

Resilience and inclusion project for health and improved living conditions for women, children, and people with disabilities in Lakes State and Warrap State

TOR for the Study on disability in Lakes State and targeted counties in Warrap State

AID12869

Background

According to OCHA¹, people with disabilities account for 15 percent of those in need of humanitarian aid. In Lakes State, an estimated 20 percent of households have at least one member with any form of physical or cognitive impairment. Yet, in 2023, patients with disabilities who accessed Health Pooled Fund-²supported health facilities in Lakes State were less than 1 percent of all outpatients. The access of people with disabilities to health care facilities is determined or influenced by multiple factors, related to their natural and social environment, their educational and economic resources, the level of discrimination experienced in their families and/or community and/or services, their physical and psychological state. **Access is particularly limited for vulnerable groups**, such as pregnant women and children with disabilities, whose intersecting needs (gender, age, disability) further compound exclusion. In Lakes State, the number of pregnant women with disabilities reported by prenatal clinics was found to be less than 1 percent of all women who accessed the service. It is easy that the low number of pregnant women with disabilities reaching the health facilities is due to the increased barriers faced by this group of patients, who already face barriers related to their gender and pregnancy, due to disability. Regarding Warrap State, it is difficult to find information through international sources regarding the condition of pregnant women with disabilities. However, study conducted in Gogrial West, Warrap State, highlighted that antenatal care coverage is low, with only 32% of women receiving such care.³ Furthermore, less than 2% of deliveries occur at clinics with skilled attendants. Factors contributing to these low figures include a lack of qualified health personnel, inadequate healthcare infrastructure, and sociocultural barriers. While specific data for pregnant women with disabilities is lacking, women with disabilities in Warrap State face compounded challenges. These include physical barriers to accessing healthcare facilities, lack of assistive devices, and societal stigma. For instance, during a focus group organized by UNMISS, women with disabilities reported being excluded from community support and lacking access to justice, education, and employment opportunities.⁴

¹ [Global Humanitarian Overview 2021 | Humanitarian Action](#)

² Health Pooled Fund, a consortium of funding and implementing agencies led by the UK government and jointly funded by the Governments of the United States, Canada, Sweden, the EU delegation, GAVI Vaccine alliance and sustaining South Sudan Health System from 2012 to 2024.

³ [A mixed methods assessment of barriers to maternal, newborn and child health in gogrial west, south Sudan - PMC](#)

⁴ [Living in shadows: Disabled women speak at their first-ever focus group in Warrap | UNMISS](#)



These data show how far we are from inclusive health care. On the one hand, people with disabilities certainly face greater impediments when trying to access it, both from the demand and supply side, considering their fear of stigma and the geographic and economic barriers for those who often depend on their relatives and neighbours to travel and/or bear any indirect costs of care. On the other hand, health care personnel are not always able to identify patients with disabilities and register them as such. Disability is a very complex state that is difficult to manage, especially for staff who are unqualified or who have not experienced this type of caseload. In addition, people with disabilities assisted for any matter unrelated to their peculiar status are rarely reported with the specification of their disability. All these elements explain the poor (likely under) reporting: the Ministry of Health's district health information system (DHIS2) does not have a specific session on disability and does not include any indicator dedicated to the issue of disability, which makes it difficult to understand the extent of need and monitor the level of responses. This only complicates obtaining adequate and especially medium- to long-term funding, such as that required by chronic issues. This is evidenced by the fact that HSTP, unlike HPF, provides no activities and, therefore, no funds for these issues.

The project titled "Resilience and inclusion project for health and improved living conditions for women, children, and people with disabilities in Lakes State and Warrap State", funded by the Italian Agency for Development Cooperation (AICS) and implemented by a consortium led by the NGO Doctors with Africa CUAMM (CUAMM) and including Amref Health Africa ETS, Amref Health Africa in South Sudan, CBM Italia ETS and CBM International, seeks to bring attention to an issue that the new financing mechanism of the South Sudanese health care system seems to ignore, providing no resources or initiatives that can promote people with disabilities access to and use of both services dedicated to their specific needs and to the more general health care. This is particularly relevant for those groups where a disability status goes to further increase other vulnerabilities and related barriers to be overcome in order to benefit of any services, as those determined by gender and age. This is because it was decided to target pregnant women and children first and foremost, to make maternal and child health care as inclusive as possible, while at the same time seeking to reduce the risk and impact of disability in these groups through prevention and early identification and initiation of treatment.

The proposed intervention focuses on training health care personnel to make the facilities at which they work more accessible and responsive to people with disabilities, entry points for both general and specific care for their unique conditions. Thus, there will be a focus on identification and management of the patient with disabilities in a broad sense and the proper collection and transmission of related data. At the same time, however, we will look at the quality of services provided so that they can play an active role in the prevention and containment of disability. Thus, continuity will be given to previous AICS-funded initiatives (most recently AID11959), working on improving staff capacity in preventing, identifying and following up early on disabilities during gestation and delivery and the early months of a child's life, as a complementary initiative to improve the quality of maternal and new-born care.

It's on this background that CBM International intends to hire a qualified consultant to conduct an assessment on disability status in Lakes and Warrap state and on the extent the existing health system is responsive to the needs of people living with disability, in particular pregnant women and children

Purpose of the assessment

The low access to and use of health services by people with disabilities, in spite of these latter representing a quite significant percentage of total population, suggests a real disparity between people with and without disabilities in benefiting from the available care.

The proposed assessment aims to get evidence to understand the extent of this disparity and its deeper causes in the particular context of the project area, in order to enable local authorities and their partners to implement interventions that sufficiently respond to local needs in terms of protection and inclusion of people with disabilities.

Objectives of the consultancy

CBM is seeking highly qualified consultant to conduct an assessment on disability status in Lakes and Warrap states, specifically in selected Health facilities and locations where the mentioned project is taking place

The overall objective of the consultancy is to assess the current situation in relation to existing key barriers to accessing maternal, child health (MCH) and early childhood development (ECD) services for mother and children with disabilities in Lakes and Warrap States. This includes evaluating the knowledge, attitudes and practices of health personnel, cultural barriers and community beliefs, existing referral systems and services availability, affordability, acceptance and quality. In particular, the consultancy will have the following objectives:

1. Provide up-to-date, area-specific data on disability (prevalence, demographic characteristics, type), with particular attention to those factors (e.g., gender and poverty) that profoundly influence the experience of disability, especially in terms of access to opportunities and resources
2. Assess the needs of people with disabilities in health and nutrition, with a view to sustainability and not just vulnerability.
3. Map current referral pathways and stakeholders related to disability services.
4. Review relevant policies, guidelines, and good practices on inclusive health programming
5. Assess the availability, accessibility, affordability, quality and responsiveness of MCH and ECD services to the needs of mothers and children with disabilities, including the perceived quality of care received and concrete experiences of persons with disabilities in the health services

6. Understand the knowledge, attitudes, and practices of health care providers regarding disability inclusion
7. Understand local communities' perceptions and level of awareness about disability and health services available to people with disabilities.
8. Identify possible solutions (practical, feasible, sustainable and acceptable) to reduce disparity in access to health services (e.g., access ramps, alternative communication tools, simplified versions of information materials).

Key deliverables: The consultant is expected to deliver the following:

1. Study protocol and all related documentation (including data collection tools) to be presented to the Research Ethical Review Board of the South Sudan Ministry of Health
2. An Inception Report drawing on existing data;
3. A detailed high quality full assessment report whose content should align with the objectives of the assessment, with key content including but not limited to:
 - All relevant registration records of the MCH OPD departments and clinics, the Physiotherapy dept. and other resources;
 - Potential attitudinal and cultural barriers related to local beliefs and attitude towards children with disabilities among health staff, families and community members;
 - Potential attitudinal, physical, educational, cultural barriers faced by people with disabilities (pregnant women and children in particular) to access health and ECD services;
 - Recommendations on how to address the above mentioned barriers;
 - Clear mapping of referral networks for people with disabilities (pregnant women and children in particular) to access social protection, assistive devices, nutrition support act.;
 - Mapping of potential stakeholders to be engaged in promoting people with disabilities access to health and social assistance, in particular pregnant women and children;
 - List of relevant policies and guidelines;
 - List and review of existing research on Disability inclusion in South Sudan, highlighting the proposed base recommendations and tools for tailor-made but aligned approach.
 - List of existing best practices and recommendations for their implementation as part of an Inclusive MCH programme in the intervention context situation.
 - Recommendations for a longer-term, sustainable inclusive health service plan which address the barriers to access health services in a multisectoral approach.

4. A detailed work plan and methodology which defines timeframes of the consultancy and plan for the travels.
5. Tools for disability disaggregated data collection aligned with Washington Group criteria (if applicable)
6. Presentation of findings to project consortium members and national/state/county health authorities, community representatives and key stakeholders

Purpose of the assessment

The purpose of the assessment is twofold:

- 1- Retrieve data and information related to persons with disabilities in Lakes and Warrap State;
- 2- Guide CBM International team in reviewing contents and teaching modalities for the training initiatives on disability and inclusive services addressing project targeted facilities staff, to ensure that these are aligned with the needs of the communities that should benefit from those services and responsive to the experiences and perceptions of people with disabilities regarding the health system.

Methodology

The consultant is expected to propose a suitable methodology, including qualitative and quantitative data collection methods, and tools which are inclusive, aligned with international disability inclusion standards and respectful of South Sudan Ministry of Health Research Ethics Review Board. Qualitative data collection will take place through facility assessments and conduction of semi-structured interviews with key informants (e.g., local leaders, health authorities, CSOs/OPDs) and Focus Group Discussions (FGDs) with people with disabilities, caregivers, health workers, and community members. The data collection will consult and involve persons with disabilities and their families to ensure their voice, choice and rights are well presented in the study and recommendations. Furthermore, the consultant will work closely with the program and the monitoring and evaluation team of CBM, South Sudanese Union of Person with Disabilities (SSUPD) and the implementing partner to ensure that proper data is collected and the tools are in line with the objectives of the assignment.

Quantitative data collection will take place through the completion of a questionnaire, the information from which will then be supplemented with information already available locally.

derived from the Washington Group Set of Questions and/or kept at the South Sudanese Union of Persons with Disabilities.

The consultant will report to the CBM International South Sudan Country Program Manager work closely with the program officer for IHA/CBID (Inclusive Humanitarian Action and Community-Based Inclusive Development) Initiatives and the implementing partner ADA (African Development Aid).

Roles and Responsibilities of CBM:

- Conduct entry meeting with the consultant to induct him on the project and the intended outcomes of the assessment
- Provide to the consultant clear and detailed information on the activities of the project and what is required from the assessment
- Support and coordinate the logistics related to the consultant's travels and movements including statutory documents if needed
- Provide feedback / support during the implementation of the assessment
- Ensure that the consultant is link with focal points persons including government and humanitarian agencies
- Review the consultancy report and provide feedback where necessary

Assignment Duration

The assessment is expected to be done in 30 days of concrete commitment, ideally starting from 14th June. As per the end date, the consultant and team will have to consider waiting time after the submission of the scope of work document to the Ethics Committee of the Ministry of Health. Therefore, the final timeline will be discussed with the successful consultant upon contracting.

The draft report is due indicatively by 20th of July, the final report by the 30th of July.

Required Qualifications

The ideal consultant should have:

- Experience and knowledge or background in rehabilitation, public health, or related medical fields
- Knowledge and proven experience on disability inclusion, inclusive health or child development and project locations
- Familiarity with WQSQ to capture the questions around disability in the hospital facilities health centres



- Understanding of the South Sudanese context (preferable in Lakes and Warrap States) and/or previous work experience in similar settings.
- Strong skills in qualitative research and participatory approaches
- Strong analytical skills
- Fluency in English (written and spoken) and Juba Arabic.

The terms of reference are subject to modification without changing the objective of the project, scope of work on mutual consultation.

Expression of interest

The applicant should submit an expression of interest including an organization profile, technical and financial proposal, resume, professional references, evidence of similar assignment conducted in the past and detail work plan.

The expression of interest should be sent to info.southsudan@cbm.org electronically not later than **16th June 2025**.

