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Unmet Healthcare Needs and Barriers to Care among Individuals with Disabilities in Dongola Localty, Northern State , Sudan 2026.

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A- Introduction

Background:

According to the World Health Organization (WHO) and the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), disability is defined not merely as a medical or biological impairment, but as a complex, dynamic interaction between an individual's health condition or impairment (such as physical, visual, hearing, or intellectual) and environmental and attitudinal barriers that hinder their full and effective participation in society on an equal basis with others [1, 2].

An estimated 1.3 billion people worldwide — about one in six — live with a significant disability, and roughly 80% are in low- and middle-income countries [1]. Relative to the general population, this group faces close to double the odds of encountering inadequate provider skills or facility infrastructure, triple the odds of being denied care outright, and quadruple the odds of poor treatment once they do reach a facility — contributing to a life-expectancy gap that can reach two decades [1].

Sudan ratified the UN Convention on the Rights of Persons with Disabilities in 2009 and, in 2017, replaced its earlier legislation with the Persons with Disability National Act, which established the National Council for Persons with Disabilities — a body overseen by the Presidency, with half its membership drawn from disability organizations themselves, and mandated to register and represent people with disabilities nationwide through state-level branches such as the one in Northern State [2].

Since April 2023, the conflict between the Sudanese Armed Forces and the Rapid Support Forces has displaced an estimated 11.5 million people and left over a third of the country's health facilities non-functional [3]. WHO now describes Sudan's as the world's largest ongoing health crisis, with more than 21 million people — out of 33.7 million in need of humanitarian assistance overall — requiring health assistance in 2026 [3]. For a population that already faced disproportionate financial, geographic and institutional barriers to care before the war [1], this collapse in service capacity raises the likelihood that unmet healthcare needs among people with disabilities have deepened in ways no current data has captured.

Problem Statement:

Evidence from other settings consistently shows people with disabilities facing more unmet healthcare needs and more barriers to care than the general population. A national linked-data analysis in Korea found self-reported unmet healthcare needs running significantly higher among registered persons with disabilities compared to those without (13.2% vs. 10.1%), traced mainly to functional limitations and low income rather than disability status on its own [4]. In Ethiopia, a survey among adults with physical disabilities found that only 25.4% had "good" access to healthcare, with physical/transportation barriers affecting 61.5%, medical equipment barriers affecting 62.7%, and communication difficulties affecting 59.3% of respondents [5].

The only multi-country data that includes Sudan directly—collected in 2011–2012 across Khartoum, Kassala, White Nile, and Kordofan—revealed that Sudanese respondents reported significantly higher perceived barriers to care than their counterparts in Namibia, Malawi, and South Africa across nearly all measured indicators [6].

However, this Sudan-specific evidence is now well over a decade old. It predates the 2017 Disability Act, the current National Council structure, and—most importantly—the ongoing conflict since 2023 that has left over a third of health

facilities non-functional [2,3]. Currently, no published study has evaluated unmet healthcare needs or barriers to care among the registered disability population in Northern State, and none has utilized the Disability Council's official registry as a sampling frame—despite it being the most complete, legally mandated database in the state.

Justification:

Researching healthcare access among individuals with disabilities in Dongola is essential for two main reasons. First, sampling through the Disability Council's official registry ensures a representative sample across all disability types (motor, visual, hearing, and intellectual). Unlike hospital-based studies that only capture people who reached care, the registry includes individuals facing complete barriers to health services.

Second, available data on disability barriers in Sudan is over ten years old and predates the current health system crisis. Assessing these unmet needs now provides health authorities in Northern State and the Disability Council with updated, evidence-based data needed for inclusive health planning and advocacy.

Research Objectives:

1. General Objective

To assess unmet healthcare needs and barriers to healthcare access among individuals with disabilities with the Disability Council in Dongola Localty ,Northern State , Sudan in 2026.

2. Specific Objectives

- To determine the proportion of registered individuals with disabilities reporting unmet healthcare needs in the preceding 12 months.
- To identify and classify the barriers to healthcare access reported by respondents into financial, geographic and institutional categories.
- To describe how unmet needs and barriers vary across disability types (motor, visual, hearing, intellectual and others).
- To examine the association between sociodemographic characteristics (age, sex, education, residence) and the likelihood of reporting unmet healthcare needs.

Study Hypotheses:

- Null Hypothesis (H0): There is no difference or correlation between the study variables (sociodemographic

characteristics such as age, sex, education level, and residence) and the presence of unmet healthcare needs among individuals with disabilities in Dongola.

- Alternative Hypothesis (H1): There is a statistically significant difference or correlation between the study variables (sociodemographic characteristics such as age, sex, education level, and residence) and the presence of unmet healthcare needs among individuals with disabilities in Dongola.

B- Literature Review

Global study:

Using linked data from Korea's National Health and Nutrition Examination Survey and national insurance records (2013–2021), this analysis compared unmet healthcare needs (UHN) between 1,799 registered persons with disabilities and 24,634 people without [4]. Guided by Andersen's Behavioral Model, predictors were grouped into predisposing factors (age, sex, education), enabling factors (income, insurance, employment) and need factors (self-rated health, functional limitations). People with disabilities reported significantly higher UHN (13.2% vs 10.1%). Once the full set of variables was accounted for, disability status on its own stopped being a significant predictor — the gap was explained instead by functional limitations, low income and poor self-rated health, with women and those with mobility problems the most affected within the disability group.

African study:

This cross-sectional study sampled 327 adults with physical disabilities from the membership registries of six disability associations in Hawassa, Ethiopia [5]. Access to healthcare was strikingly poor: only 25.4% of respondents were classed as having "good" access, and nearly three in four reported at least one barrier, most often physical/transport barriers (61.5%), problems with medical equipment (62.7%) and communication difficulties (59.3%). Being male, being married, having costs covered by an NGO, and reporting no experience of discrimination were all linked to significantly better access.

Local study:

Part of the multi-country "EquitAble" project, this population-based household survey covered 9,307 people across Sudan, Namibia, Malawi and South Africa, with four Sudanese sites: Umbada (Khartoum State), Kassala, Rabak (White Nile) and Shikan (Kordofan) [6]. Disability was identified using the Washington Group six screening questions, and respondents rated 18 possible barriers to care. Transport, service availability, drug/equipment shortages and cost were the four biggest

barriers overall — but Sudan stood apart from the other three countries, scoring significantly worse on almost every barrier except transport and faith/belief. Unusually, barriers in Sudan increased with education level rather than decreasing, the opposite of the South African pattern.

C- Materials and Methods

Study Design:

A descriptive cross-sectional study.

Study Area:

Dongola, the capital of Northern State, Sudan, on the east bank of the Nile. Dongola town has a population of roughly 56,000, within a wider Northern State population estimated at just under one million. Data collection will take place at the headquarters of the Northern State Disability Council and through the Council's registry of individuals with disabilities across the locality.

Study Population:

Source population: all individuals with disabilities residing in Northern State.

Study population: individuals with disabilities registered with the Northern State Disability Council in Dongola localty , across all disability types (motor, visual, hearing, intellectual and others), with no restriction to a specific category.

Inclusion Criteria:

- Registered with the Council in Dongola at the time of data collection
- Any age, any disability type
- The individual, or their parent/legal guardian, consents to participate

Exclusion Criteria:

- Registration records that are incomplete or cannot be located
- Not reachable after repeated attempts during the data collection period
- Refusal to consent, by the individual or their guardian

Study Period:

The study will be conducted over a period of 11 weeks (from September 20 to November 30, 2026), encompassing proposal finalization, ethical approval, field data collection, data analysis,

and final report writing. Field data collection will specifically take place from October 4 to October 22, 2026.

Proxy Respondents:

For individuals with intellectual disabilities, or children unable to respond independently, a parent or legal guardian will be interviewed as a proxy respondent, reporting on the individual's healthcare-seeking experience and the barriers encountered. Where the individual can partially communicate, their own responses will be sought first and supplemented by the guardian.

Sampling:

Sample size: Calculated using the single-proportion formula (n = Z^2 * p(1-p) / d^2) with Z = 1.96, p = 0.5, and d = 0.07, yielding n = 196. Adding a 10% non-response allowance brings the final target sample size to 216 registered individuals.

- Sampling technique: Systematic random sampling will be used based on the Council's complete registry list. If full access is unavailable, convenience sampling of attendees will be used with proportional quotas across disability categories.

Methods of Data Collection:

Data will be collected through a structured, interviewer-administered questionnaire because a meaningful share of the study population has visual, hearing or intellectual impairments that make independent form-filling unreliable. The questionnaire will have four parts: (1) sociodemographic characteristics, (2) disability type and severity, Using the Washington Group Short Set already validated in comparable studies, (3) healthcare-seeking behavior and unmet needs in the past 12 months, and (4) barriers experienced, grouped into financial, geographic and institutional items drawn from the tools used in the studies already reviewed .

For visually impaired respondents, questions will be read aloud and answers recorded by the interviewer. For Deaf or hard-of-hearing respondents, a sign-language interpreter (coordinated through the Council) or written exchange will be used. For intellectual disabilities and children, the proxy-respondent approach described under Study Population applies. The tool will be piloted on a small group of Council members not included in the final sample before full data collection begins.

Study Variables:

Outcome variables: unmet healthcare need (binary — needed care in the past 12 months but did not receive it); type of barrier reported (financial / geographic / institutional / none).

Independent variables: sociodemographic (age, sex, marital status, education, residence, employment); disability-related (type, severity, duration since onset); health-system-related (distance to nearest facility, insurance status, cost coverage by family/NGO).

Data Analysis:

Data will be entered and cleaned in SPSS. Categorical variables will be summarized as frequencies and percentages, continuous variables as mean ± SD or median (IQR) depending on distribution. The chi-square test will assess associations between categorical variables and unmet healthcare need, and binary logistic regression will identify independent predictors, reporting adjusted odds ratios with 95% confidence intervals. A p-value < 0.05 will be considered statistically significant.

Ethical Clearance:

Ethical approval will be obtained from the Faculty of Medicine's Research Ethics Committee prior to data collection.

Research Plan:

The study proceeds in five phases: (1) ethical approval and Council permission; (2) finalizing and piloting the tool; (3) sampling and data collection; (4) data entry, cleaning and analysis; (5) report writing and seminar preparation.

D- Timeline

ACTIVITY	TIME FRAME
Submission of Research Proposals	September 20–24, 2026
Presentation of Research Proposals	September 27–October 12, 2026
Data Collection	October 4–22, 2026
Data Analysis	October 30–November 08,2026
Writing and Discussion of Results	November 09-18, 2026
Writing Final Report	November 19- 21, 2026
Electronic Submission of Research to Department	November 22_25,2026

Research Assessment / Evaluation	November 26_27,2026
Research Revisions and Modifications	November 28_30,2026
Research Defense / Viva	December 01_02,2026

E- Budget

CATEGORY	ESTIMATED COST (SDG)
Printing & Photocopying	75,000
Study material	25,000
Field Work & Transportation	150,000
Internet	40,000
Data Analysis & Processing	100,000
Final Publication & Reporting	100,000
Total Estimated Budget	**490,000 SDG**

F- References:

1. World Health Organization. Global Report on Health Equity for Persons with Disabilities. Geneva: WHO; 2022.

2. Republic of Sudan. The Persons with Disability National Act, 2017.

3. World Health Organization. Public Health Situation Analysis – Sudan Conflict and Complex Emergency. Geneva: WHO; 2026.

4. Lee B. Determinants of Self-Reported Unmet Healthcare Needs by Disability Status: A Secondary Cross-Sectional Analysis of Linked National Survey and Administrative Data from Korea. Healthcare. 2026;14(12):1748.

5. Tesfaye T, Woldesemayat EM, Chea N, Wachamo D. Accessing Healthcare Services for People with Physical Disabilities in Hawassa City Administration, Ethiopia: A Cross-Sectional Study. Risk Management and Healthcare Policy. 2021;14:3993–4002.

6. Eide AH, Mannan H, Khogali M, van Rooy G, Swartz L, Munthali A, Hem KG, MacLachlan M, Dyrstad K. Perceived Barriers for Accessing Health Services among Individuals with Disability in Four African Countries. PLoS ONE. 2015;10(5):e0125915.

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