was the most prevalent source of information on health crises for People with Disabilities. Other sources of information included TV, social media, and newspapers. However, newspapers were least prevalent sources of health information. In addition, there was a need for sign language interpreters on TV to aid in information dissemination to the Deaf.

In South Sudan, there exist several local, national, and international organisations that disseminate health information to People with Disabilities. The Ministry of Health (MoH) was among the most trusted entity relied upon by most People with Disabilities. Associations of People with Disabilities, chiefs' offices and churches also played a key role in communicating health-related information. The most prevalent health information relayed on COVID-19 was awareness and preventive measures such as vaccination and wearing masks.

Looking at the demand side of health information, People with Disabilities desired information on all health-related matters such as COVID-19 and outbreaks of other pandemics. In addition, they desired to know the security status in South Sudan as well as information on religion, human rights, politics, and law.

Most of the respondents said that they did not receive timely information on health-related issues including COVID-19. This was firmed up by the actors in information provision who acknowledged there are gaps in engagement People with Disabilities.

People with Disabilities admitted that they trust health information received from radio and TV. They noted that these sources were more trusted because the entities verified health information prior to broadcasting it. Social media were the least trusted sources of health information. They also noted that they can differentiate between false and true information. They were able to determine the veracity of health information by assessing the sources of the information.

Feedback from People with Disabilities about health information dissemination by the humanitarian actors was done through phone hotlines, information desk, community-based surveillance, and house-to-house follow-up visits. Despite the existence of feedback mechanisms, People with Disabilities still face many challenges in accessing information.

## RECOMMENDATIONS

### Government agencies

- The use of a variety of communication channels will ensure that people with various kinds of disabilities receive health information in forms that are accessible to them. The government must consider establishing media policies that will ensure news providers use sign language interpreters on television when relaying health crisis information to enhance information supply to People with Disabilities.
- The government can consider signing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and enforcing other legislation relating to People with Disabilities to guarantee the rights of People with Disabilities.

### Humanitarian actors

- Humanitarian actors that disseminate health information should complement government and media response by reaching out to People with Disabilities in remote areas. This can be done by working with trusted local community leaders to pass health information to People with Disabilities. Additionally, they can work together to recruit and train local health champions to be trusted vectors of local, informed sources of information, delivered in local languages.
- Humanitarian actors should train the local health champions to conduct fact-checking to help combat misinformation. This should be expanded, not just to capture information on COVID-19 but also on other health crises like Ebola, among others.

### Information Providers (Media, NGOs, Government and community leaders)

- The provision of timely information can be guaranteed by enhancing communication between communities, humanitarian and development actors, and the media. Decentralisation of information sources should be prioritised by working with People with Disabilities to contextualise health information content, channels, and transmission.
- There is a need to do more to gain feedback from people with various kinds of disabilities such as intellectual disabilities, the Blind, the Deaf and people with multiple disabilities. Adopting an all-inclusive communication approach will be instrumental in protecting the most vulnerable members of our community.
- There is need to train media personnel and other information providers on etiquette of disability reporting.

## 2. INTRODUCTION

South Sudan gained independence in 2011 following a lengthy civil war pitting the Muslim-Arab dominated north against the Christian majority south. 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 at the same time worsened the marginalisation and exclusion of People with Disabilities. There are many attitudinal, environmental, and institutional barriers that confront People with Disabilities. At a policy and legislative level there is lack of concerted efforts to foster the inclusion of People with Disabilities (Rohwerder, 2018). South Sudan is one of the most poor countries in the world with limited health facilities (World Bank, 2008). 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 the country and the available evidence base is extremely limited. Further research with people with diverse types of disabilities, and in different areas of South Sudan is needed to understand the information landscape relating to People with Disabilities living in the country, as well as the barriers and challenges they face regarding information access, and how they have responded to them.

In recent years there has been increasing attention on the rights and needs of People with Disabilities manifest through the development of policies, standards, and guidelines to ensure their inclusion into

social, political and economic processes. This includes recommendations from the World Humanitarian Summit in 2016 whereby a Charter on the inclusion of People with Disabilities in Humanitarian programming and Inter-Agency Standing Committee Task Force Guidelines (2019) was produced. This charter encourages all stakeholders to take all necessary actions to ensure the inclusion of People with Disabilities and that they receive dignified support. Despite such attention and effort, the inclusion of People with Disabilities in humanitarian responses remains limited. Further, there is evidence that suggests a lack of political will in South Sudan to implement key provisions of disability policies. For instance, although the South Sudan Disability Act was enacted in 2012, the government delayed in establishing a National Council for Persons with Disabilities, which is required by the Act and only implemented it in 2022 (Inclusive Friends Association, 2019). This implies that significant work by the council of developing policies and programs for People with Disabilities and ensuring that their rights are protected was much delayed. In addition, there are limited resources allocated towards the implementation of disability policies in South Sudan (USAID, 2019). The government has not provided adequate funding for the provision of assistive devices, accessibility modifications, and other forms of support for People with Disabilities. This lack of funding limits the ability of the government to fully implement disability policies and make meaningful improvements in the lives of

People with Disabilities. Furthermore, there is a lack of awareness and understanding of disability issues among government officials, which hinders the effective implementation of disability policies (Handicap International, 2016). This lack of awareness leads to a lack of prioritisation of disability issues and a failure to adequately address the needs of People with Disabilities.

People with Disabilities often have unique needs and specific vulnerabilities but in many humanitarian contexts, these are often submerged under the category of 'most vulnerable'. Organisations working with and representing People with Disabilities are also often absent from humanitarian programming and as a result the needs of People with Disabilities are thus not included in response action. Due to societal attitudes, People with Disabilities are more likely to be poor, socially marginalised, and excluded from decision making processes and may not receive timely warnings and information (Twigg, Kett, & Lovell, 2018). In the past, Internews has conducted IEAs in South Sudan using a methodological approach that is inclusive and participatory but has also not been able to fully capture issues relating to People with Disabilities because of societal, policy and practical constraints. To ensure that Internews' RiT 2.0 IEAs are inclusive of People with Disabilities, this study assessed access to information and information flows among People with Disabilities in Central Equatoria and Northern Bahr El-Ghazal States in South Sudan.

## 2.1 Attitudes towards disabilities

Attitudes towards People with Disabilities in South Sudan has led them to face significant political, economic and social political barriers that limit their social inclusion (ICRC, 2020). Politically, the country is characterised by political instability and conflict which further exacerbates the challenges faced by People with Disabilities. They include limited access to health care, education, and other basic services. The government's limited ability to implement disability policies has hindered the effective protection of the rights of People with Disabilities (WHO, 2020). Further, awareness of disability issues among key decision makers and the public is low hence affecting the enjoyment of human rights by People with Disabilities (Legge, 2016).

Economically, South Sudan has one of the lowest human development indices (HDI) rankings in the world, with elevated levels of poverty and unemployment (UNDP, 2021). People with Disabilities are heavily represented among the poorest and unemployed in South Sudan. They are disproportionately affected, with many living in extreme poverty and facing significant barriers to employment. The 2011 National Disability Assessment showed that 89.3% of People with Disabilities were unemployed and there are almost no social safety nets and food security schemes for People with Disabilities (Legge, 2016). Further, people with intellectual and psychosocial disabilities were least likely to be employed and most likely to be exploited if working

(MoGCSWHADM, 2013). The lack of economic opportunities deepens their marginalisation.

Socially, there are negative attitudes and misconceptions towards People with Disabilities in South Sudan, leading to stigmatisation and discrimination (UNICEF, 2018). The social exclusion limits their access to education, employment, and other opportunities. They also face barriers to social participation and are often excluded from community activities. In addition, negative social attitudes and structural discrimination prevail, and People with Disabilities have limited access to essential services and employment (CARE, 2016). They are more likely to be illiterate, unemployed and unproductive than their peers without disabilities due to widespread exclusion (Legge, 2016).

The government has limited ability to respond to the medical, educational and mobility needs of People with Disabilities, both in the pre- and post-independence periods (HRW, 2017). Research found that most local authority and services providers expressed a lack of knowledge and experience to provide services and enable equal participation for People with Disabilities (MoGCSWHADM, 2013). People with Disabilities are 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 People with Disabilities, their families, and the socio-economic development of South Sudan (Rieser, 2014).

Some cultural beliefs and practices in South Sudan have led to stigmatisation and discrimination against People with

Disabilities. Most people in South Sudan view disability within the medical model, that is they view disability as a limitation of a body function rather than a combination of disability and barriers within the environment as the social model of disability dictates (Legge, 2016). Cultural beliefs and practices present barriers to access to health care, education, and other services. For instance, schools may not be accessible or may not have accommodations for students with disabilities.

In some communities in South Sudan, disability is viewed because of a curse or punishment, leading to social exclusion. Disability is viewed with superstition or explained with religious motives (Gilbert, 2016). Some families may not seek medical treatment for their kin with disabilities, believing that traditional healing practices or religious interventions are more effective. In some communities, children born with disabilities are thought to be a sign that the family is being punished by God (CARE, 2016). There are even some reports that in some ethnic groups' children born with disabilities are killed. Sometime fathers abandon families when children with disabilities are born (Faehnders, 2018). Families have hidden children born with disabilities from public view as they are seen as a source of shame (Jørgensen, 2018). People with Disabilities have reported that they had a lower social status within their communities and were not taken as seriously (Forcier et. al., 2016). Harassment of People with Disabilities is prevalent with some of them reporting being insulted, laughed at, had stones thrown at them, being publicly discriminated against, gossiped about, suspected of theft, and

abused by family, neighbours and strangers (Gilbert, 2016). People with Disabilities are viewed as beggars and there are low expectations as to what they can achieve and contribute (Anyang, 2016). There are reports that People with Disabilities acquired because of the conflict discriminate against people born with a disability or those who have gotten their disabilities because of a health condition (McNeish, 2013).

Humanitarian actors in South Sudan have identified negative attitudes and misconceptions of disability which act as barriers to their equal participation in social and economic life and access to services (MoGCSWHADM, 2013). Indeed, the social, economic, and political situation in South Sudan has significant implications for the lives of People with Disabilities in the country. The challenges faced by People with Disabilities are intricately linked to the broader challenges facing the country, including poverty, unemployment, conflict, and political instability.

## 2.2 Rights and legal frameworks

There is no specific legislation relating to the rights of People with Disabilities in South Sudan (Legge, 2016). The country has not signed or ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Although the transitional constitution has several clauses which refer to the rights of People with Disabilities and people with special needs, Article 30 does not explicitly guarantee equal protection against discrimination and abuse of People

with Disabilities (Sida, 2014). This is despite efforts by OPDs to ensure there were better provisions for People with Disabilities in the Constitution (Legge, 2016). The concern for war veterans has been a driving force in recognising the rights of People with Disabilities. The Government's national action plan on United Nations Security Council Resolution (UNSCR) 1325 on women, peace and security, does however reference women with disabilities, as do several other pieces of legislation (Goss, 2015). However, enforcement of the legal provisions for the promotion and protection of the rights of People with Disabilities is lacking.

The Ministry of Gender, Child and Social Welfare and the Ministry of Health handles issues concerning disability. The Ministry of Gender and Social Welfare is mandated to safeguard the rights and welfare of People with Disabilities (Anyang, 2016). OPDs have been working with them to try and develop the 2013 National Disability and Inclusion Policy and the Inclusive Education Policy (MoGCSWHADM, 2013). 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). However, a lack of both political will and government funding means that the policies have not been implemented (Forcier et. al., 2016). There is no separate budget line for People with Disabilities.

It is reported 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 people who acquired disabilities because of war, widows, and orphans (Sida, 2014).

Cast against this legal, policy and contextual background the IEA sought to undertake the following:

## 2.3 Main objective

The objective of the IEA was to determine access to information and information flows among People with Disabilities.

## 2.4 Specific objectives

The specific goals of the study were:

- i) To determine the information needs of People with Disabilities, particularly during health emergencies.
- ii) To find out sources of information for People with Disabilities and the extent to which such sources are trusted.
- iii) To determine the drivers and barriers to health information for People with Disabilities.
- iv) To determine the uses of health crisis information among People with Disabilities.

## 3. RESEARCH SCOPE AND METHODOLOGY

### 3.1 Study design

The study utilised the IEA approach, an Internews methodology aimed at gaining a holistic understanding of people's information practices. The methodology aims to gain a deeper human-centred understanding of how people and communities find, share, value, and trust information within their local contexts, irrespective of whether it comes from media agencies or not. This approach aims to explore all the factors that govern information needs, access, sourcing, movement, uptake, and impact in an ecosystem by focusing on both the supply-side-media outlets and their capacity, other partners, and the business and governmental forces that influence -and on the community demand side of the information ecosystem. Local research assistants, enumerators, sign language interpreters, transcribers, and guides from South Sudan were engaged to conduct this study. The study also involved local Organisations of People with Disabilities (OPDs) from South Sudan. The qualitative research methodology that was adopted for this study aimed at gaining an in-depth understanding of the information ecosystem for People with Disabilities in South Sudan. The researchers conducted a desk review, FGDs and KIIs to collect the data. Open-ended interview and FGD guides were administered to KIIs and FGD participants. A pre-test was conducted to ensure that the questions were clear and unambiguous for research participants. Data collection clerks were trained to have a mutual understanding of the questions.

**A total of 13 KIIs and six FGDs were conducted.**

The study was conducted in Central Equatoria and Northern Bahr El-Ghazal states in South Sudan. Central Equatoria is a state in South Sudan with an area of 43,033 km<sup>2</sup> and whose capital city is Juba. Northern Bahr El Ghazal is a state in South Sudan with an area of 30,543 km<sup>2</sup> and whose capital city is Aweil (see Figure 1). These states were chosen following an assessment of the security and accessibility situation in these areas which were found to be favourable. Respondents in the study were selected purposively considering type of disability and gender. A total of 13 KIIs and six FGDs were conducted.



Figure 1: The 10 states of South Sudan

## 3.2 Desk Research

Desk research was conducted between November 2022 and December 2022. The researchers used the desk review to explore existing literature on the general information landscape in South Sudan as well as information specific to People with Disabilities regarding communication during health emergencies. The inclusion criteria for literature were publications from refereed journal, and national and internal organisation reports. The desk review guided the research work on the development of the data collection tools, developing the research design, and the data analysis protocol. In addition, a mapping of OPDs was conducted to find out their reach and activities. This helped in narrowing down the geographical scope, key stakeholders, and specific disabilities in South Sudan.

## 3.3 Key Informant Interviews

A purposive sample of 13 stakeholders were selected for KIIs. The stakeholders were drawn from the government, media (from television and print), OPDs and humanitarian organisations (see Table 1). The KII participants were selected after an exhaustive secondary literature review and consultations with partner organisations. Gender representation was also considered with 31 percent of the key informants being women (see Figure 2). The KIIs provided data on how People with Disabilities access health crisis information and the barriers or constraints they meet in accessing information.

**Table 1: List of Key Informants**

NO.	Gender	Name of Organisation	Type of Organisation
1	Male	MoH	Government
2	Male	Kiss TV	Media
3	Male	Universal Printer	Media
4	Male	Union of the Visually Impaired	Organisations of People with Disabilities
5	Female	Union of the Visually Impaired	Organisations of People with Disabilities
6	Male	Union of Visually Impaired	Organisations of People with Disabilities
7	Male	Central Equatoria State Union of Visually Impaired	Organisations of People with Disabilities
8	Male	Central Equatoria State Union of the Physical Disabled	Organisations of People with Disabilities
9	Male	World Health Organisation (WHO)	Humanitarian Actors
10	Female	Humanity and Inclusion (HI)	Humanitarian Actors
11	Female	UNICEF	Humanitarian Actors
12	Female	World vision	Humanitarian Actors
13	Male	ICAP	Humanitarian Actors

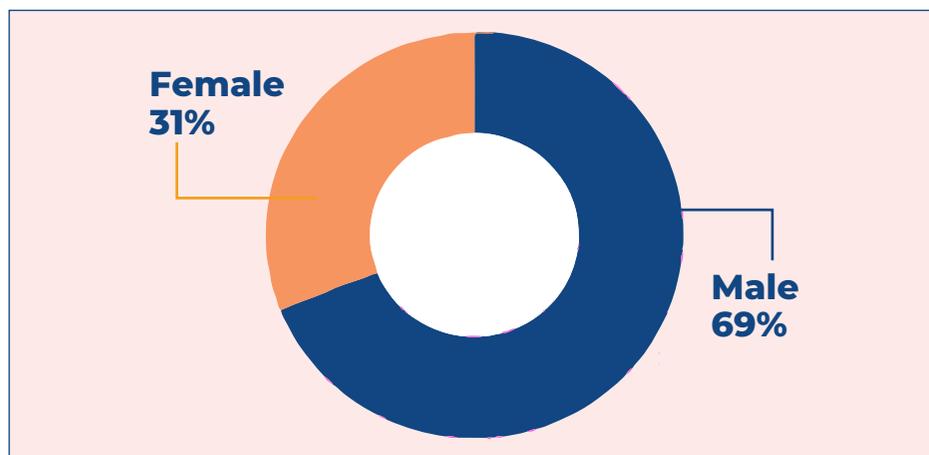


Figure 2: Gender of Key Informants

### 3.4 Focus Group Discussions

The researchers conducted six FGDs with people with various categories of disabilities. The FGDs targeted 16 members per session and in total 97 individuals participated in these FGDs. The sampled respondents included the Deaf, Blind and people with physical disabilities. The researchers aimed to get the nuanced views and perspectives of people with various kinds of disabilities on access to information on COVID-19 and other health-related crises.

Table 2: Communities participated in FGDs

Groups	Location	Male	Female	Total
People with physical disabilities	Juba	10	6	16
	Aweil	10	6	16
Blind	Juba	12	4	16
	Aweil	13	3	16
Deaf	Juba	11	5	16
	Aweil	12	4	16
<b>TOTAL</b>		<b>68</b>	<b>28</b>	<b>96</b>

The participants had the freedom to choose either Arabic or Dinka as the language for the FGDs. The FGDs sought to find out how People with Disabilities access and share information, which information platforms they source information from, and the extent to which they trusted these information channels. The FGDs also solicited information on how and in what ways People with Disabilities were included in humanitarian programming.

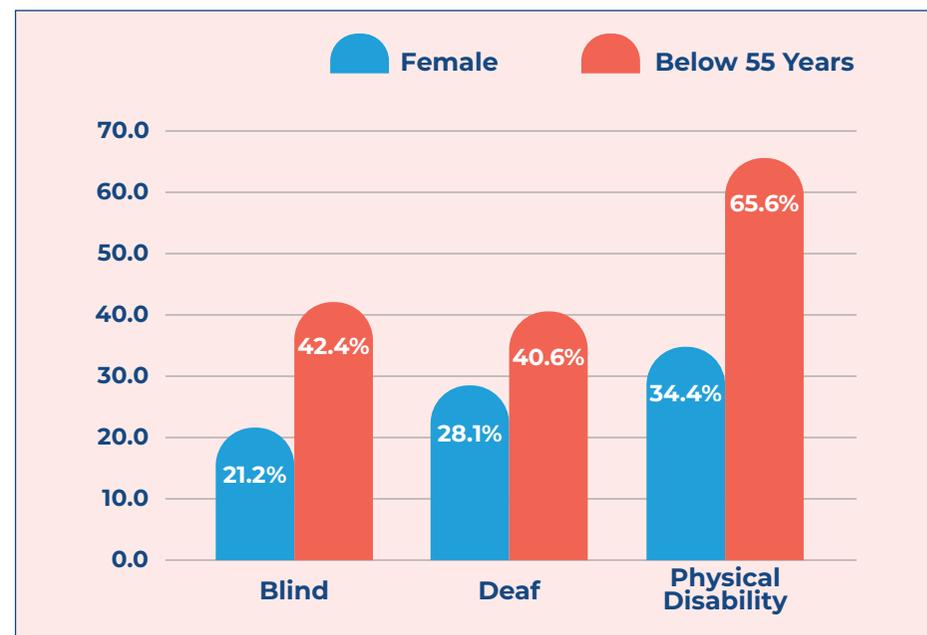


Figure 3: Distribution of gender and age among the FGD respondents

**The FGDs sought to find out how People with Disabilities access and share information, which information platforms they source information from, and the extent to which they trusted these information channels.**

### 3.5 Ethical Protocol

The study, which involved participants from a vulnerable group, adhered to strict ethical guidelines to ensure that none of the participants suffered any form of harm arising from their participation in the study. Prior to the inception of the study, ethical approval was granted by the relevant body in South Sudan. Participants were informed of the purpose of the study after which they were invited to participate in the study. Participation in the study was therefore voluntary and based on informed consent. The interviewers received consent to conduct and record the FGDs and KIIs prior to starting the process. The scope and purpose of the FGDs was explained to the participants in Arabic and Dinka languages. Furthermore, throughout the interviews the researchers interviewing the respondents promoted effective communication techniques that encouraged active listening, individualising, and requesting restatement by the subject. With the easing of restrictions due to the COVID-19 outbreak in South Sudan, the team was able to conduct in-person FGDs and KIIs. The research team followed all the mandated COVID-19 restrictions and guidelines of the Government of South Sudan while conducting these activities.

### 3.6 Data collection

Data was collected from December 2022 to January 2023 in Central Equatoria and Northern Bahr El-Ghazal states in South Sudan. A total of 13 research assistants from Central Equatoria State were trained and they conducted FGDs and KIIs in Juba while a further 13 research assistants were trained in Northern El-Ghazal State and helped conduct FGDs in Aweil. Sign language interpreters and guides were used during the FGDs in Juba and Aweil. Data Analysis

The qualitative interviews conducted for FGDs and KIIs were recorded and thereafter sent for transcription. The transcriptions were read and assigned a specific label as per the respondent's group, location, and disability category. Thematic analysis was used to analyse the qualitative data collected from all the participants. The data was categorised into themes and sub-themes, then interpretation was done as per the responses.

### 3.7 Limitations

The study had the following limitations:

- The limited period within which to conduct the research hampered access to more respondents and more groups of People with Disabilities.
- People with other kinds of disabilities e.g., people with intellectual disabilities and people with multiple disabilities were not included due to logistical constraints.
- Some of the study participants were selected through informal networks and this might have inadvertently created a selection bias in that participants without access to a mobile phone, internet, or who lack reading skills might have been excluded.
- The study did not reach out to an equal number of men and women, even after targeted interventions.
- The study did not reach key areas in Sudan concentrating only on two states, as it was a pilot.
- The study was limited to the qualitative approach. The qualitative approach is in line with the Internews IEA methodology and was considered appropriate because this study sought in-depth and unique insights about People with Disabilities, which a quantitative or mixed methods approach would not have provided.

## 4. INFORMATION SUPPLY

### 4.1 Media Landscape in South Sudan

Radio is the most popular media in South Sudan, with more than 40 radio stations operating in the country's 10 states. The main ones – Miara, Eye Radio, Catholic Radio Network face intimidation from the authorities and censorship. There are two state-owned television networks, the national South Sudan Broadcasting Corporation and the regional EBC, and six newspapers, four published in English and two in Arabic. Only two of the English-language newspapers – No. 1 Citizen and City Review – are free of government influence (RSF, 2021).

South Sudan's independence opened a pathway for press freedom leading to a sharp rise in the number of media institutions. However, hardly two years after independence South Sudan plunged into civil war. The war resulted in the killing of hundreds of thousands and the displacement of at least 4.5 million civilians (UNHCR, 2019). The war decimated the country's economy and altered information flows and dynamics.

In the first instance, media organisations face immense logistical, technical, and financial challenges, worsened by conflict and violence across the country. The 2013 civil war led to political and economic crises, resulting in a broken government structure which negatively impacted mass media growth and development. Prior to the 2013 conflict outbreak, South Sudan ranked high among countries with a harsh environment for journalists and curtailed freedom of expression and free press (Freedom House 2019). The country's authorities, the National Security Service (NSS), employed a heavy-handed approach and violent tactics including arrests, torture, and punitive laws, like the previous Khartoum regimes which used to censor

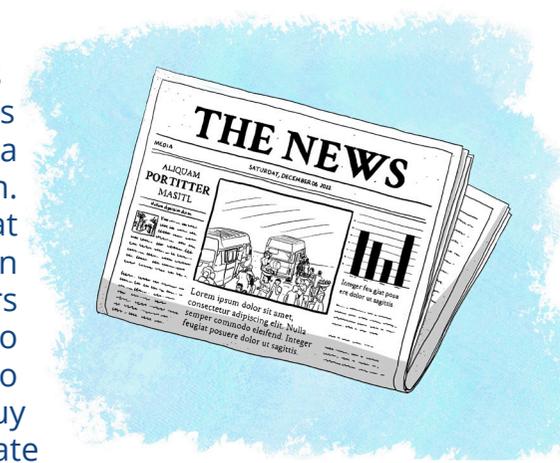
journalists and suppress freedom of expression. Open violence against journalists only worsened as the war continued. Furthermore, the continued sporadic fighting among various warring factions hindered access to many parts of the country, causing a sharp drop in mass media circulation which has in effect severely hindered many South Sudanese from access to news and information.

### 4.2 Media Providers

#### Newspapers

Access to newspapers among People with Disabilities is constrained. None of the respondents interviewed cited newspapers as a source of health crisis information. One of the respondents said that most of them can read information disseminated through newspapers while others noted that access to newspapers was a challenge due to lack of financial means ability to buy newspapers. These results resonate with an earlier study by United States Agency for International Development (USAID)-2012 which found that newspaper readership levels are low due to low literacy levels.

Low access to newspapers for People with Disabilities could also be attributed to the fact that many newspapers which were in circulation in South Sudan have been shut down owing to a combination of political factors and a tough economic



environment. Over nine newspapers have folded either due to pressure from the government or financial constraints. A few newspapers which have weathered the difficult environment include Juba, Monitor, The Dawn, The Citizen No.1, Review City and The Citizen. Presently, the print media market is dominated by the Juba Monitor which is partially supported by USAID to strengthen the transition and stability program in the country. Juba Monitor remains a popular newspaper read by mostly the educated and professional elites (Media Landscapes, 2023).

## Radio

Research material from both KIIs and FGDs highlights that radio was the most common mode of providing health related crisis information to the disability community. This was done through radio talks on various subject matters and through special announcements. FGDs revealed that people with physical disabilities preferred radio as a source of information.

A Deaf respondent said, "Radio is essential because we can give it to one of our family members, and they can interpret what the radio says". While a respondent who is Blind noted, "At the national level, we depend on Eye radio and Miraya FM. When it comes to local news, we tune in to Akol Yam FM". The respondents noted that radio was affordable making it a preferred medium of information.

The findings corroborate with a study conducted by Internews (2017) which established that radio was the most widely consumed media in South Sudan among refugees. In a recent survey conducted by Forcier (2021), 93% of participants reported they had access to radio. In Juba, 66% of respondents had access to radio with men more likely (70%) to have listened to radio than women (62%).

Radio operations and reach are concentrated in Juba city but

few covering in the States. In 2021 National Audience Survey, the radio stations' weekly reach in major towns in the country besides Juba were Radio Miraya (46.6%), Eye Radio (43.8%), BBC World Service in English (15.1%), Voice of America (19.1%), City FM (21%), Liberty FM (14.7%) (Forcier, 2021).

## Television

Television was not mentioned as a common source of information for People with Disabilities. Most People with Disabilities noted that they do not have access to television sets. Respondents who are Deaf opined that TV would have been the best source of information if they had interpreters. A Deaf respondent said, "TV could be a good source of information if there is an interpreter. However, television stations in South Sudan do not have interpreters". The absence of interpreters during news and other public announcements could be attributed to weak media regulations in South Sudan. Further, the growth and development of television in South Sudan has been hampered by economic hardships. Television stations are saddled with huge operational and production costs. TV stations are also hindered by limited electricity and telecommunication infrastructure.

As of 2018, the state-run South Sudan Television (SSTV), which has since been renamed to South Sudan Broadcasting Corporation (SSBC), is the only station operating in the country after KISS TV channel established in 2020 in Juba. The SSBC channel was fully set up in 2013 (SSBC, 2018)<sup>7</sup>. Several studies have revealed the cause of low access to TV. This includes a study by Internews (2017) which showed that the use of digital satellite technology has a limited reach, reaching slightly above 10% of the South Sudanese.



Thus, a significant percentage of the population does not have access to television. Most of the South Sudanese population is hindered from accessing TV stations due to energy shortages. Less than 29% of the population had at least one source of power and only eight percent had television sets in their household. Regarding nationwide television penetration, even the most popular station had a reach of less than five percent, with South Sudan Television dominating the TV market with 47%, followed by Al Jazeera Arabic (35%) and Al Jazeera English (28%).

## Social media networks

Social media has grown in popularity in South Sudan, particularly Facebook, Twitter, and WhatsApp. Results from FGDs indicate that most People with Disabilities have access to social media. In one of the discussion forums, a Deaf male interviewee from Juba said, “Some of us access information through Facebook, and later, we inform the rest of our friends about COVID-19.” However, another interviewee cautioned the members against social media. He noted “There is a lot of wrong information on social media because anyone can post anything”. A study by Internet World Stats (2019) estimated active social media users in South Sudan to have grown by 21% year-on-year between 2018 and 2019. Most social media users, however, are concentrated in Juba. South Sudan has an internet penetration of 16.8 percent (media Landscapes, 2023).



## 4.3 Organisations and associations

The study sought to find out some of the main organisations and associations involved in community engagement and communication on health risk factors. The South Sudan MoH was cited as one of the most active ministries involved in passing health information messages to People with Disabilities. At the international level organisations such as UNICEF, WHO, UNKEA, South Sudan Red Cross and World vision were among the organisations that were engaged in communicating health crisis information to the disability community. At the local level, the Council of Churches, media organisations, the chief’s office, and community meetings also played a role in communicating health crisis information. These organisations reached their members through various channels such as radio, physical contact, social media, among others. A participant who is Blind said that “I get health information from radio, the World Health Organisation, the Ministry of Health, and media”.

Respondents noted that People with Disabilities experienced challenges with mobility and thus could not easily reach locations where community discussions, interactions, or awareness promotions about COVID-19 were being held.

***The most popular station had a reach of less than five percent, with South Sudan Television dominating the TV market with 47%.***

Results from KIIs showed that the common health messages passed to People with Disabilities by the various organisations include; general awareness about existence of COVID-19, the risks posed by COVID-19, precaution measures such as vaccination and the COVID-19 preventive measures. On the contrary, FGD findings show that in addition to health information People with Disabilities prefer to receive other information such as the status of peace in the Country.

## 4.4 Media policy and regulations

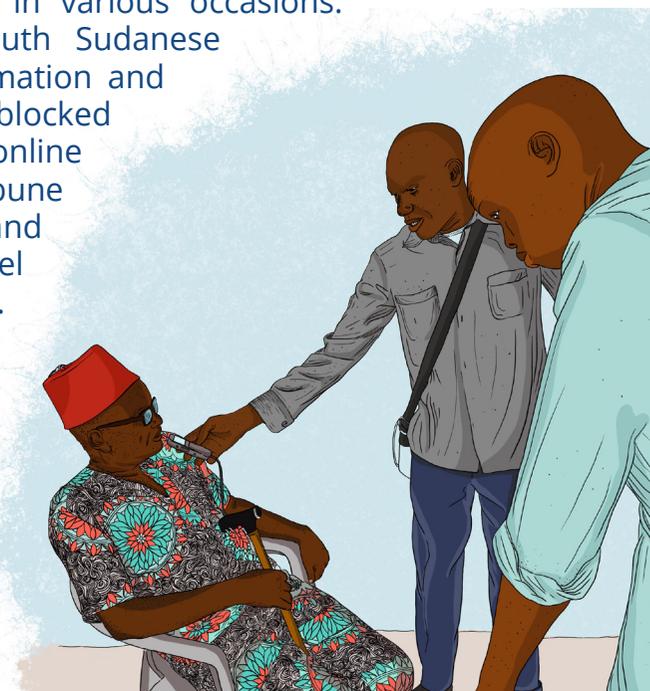
In 2013 and 2014, South Sudan promulgated a progressive legal framework. The enactment of the Media Authority Act (2013), the Broadcasting Corporation Act (2013), and the Right of Access to Information Act (2014) provided a modicum of opportunities for the promotion of press freedom and access to information in the country. Despite the existence of these progressive laws, there are overlaps and gaps with other existing stringent laws provided within the National Security Act which give the National Security Services mandates that violate media freedom and the freedom of expression. For example, the Penal Code Act (2008) limits space for the free operation of media and criminalises defamation and libel cases (Okello, 2022). Repressive strategies are used to censor journalists with critical views of the government. Indeed, South Sudan has a country ranking of 139 in Press Freedom (Media Landscapes, 2023).

South Sudan's transitional constitution guarantees freedom of expression and press freedom under Article 24, with exceptions for public order, safety, or morality. The article also calls on media to "abide by professional ethics." Article 32 of the transitional constitution guarantees the right to access official information, with exemptions for public security and personal privacy. However, the government regularly violates

media freedom which contributes to a hostile environment for the press. The NSS Law, which took effect in early 2015, grants the NSS unfettered authority to arrest and detain suspects, monitor communications, conduct searches, and seize property without clear judicial oversight. Defamation remains a criminal offense under the penal code. However, under the 2013 Media Authority Act, defamation claims against the media should be settled by a Press and Broadcast Complaints Council, with several safeguards for media freedom. The lack of an effective legal framework for the media leaves outlets and journalists vulnerable to abuses by the authorities (Freedom House, 2016).

The Media Authority Act provides for digital media registration and regulation (Media Landscapes, 2023). However, the Media Authority of South Sudan, the body established to oversee media operation in South Sudan, has summoned and sanctioned the digital press in various occasions.

In 2017, the South Sudanese Ministry of Information and Broadcasting blocked access to two online media, Sudan Tribune and Tamazuj and two blogs Paanluel and Nyamapile. Such acts have undermined the provisions for free press and the freedoms of expression (Okello, 2022).



## 5. INFORMATION DEMAND

### 5.1 Health Information Needs

Results from FGDs showed that most People with Disabilities wished to get information on health crises in the country. Apart from that, they also wanted information on the prevailing security situation in South Sudan, religion, politics, and the legal and human rights situation in South Sudan. Some respondents noted that once they are assured of a stable security situation in the country, then their psychological well-being would improve. Some respondents said that they needed health information, especially on where to access medical help in case of a disease outbreak. A male FGD participant said, “I am most interested in knowing about the precautionary measures for certain diseases to protect myself. For instance, the symptoms for Ebola are internal and external bleeding while those of COVID-19 include coughing. That is why the ministry of health should continue to give information on the radio about diseases. Such information enables me to inform other People with Disabilities about the symptoms and preventive measures”.

A woman with disabilities who participated in the FGD stated, “I would like to get information on which hospitals women with disabilities who are pregnant can go for monthly follow ups. I would also like to know what kind of vaccines we can give to our children after birth”.

A Deaf participant stated in an FGD, “We need awareness about pandemics like COVID-19 and Ebola on radios. We also need sign language interpreters to help us understand that information which is broadcasted on radio”.

A Deaf man who took part in the FGD said, “We need interpreters, even on TV stations, to understand health messages clearly. Otherwise, all of us will get infected. For example, sometimes the government announces the lockdown, but we still go

outside sometimes, and the police arrest us because we did not know that the lockdown was announced. We need interpreters to help us understand announcements about health-related issues, including Ebola”.

In a KII with a media producer, it was found out that there was no special programming for People with Disabilities in the media in South Sudan. The producer also said that his station did not engage directly with People with Disabilities.

A Deaf participant stated in an FGD, “We need health information and chiefs should be skilful in communicating with the Deaf and advocating for the rights of People with Disabilities. We do not get much health information in the villages, and we feel this is discrimination against People with Disabilities. For example, there should be signs showing where there is a hospital on our roads so that the Deaf can access health services quickly.”

Research found that most local authorities and service providers expressed a lack of knowledge and experience to provide services and enable equal participation of People with Disabilities. People with Disabilities are 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 People with Disabilities, their families, and the socio-economic development of South Sudan (Rieser, 2014).



***“We need interpreters, even on TV stations, to understand health messages clearly.”***

A participant who is Blind stated in an FGD, “Health information should be inclusive. When COVID-19 broke out in the country, people with visual disabilities had some challenges accessing written information. When awareness creation about the disease was being done, People with Disabilities were left out as if they were not part of the community. Some people think that even if People with Disabilities become sick, it does not matter and therefore they do not bother to inform us to attend health awareness meetings in the community”.

Indeed, studies show that there are negative attitudes and misconceptions towards People with Disabilities in South Sudan, leading to stigmatisation and discrimination. The social exclusion limits their access to essential health services (UNICEF, 2018). Studies also say that the South Sudanese government has limited ability to respond to the medical and mobility needs of People with Disabilities (HRW, 2017).

## **5.2 Access to timely and accurate information health crisis related information**

Most of the respondents felt they were significantly left out in the access to health-related information about COVID-19 and other pandemics since most of them had limited access to media such as radio and TV. A participant with physical disabilities said in an FGD, “As a Person with Disability, how can I get health information when I do not have a radio and cannot go to the market to get some information? This means that People with Disabilities are significantly (left) behind in the news related to diseases outbreaks because the information reaches us quite late”. Viewed in this way, access to information is tied to prevailing economic hardships facing People with Disabilities. Research shows that South Sudan has one of the lowest HDI rankings in the world, with prominent levels of poverty and unemployment. People with Disabilities are heavily represented among the poorest and unemployed in South

Sudan. They are disproportionately affected, with many living in extreme poverty (UNDP, 2021).

FGD participants also noted that the information on COVID-19 received from various entities was sometimes inaccurate. There was a lot of false information and misinformation. A female participant with physical disabilities said, “I heard inaccurate information that people who receive COVID-19 vaccines will die. Later, I went to the hospital to be vaccinated after realising that that information was incorrect.”

Another respondent felt that access to information had deteriorated now compared to earlier years. He said, “I remember in the 1990s here in Juba when any health information that needed to be disseminated would be told to everyone, including children. This is how we used to get health information, which was adequate, but now I do not think health partners are doing enough to disseminate news to everyone, including People with Disabilities. The Ministry of Health and the World Health Organisation must ensure that people receive accurate information”.

In a KII, an official from a humanitarian organisation said, “One of the big challenges is tracing and identification of People with Disabilities in order to pass health information to them”.

 **“As a Person with Disability, how can I get health information when I do not have a radio and cannot go to the market to get some information?”**

## 5.3 Information Gaps

A key informant from the South Sudan MoH observed that although the South Sudanese government made efforts to involve key stakeholders from the community, they lacked the necessary support to sufficiently involve the disability community while implementing various health information related initiatives. In a KII, an official from the MoH stated, “We must involve People with Disabilities to determine their information needs and priorities. Currently the biggest challenge we are facing is lack of necessary support to carry out the health information dissemination plan to the disability community. If we follow the Ministry of Health national structure and design channel, we can reach all People with Disabilities”.

Key informants from humanitarian organisations interviewed acknowledged working closely with the Union of People with Disabilities. However, they admitted that the engagement was infrequent. The main gap experienced by the humanitarian actors was the lack of multiple methods of issuing the information to targeted People with Disabilities which resulted in people with certain kinds of disabilities - such as intellectual disabilities and multiple disabilities - missing the information disseminated.

In a KII, an official from a humanitarian organisation said, “Humanitarian actors lack knowledge to pass information to People with Disabilities. We experience a language barrier and sometimes we lack sign language interpreters to help us communicate with them. There is also a lack of accurate data about People with Disabilities in South Sudan. People with Disabilities in the country are also not united and therefore accessing them is a challenge”.

In South Sudan, there exist negative social attitudes and structural discrimination prevails, and People with Disabilities are more likely to be illiterate than their peers without disabilities (Legge, 2016). This limits their ability to communicate in

languages such as English and Arabic hence making it difficult for humanitarian actors to reach them with health information. In addition, studies show that humanitarian actors may lack adequate knowledge and experience to provide services to People with Disabilities in South Sudan (MoGCSWHADM, 2013).

## 5.4 Community engagement and feedback mechanisms for People with Disabilities

People with Disabilities have unique viewpoints that can enhance the planning, design, and delivery of health crisis information. The study sought to find out the mechanisms used by various humanitarian actors to get feedback from People with Disabilities regarding the dissemination of health information. Results reveal that most humanitarian actors use phone hotlines to receive feedback from People with Disabilities. Other feedback mechanisms cited include the use of information desks, community-based surveillance and house to house follow-ups. Feedback was also sourced through radio phone in programs and outreach in churches. Findings show that a major obstacle to obtaining feedback from People with Disabilities was language barrier. For instance, most of the population do not understand sign language making it challenging to interact with the Deaf. Another challenge was the lack of funding to support feedback mechanisms from People with Disabilities. The respondents acknowledged that the challenge in obtaining feedback from People with Disabilities had not been in existence even before the COVID-19 pandemic, although it had worsened the situation. The findings are in line with a study conducted by Rohwerder (2018) whose findings showed that South Sudanese authorities have had limited capacity to respond to the needs of People with Disabilities and that the support provided by national and international organisations is not enough to meet the immediate and long-term needs of People with Disabilities.

## 6. INFORMATION DYNAMICS

### 6.1 Trusted Medium of Information

Participants in FGDs acknowledged that health personnel, radio, and TV were the most trusted sources of information. They stated that those entities were likely to verify health information before sharing it with the public. The findings are supported by studies that show that radio is one of the most trusted mediums in South Sudan (Media Landscapes, 2023). Although some People with Disabilities relied on social media to access information, most of them did not trust information sourced from the platform. In one of the discussion forums, a male participant with hearing impediments stated that, “I don’t trust the information I receive from social media”.

### 6.2 Differentiating True and False Information on COVID-19 and Other Health Crises

Findings from KIIs indicate that there are many rumours that circulate about health crises. Social media and citizens were cited as the main source of false information. A government health official said, “social media keep circulating health information most of which is not reliable. Information that circulated on social media about the death in Kajokeji from Ebola was not accurate. Sometimes people who do not believe in vaccines also spread falsehoods about vaccines”.

Most of the respondents said they were able to differentiate true information from false. They often tried to verify the information they received. Other participants noted that they trusted messages from their leaders. A female participant with physical disabilities said, “I was scared of getting vaccinated. But after I heard that President Salva Kiir and his first Vice President

Riek Machar had been vaccinated, I decided to get the COVID-19 vaccine. I am thankful everything went well”.

### 6.3 Challenges People with Disabilities Face in Access to Health Crisis Information

People with Disabilities acknowledged facing many challenges that are directly and indirectly related to their access to health information. These issues act as significant barriers that need to be addressed to ensure that People with Disabilities have equal access to healthcare services.

Firstly, there is a language barrier that can prevent People with Disabilities from accessing health information. This is usually the case when English is used. For example, most TV and radio stations broadcast in English which may not be understood by some People with Disabilities. This is because the prevalent languages spoken in South Sudan are Arabic and other African languages. A participant with physical disabilities said in an FGD, “One of the biggest challenges is not how to get information but how to understand it clearly. For instance, the precautionary measures when there is a disease outbreak are given in English. However, some People with Disabilities do not understand English and therefore they may not be able to protect themselves. Let us take the use of masks as an example.



**“One of the biggest challenges is not how to get information but how to understand it clearly.”**

First, people need to be informed what a mask is in a language they understand. Another example is the mispronunciation of the Corona disease. Some people referred to it as Macrona. That is why I think language is one of the challenges to access of health information”.

The absence of accessible forms of communication, such as closed captioning or large print, can make it difficult for people with visual or hearing disabilities to access health information. The lack of sign language interpreters or social workers to assist them can also create communication barriers. A Deaf participant stated in an FGD, “older people with hearing disabilities face some challenges when they go to the hospital because they are not well understood”.

The language problem is compounded by few people in society who understand sign language. A Deaf male participant said in an FGD, “I write on paper when I want to buy groceries because buying things in the market is challenging. Sometimes some sellers need help reading and need help understanding sign language. I have tried to teach some kids, but they were not interested. The road is dangerous because we cannot hear vehicles’ horns, and we can be knocked by a car. Some police officers blame us when they find us in the night despite that we try to explain to them, but they do not listen. Even at home, we are not well understood. That is why we need interpreters”.

The lack of attention that was experienced by People with Disabilities during the COVID-19 pandemic is also a significant concern considering other health crisis that are bound to arise. A comparable situation was experienced during the Ebola outbreak. This points out that People with Disabilities are at higher risk of contracting diseases when they arise and may not receive the specialised health support they may need.

Stigmatisation and discrimination towards People with Disabilities due to cultural stereotypes and lack of understanding can also prevent them from accessing healthcare services. The issue of health workers not differentiating between pregnant

women with disabilities and those without disabilities is also a significant concern. Women with disabilities may require specialised care and support during pregnancy. A female participant said in an FGD, “people talk harshly to women with disabilities who are pregnant. They make them feel they have done something wrong. At the hospital, women with disabilities are denied family planning services. When they see a woman with disabilities at the family planning section, some people ask, “What is she doing here?” A study by Rohwerder (2018) shows that 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.

The lack of mobility services, such as ramps, at health facilities can make it difficult for People with Disabilities to access healthcare services. A male participant with physical disabilities said in an FGD, “In the hospital, accessibility for us is not easy. For instance, we cannot reach some places because of the stairs.” Studies indicate that 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. They struggle to access and afford healthcare, including assistive devices and are among those most vulnerable to malnutrition (Rohwerder, 2018).

**“Older people with hearing disabilities face some challenges when they go to the hospital because they are not well understood.”**

The ongoing conflict in South Sudan has made it difficult for People with Disabilities to access healthcare services, with many of them being displaced from their homes and communities (WHO, 2021). This has worsened their vulnerability and limited their access to support services. A Deaf participant stated in an FGD, “During late hours, we cannot go to the hospital because on our way, we might find gangs, and they put our lives in danger. So, we choose to stay home to avoid such things”.

Addressing these issues and improving access to health information for People with Disabilities is crucial for ensuring that they can access healthcare services, receive the care, and support they need. This can be achieved through the implementation of policies and guidelines that prioritise the needs of People with Disabilities in the provision of healthcare services. Also, the training of health workers on disability awareness and how to provide specialised care and support to People with Disabilities is essential.

## 6.4 Proposed Measure for Improving Health Information Access for People with Disabilities

Respondents in both FGDs and KIs proposed several measures for improving health information access for People with Disabilities. Firstly, all health facilities should consider the needs of People with Disabilities in their strategic plans. For example, during construction of health facilities and subsequent service delivery the unique needs of People with Disabilities and their access to these facilities (universal design) should be considered so that they access healthcare without facing any barriers.

Delocalising health services for People with Disabilities in rural areas is also crucial for ensuring that they have equal access to healthcare services regardless of their location. The government should also support NGOs and CBOs dealing with People with Disabilities to operate in the country, as this can help in providing specialised care and support to People with Disabilities.



Enacting laws and policies such as the UNCRPD and ensuring representation of People with Disabilities in key government ministries and forums can help in advocating for the rights of this group and ensuring that their unique needs are considered in decision-making processes.

In addition, having representation of People with Disabilities in parliament is a crucial step towards ensuring that the disability community is well-represented and that their needs are considered when laws and policies are being developed. Finally, easing provision of universal health care for People with Disabilities is crucial for ensuring that they have equal access to healthcare services, as part of the highest attainable standard of health for People with Disabilities. This is in line with The World Health Assembly Resolution WHA74.8 which calls for member states to ensure that People with Disabilities receive effective health services as part of universal health coverage and equal access to cross sectorial public health interventions.

## **6.5 Coping Strategies that Humanitarian Organisations use to communicate with the disability Community during the COVID-19 pandemic**

While some organisations acknowledged not having any coping mechanism developed in response to communication to People with Disabilities on COVID-19 and other health related issues, some organisations revealed that they source for expertise on handling People with Disabilities to effectively communicate with them. Some of the ways in which they engage with People with Disabilities is by printing of Information, Education and Communication (IEC) materials that are inclusive, and which can be shared by and among People with Disabilities.

## **6.6 Mechanisms for improving information dissemination to People with Disabilities**

The respondents suggested varied ways of enhancing information dissemination to People with Disabilities. These included translating health information to all languages, inclusivity through participatory involvement of People with Disabilities in program development and implementation, and targeted delivery of messages to People with Disabilities e.g., the Blind, and the Deaf. They also suggested creating materials in large prints for people with limited vision. In addition, there should be more awareness creation in the community about disability. The government can institute intentional and rapid involvement of People with Disabilities in matters concerning the disability community. In addition, resource mobilisation should be done to have adequate funding for programs on health information dissemination to the disability community.

## 7. KEY FINDINGS

Regarding information supply, the study found that radio was the most prevalent source of information on health crises for People with Disabilities. Other sources of information included TV, social media, and newspapers. However, there was a need for sign language interpreters on TV to aid in information dissemination to the Deaf. In South Sudan, there exist several local, national, and international organisations that disseminate health information to People with Disabilities. The MoH was among the most trusted entity relied upon by most People with Disabilities. Associations of People with Disabilities, chiefs' offices and churches also played a key role in communicating health related information. The most prevalent health information relayed on COVID-19 was awareness and preventive measures such as vaccination and wearing of masks.

Looking at the demand side of health information, People with Disabilities desired information on all health-related matters such as COVID-19 and outbreak of other pandemics. In addition, they desired to know the security status in South Sudan as well as information on religion, human rights, politics, and law.

Many of the respondents felt they did not receive timely information on health-related issues including COVID-19. This was firmed up by the actors in information provision who acknowledged there are gaps in engagement People with Disabilities.

People with Disabilities admitted that they trust health information received from radio and TV. They noted that these sources were more trusted because the entities verified health

information prior to broadcasting it. Social media were the least trusted sources of health information. People with Disabilities also noted that they can differentiate between false and true information. They were able to determine the veracity of health information by assessing the sources of the information.

Feedback from People with Disabilities about health information dissemination by the humanitarian actors was done through phone hotlines, information desk, community-based surveillance, and house-to-house follow-up visits. Despite the existence of feedback mechanisms, People with Disabilities still face many challenges in access to information.



# 8. CONCLUSION AND RECOMMENDATIONS

## Conclusion

Access to information by People with Disabilities was constrained by economic hardships, cultural stereotypes, illiteracy, limited sign language interpreters, language barrier and discrimination or exclusion. These resulted in varying degrees of impact on People with Different kinds of disabilities. The MoH and Humanitarian Actors engaged in relaying health information acknowledged weak linkage in sending and receiving information for People with Disabilities and noted the importance of using multiple and targeted modes of communicating with the disability community. Radio was found to be the most common source of information on health crisis while newspaper was the least used source of information. Majority of the respondents trusted information from radio and TV more. However, though radio and TV were more reliable in accessing information and were more trusted media, they did not cater to the needs of all types of disabilities. For instance, the Deaf could not independently access radio information while the Blind could not access information from TV.

## Recommendations

A variety of inclusive channels of communication will ensure that people with various kinds of disabilities receive health information in forms that are accessible to them. Further regulation on the use of sign language interpreters on television during the relay of information on health crisis should be enacted to enhance information supply to People with Disabilities.

Humanitarian actors that disseminate health information should complement government and media response by reaching out to People with Disabilities in remote areas. This can be done by working with trusted local community leaders to pass health information to People with Disabilities. Additionally, they can work together to recruit and train local health ambassadors to be trusted vectors of local, informed sources of information, delivered in local languages. They should be trained to conduct fact-checking to help combat misinformation. This should be expanded, not just to capture information on COVID-19 but also on other health crises like Ebola as well.

The provision of timely information can be guaranteed by enhancing communication between communities, humanitarian and development actors, and the media. Decentralization of information sources should be prioritised by working with People with Disabilities to contextualise health information content, channels, and transmission.

There is a need to do more to gain feedback from people with various kinds of disabilities such as intellectual disabilities, the Blind, the Deaf and people with multiple disabilities. Adopting an all-inclusive communication approach will be instrumental in protecting the most vulnerable members of our community.

The government can consider signing the UNCRPD and enforcing other legislation relating to People with Disabilities to guarantee the rights of People with Disabilities.

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# ANNEXES

[1 INTERVIEW GUIDE FOR GOVERNMENT HEALTH OFFICIALS](#)

[2 INTERVIEW GUIDE FOR HUMANITARIAN ACTORS](#)

[3 INTERVIEW GUIDE FOR CIVIL SOCIETIES](#)

[4 INTERVIEW GUIDE FOR MEDIA PRACTITIONERS](#)

[5 FGD GUIDELINE FOR PEOPLE WITH DISABILITIES](#)



# THE FORGOTTEN

AN INFORMATION ECOSYSTEM  
ASSESSMENT FOR PEOPLE WITH  
DISABILITIES IN SOUTH SUDAN

**ROOTED IN TRUST 2.0  
SOUTH SUDAN**