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Roadblocks and pathways to inclusion:

Access to Sexual Reproductive Health services for women with disabilities in Uganda

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Abstract

This policy brief investigates the accessibility of Sexual Reproductive Health (SRH) and family planning services for women with disabilities in Uganda. National policies lack specific provisions for individuals with disabilities, especially women, constraining their ability to access SRH services. Employing an intersectional lens and based on interviews and focus group discussions conducted in Kampala and Kalangala, this study examines the barriers that hinder these women from accessing SRH services. It discovers three influential factors: (1) environmental barriers, (2) family dynamics, and (3) individual identity characteristics.

Findings revealed environmental barriers like societal beliefs, lack of awareness, and healthcare system limitations impact access. Family dynamics emerged as both enablers and constraints, offering support but sometimes imposing conditions due to financial or societal pressures. Individual identity characteristics such as financial independence, education level, type of impairment, and religious values significantly affected SRH access.

'Breaking down Barriers' was initiated by Liliane Foundation to contribute to more effective and evidence-based policies and programmes in the field of disability inclusive development. It does so by bringing together civil society organisations and researchers from the Netherlands, Cameroon, Sierra Leone and Zambia.

Recommendations include community awareness initiatives, specialised healthcare training, empowerment programs emphasising education and independence, and the promotion of accessible infrastructure and transport. These interventions would create inclusive pathways to SRH empowerment for women with disabilities by addressing barriers at societal, familial, and individual levels.

Rupankar (left) in conversation with a girl with a cognitive disability (middle), accompanied by Irene, the enumerator and research assistant (right), based in Kalangala

Introduction

Sexual Reproductive Health (SRH) and family planning services are crucial for public health. However, national policy guidelines in Uganda lack the specific provisions for addressing the unique needs of individuals with disabilities, particularly women. This policy brief examines the accessibility to SRH and family planning services for women with disabilities in Uganda.

A lack of awareness and understanding of SRH needs among women and girls living with disabilities is a critical concern in Uganda. Prevalent societal beliefs are that individuals with disabilities are not sexually active, leading to their exclusion from educational initiatives on reproductive health. This misconception, rooted in harmful stereotypes, hampers the communication of essential SRH and family planning knowledge, intensifying the challenges faced by women with disabilities.

The existing national policy guidelines, established following the 1994 Cairo International Conference on Population and Development, outline the eligibility criteria for FP services, emphasising education, counselling, and medical considerations. A notable oversight exists as the guidelines primarily focus on the needs of the able-bodied population. The implementation of SRH policies generally falls short for women and girls with disabilities. Their distinct needs remain inadequately addressed, resulting in a significant disparity between able-bodied women and those with disabilities in accessing essential SRH and family planning services.

This policy brief examines the barriers that women and girls with disabilities face when accessing SRH services. An intersectional lens has been employed that helps to understand the unique challenges faced by women with disabilities regarding SRH. It starts from the premise that different identities intersect to create unique barriers or advantages for individuals that influence their experiences and ability to access SRH services.

Methods

The research was conducted in both the semi-urban area of Kampala and the rural district of Kalangala in the Sesse Islands of Uganda. This diverse selection aimed to capture the nuanced challenges faced by women with special needs in different contexts. Kalangala, known for its high HIV rates, was chosen to understand the vulnerabilities of women with disabilities in one of the poorest districts. In contrast, Kampala, the semi-urban setting, was expected to provide insights into the potential disparities in SRH access and service provision.

Purposive sampling was employed, facilitated by local NGOs in Kalangala and Kampala. Respondents were selected based on their beneficiary or target group status from NGO lists, ensuring that individuals with lived experiences relevant to the research were chosen. The criteria for selection included women with special needs, diverse types of impairment, varied ages between 18-31, and a mix of identities such as disability status, age, and religion. The goal was to create a diverse sample reflecting the intersectionality of challenges faced by women with disabilities in accessing SRH and FP services.

Distributed across both sites, the study involved 16 individual interviews and 16 focus group discussion participants among service seekers. In-depth interviews were conducted to delve into the intricate aspects of the sexual and reproductive health experiences of women with disabilities. Focus group discussions gathered collective insights from groups of 10 SRH service seekers in Kalangala and 6 in Kampala. This dual methodology provided a balanced and comprehensive understanding of the challenges faced. To obtain a holistic picture of SRH and FP service accessibility, healthcare professionals from both urban and rural sites were also included in the study.

Data analysis employed inductive and deductive coding, aiming to capture the rich complexities of responses. Themes such as financial autonomy, vocational education, accessibility of infrastructure, family support, and identities emerged from the coding process, forming the basis for the policy brief's analysis and findings.

Rupankar with a healthcare professional at the health centre in Kalangala

Findings

In the fieldwork areas, SRH services are provided at different levels. At the community level, village health teams and medical interns play an important role. Community-level healthcare professionals tend to be well-connected to the community and have a deeper understanding of specific needs. SRH services are also offered by healthcare centres, which are often located far from villages and semi-urban areas.

The study found that access to SRH services for women with disabilities is shaped by a blend of three intersecting factors: *(1) environmental barriers, (2) family dynamics and (3) identity characteristics.*

Environmental barriers

At a larger societal level, the accessibility of SRH services for women and girls is influenced by societal beliefs in combination with a lack of awareness and limitations within healthcare systems. Concerning societal beliefs and lack of awareness, the research identified the following factors influencing access to SRH services:

- **Religious beliefs:** Religious convictions are pivotal in shaping attitudes towards SRH. They often dictate family decisions and individual choices, potentially imposing restrictions on contraceptive use or family planning methods based on religious teachings.

- **Stigma around disability:** Societal stigmas associated with disabilities contribute to discriminatory attitudes and behaviour by healthcare workers towards women and girls with disabilities. This can also lead to women and girls' reluctance or avoidance of seeking SRH services.

- **Awareness levels:** The degree of awareness about sexual health varies widely within communities. A lack of understanding or mistaken beliefs about SRH can lead women to hesitate or feel reluctant about accessing these essential services.

At the level of healthcare systems, two primary factors emerged that influence access to SRH services:

- **Accessibility Challenges:** The physical accessibility of health centres refers to the absence of disability-friendly and affordable transportation options and infrastructural obstacles within the buildings.

- **Training Gaps:** Healthcare professionals often lack adequate training in addressing the specific needs of individuals with disabilities. This gap in training leads to communication barriers and compromises the quality of support and information provided at healthcare facilities, further hindering accessibility.

Family dynamics

The family is a crucial mediator between individual women and girls and the environmental factors shaping SRH access. The research found that the family is influential both as an enabler and constrainer of the ability of women and girls with disabilities to access SRH services. Compared to able-bodied women, women with disabilities tend to be more dependent on their families for accessing SRH services.

Rupankar in conversation with the mother of a girl with a hearing disability in Kalangala

Families can act as crucial enablers, providing emotional, financial, and logistical support that enables women and girls to access SRH services. Furthermore, supportive family environments can empower individuals to navigate and overcome societal and religious constraints. In addition, they play a vital role in translating SRH needs to healthcare providers as open communication within families can facilitate a better understanding of individual requirements and preferences.

Despite being potential enablers, families may impose constraints. Financial concerns regarding the cost of SRH services play a role in some families. Additionally, some may hold beliefs that women with (intellectual) disabilities are unsuitable for motherhood. Finally, religious convictions rejecting the notion of birth control might also influence family members.

Individual identities

While many of the barriers that women and girls with disabilities experience in accessing SRH services are shared, there are also considerable differences between the women based on their individual identity characteristics. The following identities appeared to be particularly important in shaping access to SRH services: level of financial dependence, level of education, type of impairment, and religious values.

Financially independent women often exhibit more assertiveness in accessing and utilising SRH services tailored to their specific needs. Individuals with their own income have the autonomy to address their specific needs, which reduces reliance on family members. The power of financial autonomy extends beyond economic freedom; it instils confidence and agency, enabling them to make informed decisions about their reproductive health.

Education is important for women to make informed SRH decisions and to foster a sense of empowerment in dealing with healthcare providers. The research found that educational and financial independence are often closely linked. In particular, women who had undergone vocational training tended to be more financially independent, enabling them to access money and achieve financial independence.

Different disabilities bring different challenges. Visually and hearing-impaired women face particular problems in communicating with healthcare providers. Physically challenged women tend to be more impacted by inaccessible infrastructure. Women with intellectual disabilities may encounter skepticism from their families regarding their capacity to understand and make informed decisions about their SRH needs.

The religious convictions of women influence their choices in regard to family planning methods, contraceptive use, and broader SRH decisions. According to various religious beliefs, sex is often viewed as being solely for reproductive purposes. However, modern SRH and family planning practices are perceived as contradicting this traditional perspective. Hence, religious convictions can influence individual choices regarding family planning methods, contraceptive use, and broader SRH decisions.

Rupankar in conversation with Irene

Conclusions and recommendations

The research highlights that access to sexual and reproductive health (SRH) services for women with disabilities is shaped by three interrelated factors: (1) environmental barriers, (2) family dynamics, and (3) individual identity characteristics. Environmental barriers encompass societal beliefs, stigma around disability, and varying levels of awareness. Healthcare system challenges, such as physical accessibility and training gaps among professionals, also impede accessibility. Families play a dual role, acting as both enablers and constrainers of access by providing support yet potentially imposing conditions due to financial constraints or societal expectations. Individual identity characteristics like financial independence, education level, type of impairment, and religious values significantly influence SRH access. Financially independent and educated women tend to navigate services more assertively. At the same time, different impairments present distinct challenges: communication barriers for visually and hearing-impaired women, infrastructure issues for physically challenged individuals, and familial paternalism for those with intellectual disabilities. Additionally, religious convictions shape SRH decision-making.

To create genuinely inclusive pathways to SRH empowerment for women with disabilities, interventions must recognise and address the interrelated barriers at the environmental, family and individual levels. From the findings, the following recommendations have emerged:

- Implement community awareness initiatives targeting misconceptions regarding SRH knowledge among individuals with disabilities. Initiatives should also focus on religious beliefs and address misconceptions by emphasising the compatibility of modern SRH practices with religious teachings.

- Establish initiatives targeting families, emphasising the importance of providing support to women and girls with disabilities. These initiatives should highlight the role of families as crucial enablers and promote open communication within families to understand individual requirements better.

- Train healthcare workers in the communities and healthcare centres to address diverse needs through communication techniques, disability understanding, and inclusive SRH services. Tackle the stigma surrounding disabilities by transforming healthcare workers' attitudes and behaviour towards women and girls with disabilities.

- Establish empowerment programs for women and girls with disabilities, emphasizing financial independence and education. Encourage vocational training and skill building to bolster confidence and informed decision-making in SRH matters.

- Promote the creation of accessible infrastructure and transportation, retrofit health centres and invest in affordable transportation options. Ensure physical barriers do not hinder anyone from accessing essential SRH services.

Environmental barriers encompass societal beliefs, stigma around disability, and varying levels of awareness.

Credits

Picture on the front page: Mother Shamim walks with Agnes on her back in a sling. PHOTO: LEANDER STOLK
Other photos: SHEAMUS MULUNGI

About the authors

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For further reading

Dey R. (2023). Access to Sexual Reproductive Health and Family Planning Services for Women with Special Needs: Case Studies from Uganda. ISS: The Hague (MA-thesis)