



Terms of Reference

IMPROVING DISABILITY UNDERSTANDING IN SOUTH SUDAN

Disability Data Review- Collation and Analysis in South Sudan

October 2022

Mission statement

Title study/research :	IMPROVING DISABILITY UNDERSTANDING IN SOUTH SUDAN: Disability Data Review- Collation and Analysis in South Sudan
Humanity & Inclusion Programme :	South Sudan
Objective of the mission :	Purpose of this project aims to gather existing data from different states across South Sudan in one place to provide an important snapshot of the situation for people with disabilities in the country.
Duration of the assignment :	2 months maximum
Location of the mission :	South Sudan
Latest update of the Terms of Reference:	07/10/2022

Humanity and Inclusion

Humanity and Inclusion -HI (the new name and re-branding of Handicap International since January 2018) was founded in France in 1982. In 2009, the HI Federation was established in Brussels. The membership of the Federation has since expanded to eight countries, namely; France, Belgium, UK, USA, Germany, Switzerland, Luxembourg and Canada. HI vision asserts: “Outraged by the injustice faced by people with disabilities and vulnerable populations, we, aspire to a world of solidarity and inclusion, enriched by our differences, where everyone can live in dignity”. HI is an independent and impartial aid and development organization working in situations of poverty and exclusion, conflict and disaster. We work alongside disabled and vulnerable people to help meet their essential needs, improve their living conditions and promote respect for their dignity and fundamental rights. Currently, HI is present in at least 55 countries, with its humanitarian programs reaching at least 2 million people. In 1997, HI along with other partners was awarded the Nobel Peace Prize for its international campaigns to ban landmines sale



and use. For further information about HI please visit: <https://hi.org/> and <http://www.hi-us.org/> and <https://humanity-inclusion.org.uk/en>

Humanity and Inclusion in South Sudan

HI has been operating in South Sudan since 2006, implementing emergency and development actions aiming at improving protection, quality of life, and the promotion of rights of vulnerable individuals, including people with disabilities. HI's current portfolio adopts an integrated and multi-sectoral approach that includes interventions centered on MHPSS, Protection, Functional Rehabilitation and livelihoods, with disability inclusion as a crosscutting theme across all programmes. In 2021, HI established a base in the greater Unity, which remains among the most conflict states of the country and recoding a high number of persons with disabilities. The operational context in South Sudan today is considered largely humanitarian/emergency while phasing in resilience programming in some areas. The ongoing peace initiatives, if they succeed, might result in huge population movements of returnees (both IDPs and refugees) across the country.

HI's current interventions are funded by FCDO, MOFA Luxembourg, South Sudan humanitarian Fund (SSHF), and the Crisis and Support Centre of the French Ministry for Europe and Foreign Affairs. As part of its strategy, HI South Sudan is prepositioning to strengthen its programming in Protection, to expand existing program interventions in Health (MHPSS, reproduction health and physical rehabilitation), inclusion in humanitarian action, and livelihood, as well as to undertake innovative programming in Education in emergency. HI works in close collaboration with the South Sudan Humanitarian Clusters (Health, Protection, Food Security & Livelihoods and Education), UN agencies and Government departments (Health, Agriculture, Education, Gender and Youth, and Relief & Rehabilitation Commission). HI is also an active member of the South Sudan NGO Forum.

Information on South Sudan Context

Protracted conflict in South Sudan has contributed to an extended humanitarian crisis, which has been exacerbated by unusually high levels of flooding and the COVID-19 pandemic. Although conflict has reduced between parties to the Revitalized-Agreement on the Resolution of Conflict in the Republic of South Sudan (R-ARCSS), violence has continued in many territories of the country, threatening to reverse gains made at the national level since the peace agreement was signed in September 2018.

The South Sudan HRP, launched in March 2022, indicates that 8.9 million people, including refugees, will need humanitarian and protection assistance in 2022. Among them, an estimated 8.3 million people are expected to experience severe food insecurity by the peak of the lean season from May to July 2022. SO1-2 focus on immediate and emergency needs, specifically in high-priority locations, for HI this includes including Pibor (priority-1), as well as Bentiu and Aweil South (priority-2). According to the intersectoral severity of needs analysis, humanitarian needs are most concerning in Fangak, Duk and Pibor counties in Jonglei and Cueibet and Rumbek



East counties in Lakes, which were classified as in catastrophic need. People in 71 counties face extreme needs, while two are in severe need.

More than 5.6 million people are at higher protection risks in general, with persons with disability being the most adversely affected. The World Health Organization (WHO) Global statistics show that 15% of the World population are persons with disability. This implies that approximately 1.3 million people in South Sudan are persons with disability. Yet, this figure, in light of the impact of the past two major wars and the persisting sub-national conflict can be described as a gross understatement of the reality in the country.

Furthermore, WHO estimates the prevalence of mental disorders to be approximately 2.5M in conflict settings of South Sudan; this constitutes approximately 22% of the country's population at risk of developing long-term impairment. Despite the magnitude of the disorders, Healthcare systems have been affected. The vast proportion of the most vulnerable, particularly persons with physical and mental disabilities, find themselves excluded from the limited services. Those needing mental health and functional rehabilitation services are hardly able to walk long distances through high-risk routes on their own, particularly in counties that lie deeper from the main urban areas, necessitating the need to deliver quality services closer to their villages of origin.

While progress in mainstreaming disability inclusion in humanitarian assistance has made some traction nationally, the inability to adequately reach persons with disabilities in deeper lying counties/locations has been connected to, on one hand, the inadequate qualitative assessment of the magnitude of the needs, and challenges they face by humanitarian actors, and on the other the limited capacity of humanitarian actors to assess and respond in a manner that meaningfully responds to the voice of the persons with disabilities. Due to the prevalence of 'scarcity of everything', people with disabilities remain primary victims of institutional, attitudinal, environmental, and structural barriers that hinder them from accessing basic services. Women, girls, children, and older persons are often subjected to discrimination and marginalization due to the intersectionality of gender and disabilities.

In South Sudan, from 3 January 2020 to 18 August 2022, there have been 17,780 confirmed cases of COVID-19 and 138 deaths, reported to WHO. As of 14 August 2022, 1,623,564 vaccine doses have been administered. Currently there is no travel restrictions to enter the country other than having a Covid certificate and negative PCR results.

The humanitarian access environment remained challenging, with continuous outbreaks of sub-national violence in Unity, Jonglei, and Warrap states. Military operations in parts of Central Equatoria against organized armed groups continued to displace people, making it difficult for humanitarian actors to reach them. Bureaucratic impediments and operational interference remained a challenge for humanitarians. Cattle migrations into Central and Eastern Equatoria continued to cause tensions between cattle keepers and hosts, leading to growing insecurity, population displacement, and exacerbated humanitarian needs.

A United Nations Commission on Human Rights in South Sudan report released in March 2022 highlights widespread sexual and gender-based violence across the country and calls on



the government to address the issue through security-sector reform, and greater policing, with support from the UN mission and humanitarian agencies. South Sudan's GDP per capita in 2020 was \$747.7, with rising inflation and a 42% increase in the cost of food and basic commodities since 2021. Rising prices of oil throughout March 2022 – peaking at \$110 per barrel is likely to have a positive economic impact on South Sudan's economic outlook.

Why the study

Disability data gaps continue to persist globally as well as at national level in South Sudan. Data sources have been too scattered and disaggregation by disability has been overlooked. Where the data does exist, it often remains hidden and unused. While this is happening, people with disabilities will continue to be excluded, and we will be left with a critical development gap. Disability data is more than just numbers - it tells the story of people's lives.

It is estimated that one billion people have a disability globally, 80% of whom live in developing countries (World Report on Disability 2011). According to the World Health Organization, 15% of the world population has a disability including 93 million who are children, 13 million of those experiencing severe difficulties. According to the South Sudan census 2008, 5.1%, are known to have one or more impairments. Despite this official figure from the last census conducted in South Sudan, reality points to a much bigger figure. Because of the conflict, it is estimated that the proportion of persons with disabilities increased because of violence, mishap, mines, and unexploded ordinances, other effects of war, and issues that might be congenital. People with disabilities face greater challenges to access services, with greater challenges experienced among women, children with disabilities (75 percent perceive having less access to services, food, and education) and among the older persons. Anecdotally, there are greater protection risks for women and girls with disabilities. People with disabilities report high levels of stigma and discrimination especially when they have neurological and mental health conditions. Barriers to equitable access that people with disabilities face are often exacerbated within low- and middle-income settings.

The study will enable to better contextualize the available quantitative data. The report will support the advocacy efforts towards the ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and monitoring of the Sustainable Development Goals (SDGs). It will be a valuable resource as we work together to lead a national change for better data, to ensure that all people with disabilities, no matter who they are or where they are, are truly included.

On 3 December of every year, South Sudan joins the rest of the world in commemorating the International day for Persons with Disabilities. People with disabilities, governments, donors, the private sector and civil society will come together, this is a huge opportunity to present improved disability data, and crucial to ensure that commitments are made in line with the Sustainable Development Goal related to “leave no one behind”. Jointly with our partners, the outcome of this study shall be presented to relevant clusters, and the key advocacy points identified will be used to influence policy and action on Disability and Inclusion in South Sudan.



1. Objectives of the study

Purpose of this project aims to gather existing data from different states across South Sudan in one place to provide an important snapshot of the situation for people with disabilities in the country. It will identify the available data as well as existing gaps to inform the humanitarian community on the data gaps and data collection effort needed to build a clearer picture.

The study is aimed at gathering, assembling and analyzing the available data sets to produce a comprehensive report that has national representation and can be the reference point for disability data. The findings of the study shall lead to a greater understanding of the lived experiences of people with disability and their effect on the ability of person with disability to enjoy their rights, participate in community affairs and access services.

The study will also allow for the development of evidence-based approaches to combat stigma and discrimination toward people with disability in the context of South Sudan. The findings of this study will be used to develop context specific operational recommendations for HI programming and advocacy that aims to improve inclusion of persons with disability in South Sudan.

2. Expected Methodology

HI will engage services of a consultant to conduct systematic review of existing data on disabilities in South Sudan. The Consultant is expected to fine tune the research question and literature review. With support from HI, the consultant will conduct mapping and selection of appropriate studies to be included into the analysis. The analytical framework and eligibility criteria will be proposed and agreed upon with the consultant. The report will be subjected to series of quality control measures such as Peer reviews and validation meetings. These are aimed at making sure that the data is accurate, relevant and significant as much. To ensure a robust analysis, the study will include both quantitative and qualitative data sources. This will enable the study to capture not only the numbers such as prevalence rates but also the daily living experiences of persons with different types and severity levels of disabilities.

3. Ethical principles

The protocol for this study must respect and ensure the application of the following ethical principles:

- The activities related to the study are safe for the participants;
- The obligation to inform is respected;
- Mechanisms to ensure the confidentiality of data and information are put in place;
- The people involved in the implementation and monitoring of the study are experts and professionals;
- Each participant gives consent to participate in the survey.

Recommendations:

- Guarantee the security of subjects, partners and teams



- Ensure a person / community-centered approach
- Obtain the subjects' free and informed consent
- Ensure referral mechanisms are in place
- Ensure the security of personal and sensitive data at all stages of the activity
- Plan and guarantee the use and sharing of information
- Ensure the expertise of the teams involved and the scientific validity of the activity
- Obtain authorization from the relevant authorities and organize an external review of the proposed study/research

The protocol must respect and follow HI policies:

- Description of the mission, scope, principles of intervention and charter
- Quality framework: Project Planning, Monitoring and Evaluation Policy
- HI Policy on Protection of Beneficiaries from Sexual Exploitation and Abuse
- HI Child Protection Policy
- HI Anti-Fraud and Corruption Policy
- HI Gender Policy
- Code of Conduct: Prevention of abuse and protection of people

Mission requested

1. General objective of the consultant's mission

The consultant will be responsible for the set-up (final research protocol & administrative authorizations), implementation (data collection, processing & analysis), follow-up and valorization of the study/research results.

The consultant(s) is/are the person(s) responsible:

- To provide a research methodology and tools for the study.
- Recruit and train interviewers for the study in question if necessary.
- Collecting/assembling data in collaboration with interviewers, particularly to facilitate the identification and introduction of resource persons.
- Analyse and interpret the data that has been collected.
- Present preliminary analyses to relevant stakeholders to enrich recommendations.
- To ensure the production of the report and to integrate the necessary corrections.

2. Deliverables

	Deliverables	Recipients	Broadcasting	Delivery times
Technical documents related to the implementation of the study				
1-	A research protocol and tools	HI	Internal	Beginning of November
2-	Completed Analysis study	HI	Internal	End of mission
3	A workshop to present the results and recommendations in the form of a PowerPoint document to all the partners concerned.	HI and Partners	External	At the end of the collection
Progress/ summary/ dissemination documents				
4-	An interim report containing the analysis of the data	HI	Internal	Mid-term
5-	A final report of maximum 40 pages (in word version) including compilation of comments from the workshop and infographics. Co-design of the report structure with HI team based on preliminary result.	HI	External	End of mission
6 -	A summary of the study result of maximum 3 pages	HI	External	End of mission

The consultant accepts the possibility that HI may reproduce the methodological proposal and use the tools developed for data collection in other contexts and projects.

Communication and monitoring mechanisms between the consultant and HI

The consultant's main contact is the HI office in South Sudan and more particularly the Operation Manager/Head of Programme

Key Tasks and time frame

The consultancy will cover approximately a total of 2 months

Task	Time Frame
Development of ToRs and recruitment of Consultant	21 st of October
Development and validation of research protocols(assembling of data)	31 st of October
Data analysis and drafting of plenary findings/ draw out key findings	1 st November



Feedback and validation workshops	21 st November
Presentation of final report (internal)	30 th November
Presentation of final report (external)	3 rd December

Profiles Sought

Experts in human and social sciences - anthropology/sociology/political science etc.), 10 years' experience in conducting studies including secondary data analysis.

Expertise

- Minimum qualification: Master's degree in Human and Social Sciences or political science.
- 10 years' experience in conducting Studies especially meta-analysis studies.
- Experience in the field of disability
- Knowledge of cultural context of South Sudan is a plus.
- Established and proven experience in data collection, processing and analysis methods(qualitative)
- Demonstrated ability to analyze, synthesize and write reports (provide a list of publications)
- Capacity to train and manage a team of researchers
- Good command of English language
- Experience in participatory research approaches and gender.

How to apply

Applications must be submitted through an email to: tender@southsudan.hi.org on or before **17 October 2022**

a) For the lead partner(s) :

- Curriculum vitae (education, experience in the above-mentioned fields, lists of main publications) of the key persons responsible for the study if possible.

b) For the technical proposal :

A methodological proposal for carrying out the study, highlighting at least: a clear understanding of the issues addressed in the study and the terms of reference; the context of the study; the presentation of the objectives (general and specific); the location; the target population; a presentation of the methodological framework; the design of the study, the selection of



participants, the mechanisms for collecting, processing and analyzing the data and monitoring quality; ethical considerations.

A timetable clearly specifying the activities for the implementation, execution, monitoring, and operation of the study.

c) A financial proposal

A financial proposal indicating at least the consultancy and operational costs of the study (travel, accommodation, daily interviewers, remuneration of interpreters,).