Breaking down Barriers

2024 POLICY BRIEF 27 A literature review:

SRH barriers for girls and women with disabilities in Sub-Saharan Africa

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Executive summary

Access to Sexual and Reproductive Health (SRH) services is a critical challenge for girls and women with disabilities in Sub-Saharan Africa, despite international mandates for inclusive healthcare under the UN Convention on the Rights of People with Disabilities. Using an intersectional lens, this brief synthesises existing academic literature to explore barriers for women and girls with disabilities in accessing SRH services. It finds that SRH access is influenced by both the characteristics and availability of healthcare system services and individuals' perspectives and behaviours in seeking healthcare. Barriers related to the healthcare system include exclusion from SRH programs, inaccessible health information, and discriminatory practices by healthcare providers. On the individual level, women with disabilities face challenges in recognising their SRH needs, navigating societal stigmas and self-stigma, accessing transportation to SRH facilities, and affording services. Significant differences exist between women and girls in their experiences accessing SRH services. These differences are influenced by individual identity characteristics such as type of impairment, education level, socioeconomic status, and geographic location, which amplify disparities in SRH care access. Based on the findings, the policy brief outlines recommendations for governments and NGOs to make SRH services more inclusive.

'Breaking down Barriers' was initiated by Liliane Foundation to contribute to more effective and evidencebased 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.



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Breaking down Barriers SRH barriers for girls and women with disabilities in Sub-Saharan Africa: a literature review

Introduction

SRH (Sexual and Reproductive Health) is a state of physical, emotional, mental, and social well-being in all matters relating to the reproductive system, and not merely the absence of diseases, dysfunction, or infirmity (Collumbien et al., 2012). It implies that people are informed and empowered to make their own choices about sex and reproduction, which includes the ability to access adequate and appropriate healthcare services provided by competent health workers (United Nations Population Fund, 2022). For girls and women with disabilities, these rights are further defined by Article 25 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD), mandating governments to ensure accessibility to SRH services on an equal basis with others.

Despite the ratification of UNCRPD across Sub-Saharan Africa, there is a gap between policy intentions and the translation of the ratification to national legislation and practical implementation (United Nations, 2023). Unawareness and misconceptions among health professionals regarding the SRH needs of women and girls with disabilities lead to them being discriminated and denied autonomy as subjects of rights who are supposed to make informed decisions about their SRH. This overall negative attitude, discrimination and neglect is not just an oversight, it also has serious consequences. For example, girls and women with disabilities face heightened vulnerabilities to sexual abuse, as well as health risks related to sexually transmitted diseases and unwanted pregnancy (Sexual Rights Initiative, 2018). This policy brief synthesises existing academic research on the barriers that girls and women with disabilities face in accessing SRH services in Sub-Saharan Africa. It aims to unravel the systemic and individual factors contributing to the inaccessibility of these services. Recognising the diversity within this group, the brief adopts an intersectional lens to provide a nuanced understanding of their experiences. This implies that the study starts from the premise that girls and women with disabilities hold multiple intersecting identities–such as type of impairment or level of education–which interact and compound to shape their experiences and access to SRH care.

This policy brief addresses the following questions:

- What systemic and individual barriers do girls and women with disabilities experience accessing and using SRH services in Sub-Saharan Africa?
- 2. How do these barriers constrain girls and women with disabilities in Sub-Saharan Africa from benefiting SRH services?
- 3. How do intersecting identities of girls and women with disabilities in Sub-Saharan Africa shape their ability to access and use SRH services?



Mother, daughter, son and baby in the living room, making coffee. PHOTO: MONA VAN DE BERG

METHODOLOGY

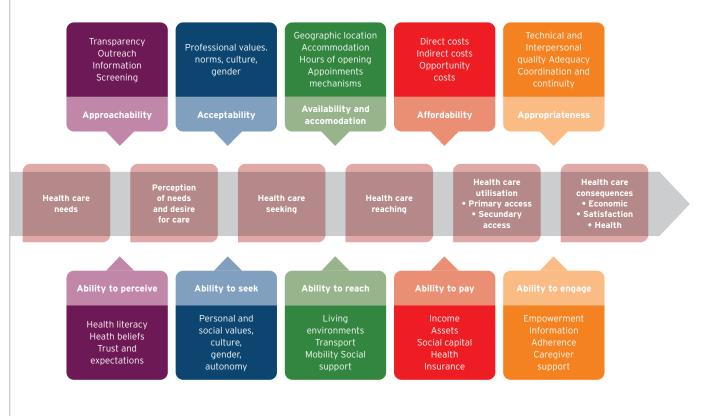
This policy brief summarises the key findings of a comprehensive literature review on the topic (Baarslag, Elbers & Trajcevska, 2023). While the general barriers to SRH are already well-known, existing studies tend to treat girls and women with disabilities as a homogenous group. Consequently, the primary objective of the research was to highlight the diversity of the experiences of girls and women with disabilities in accessing SRH care.

Rigorous selection criteria were employed to systematically organise existing knowledge on the topic. Academic publications addressing SRH care were examined, encompassing general SRH and specific services such as maternal and neonatal care or HIV/AIDS services. The focus remained on the diverse realities faced by girls and women with disabilities in Sub-Saharan Africa.

Google Scholar served as the primary source for finding relevant studies. Various search phrases were used, and then abstracts were reviewed to determine the relevance of the articles. The search was refined until saturation was reached. The concept of 'access' emerged as the pivotal criterion for inclusion in the analysis. The focus was on research explaining enablers or barriers to SRH care, leading to the exclusion of articles solely focused on the experiences of girls and women with disabilities concerning sexuality. The criterion resulted in the inclusion of 43 articles from an initial pool of 76. This rigorous selection process ensured a robust dataset for the analysis.

The Levesque model (2013) served as a conceptual framework and foundation for analysing the papers identified (figure 1). This model allows for systematically identifying barriers across multiple phases of healthcare access, recognising that both demand and supply shape access to healthcare. The demand side represents individuals' perspectives and behaviours in seeking healthcare, while the supply side encompasses healthcare system services' characteristics and availability. The individual perspectives and behaviours were explored using an intersectional lens (Crenshaw, 1991). This acknowledged the complexity of experiences, avoiding a simplistic conceptualisation of identity while allowing for nuanced exploration of experiences across ages, and types of impairment, amongst other identities.





Barriers to accessing sexual and reproductive health care

Table 1 summarises the key barriers identified in the literature, distinguishing between supply and demand aspects. The findings are organised according to the phases of the healthcare access model from Levesque (2013), which systematically identifies barriers across multiple phases of healthcare access.

Table 1: Supply and demand side barriers related to SRH services

Dimension	Supply Side Barriers	Demand Side Barriers	Intersectional Factors
Approachability and Ability to perceive	 SRH programs often exclude women with disabilities. Healthcare providers do not make sexual health information accessible. 	 Girls and women with disabilities lack access to medically accurate information Reliance on friends and family for health information. Unawareness of available facilities. 	 Visual and hearing impairments face more challenges. Intellectual impairments lead to least awareness of SRH services. Education level and English literacy impact access. Age affects awareness of available options.
Acceptability and Ability to seek	 Discriminatory attitudes and practices by healthcare providers. Healthcare providers use derogatory language and ridicule. 	 Negative prejudices by family or community members about SRH needs. Lack of support or accompaniment. Self-stigma and societal taboos create shame. 	 Education level impacts self- esteem and ability to demand services. Socioeconomic status enables challenging stereotypes.
Availability and Ability to reach	 Inaccessible infrastructure and lack of appropriate equipment in SRH facilities. Women face undignified and unsafe care conditions. 	 Inaccessible transportation limits ability to reach care. Transport costs and poor road networks in rural areas. Drivers refusing to accommodate. 	 Rural women face additional transport challenges. Physical impairments create significant navigation issues in healthcare facilities.
Affordability and Ability to pay	 High costs of services, medication, and travel. Routine referrals to city hospitals for pregnancies increase expenses. 	 Insufficient income limits access and forces reliance on others. 	 Women with disabilities often face unemployment or low income. Dependence on family for financial support. Women with lower income depend on husbands for contraceptive decisions.
Appropriateness and Ability to engage	 Public SRH facilities lack resources and competence. Incorrect assumptions and inappropriate advice. Violation of privacy and confidentiality. 	 Dependence on personal assistance forces disclosure of confidential information. Lack of full disclosure to healthcare providers due to being uncomfortable. 	• Type of impairment influences communication challenges and dependence on escorts.

Approachability and ability to perceive

Approachability refers to how visible and well-promoted SRH services are on the supply side. SRH programs often fail to include or target girls and women with disabilities as health messages and programs typically overlook their needs. Consequently, girls and women with disabilities are neither invited to existing programs nor perceive them as relevant, leading to non-participation. Additionally, healthcare providers do not make sexual health information accessible to girls and women with disabilities, limiting their access to general SRH information. This lack of information contributes to insufficient knowledge about sexual health, making them more vulnerable to health issues.

On the demand side, the ability to perceive involves individuals being aware of and informed about the available SRH services. Here we see that girls and women with disabilities often struggle to perceive their SRH needs. The primary barrier is their inability to use available SRH information, leading them to rely on friends and family for health information. This reliance results in unawareness of available health facilities, delayed care-seeking, and ignorance about where to find treatment.

From an intersectional perspective, the ability to perceive care needs varies among girls and women with different types of disabilities. Those with visual and hearing impairments face more significant challenges accessing SRH information compared to those with physical impairments, as they miss information from general media outlets. Moreover, girls and women with intellectual impairments are often least aware of SRH services due to being isolated at home. Education level also



Mother is cooking food with her daughter on her back in a sling. PHOTO: LEANDER STOLK

plays a crucial role in accessing information. Girls and women with disabilities often miss out on adequate SRH education. Additionally, girls who attend school are better informed about SRH services than those who do not, which affects their likelihood of using these services. English literacy is another determinant, as SRH information in some countries is predominantly in English, posing a barrier for those with lower education levels. Furthermore, age impacts the ability to perceive SRH information, with adolescents being less aware of family planning methods and contraceptives than adults due to fewer opportunities to encounter SRH information.

Acceptability and ability to seek

Acceptability is about the supply side and the cultural and social appropriateness of SRH services. Here we see that healthcare providers often use derogatory language and ridiculing behaviour towards girls and women with disabilities. As a result, these women feel uncomfortable, refrain from asking questions during health visits, and are demoralised from using SRH services in the future. This negative treatment leads to reluctance in seeking care even when needed.

On the demand side, or the ability to seek, two major barriers prevent girls and women with disabilities from seeking care. The first barrier is negative prejudices about their SRH needs, with decisions often made by family or community members who may believe these women are asexual and do not need such care. This results in a lack of support or accompaniment, causing many to forgo treatment. The second barrier is self-stigma, where societal taboos make these women ashamed of their sexuality, leading to fear of being perceived as sexually active. This shame prevents them from asking questions or seeking care at all, and fear of appearing ignorant about their health conditions further discourages them from seeking help or disclosing information during visits.

An intersectional lens reveals that education level and socioeconomic status further influence the ability to seek care. Education impacts self-esteem and the ability to demand and obtain services, but many girls and women with disabilities only complete primary education or are uneducated, therefore missing out on this empowerment. Socioeconomic status also plays a role, enabling women with a higher status to challenge asexual stereotypes and make decisions about their health. Unfortunately, only a small percentage of women with disabilities are employed.

Availability and ability to reach

On the supply side, availability concerns the physical presence and convenience of accessing SRH services. Here, the existing literature identifies two major barriers that undermine the availability and accommodation of SRH services for girls and women with disabilities. The first barrier is inaccessible infrastructure and lack of appropriate equipment, signalling that SRH facilities are not designed with their needs in mind. As a result, they cannot move around or use the facilities independently, often needing someone to accompany them to communicate with healthcare workers. The second barrier is that these women face undignified and unhygienic circumstances, sometimes receiving improvised and unsafe care or being unable to use the services at all. These conditions discourage them from seeking care and can lead to them forgoing treatment.

The demand side is about the ability of individuals to reach and utilise SRH services effectively. Inaccessible transportation makes it difficult for girls and women with disabilities to reach SRH care. With transport options being inaccessible, they struggle to bring assistive devices or support themselves on buses and motorcycles, leading to delays or cancellations of healthcare appointments. Taxi and bus drivers sometimes refuse to accommodate them, forcing them to postpone appointments and delay reaching care.

The intersectional lens highlights how rurality and the type of impairment further limit the ability to reach SRH care. Women with disabilities in rural areas face additional challenges such as transport costs, poor road networks, and limited means of transport. This contributes to lower service uptake compared to metropolitan areas. For those with physical impairments, the inaccessible infrastructure at SRH facilities poses significant problems, requiring additional support to navigate, which creates an additional barrier.

Affordability and ability to pay

The affordability of SRH facilities on the supply side is limited by the high costs of services, including counselling, medication, medical items, and travel expenses, which often exceed what girls and women with disabilities can afford. This leads them to either avoid using the services altogether or seek cheaper and inferior alternatives. Additionally, routine referrals to city hospitals for pregnant women with disabilities, based on (sometimes incorrect) assumptions of complicated births, result in extended travel and higher expenses, causing delays in seeking care or complete avoidance of treatment.

On the demand side, a significant issue is that many girls and women with disabilities lack income. This forces them to rely on others for support or minimise costs by forgoing necessary medicines or services. This financial strain leads to delays in seeking care, discontinuation of treatment, or complete avoidance of necessary healthcare services.

Socio-economic status heavily influences the ability to pay for SRH services. Women with disabilities often face unemployment or earn low incomes due to a lack of education and negative prejudices from employers. This lower socioeconomic status limits their access to SRH care, as their incomes are insufficient to support both their livelihoods and the costs associated with SRH services, including transport and the need to pay for escorts. Unemployment and low income make women with disabilities dependent on others, such as family members or husbands, to pay for SRH services, thus creating additional barriers. Studies show that women with disabilities in lower wealth groups are more dependent on their husbands for decisions regarding contraceptives than those in higher wealth groups. This dependence on family for financial support further restricts their access to necessary healthcare.



Young woman at the market in Nansana. PHOTO: RONNIE DANKELMAN



Young woman lives with her grandmother. PHOTO: MONA VAN DEN BERG

Appropriateness and ability to engage

On the supply side, appropriateness refers to the quality and relevance of SRH services. Two significant barriers are relevant here. Firstly, public SRH facilities often lack the resources to provide quality care, including the necessary staff to offer extra support such as professional sign language interpreters. Consequently, these individuals receive poor treatment and, if possible, may opt to save money by seeking care at private facilities instead. Secondly, SRH facilities generally lack the competence to address the specific health needs of girls and women with disabilities. Incorrect assumptions about their health, neglect of reproductive health education, and inappropriate advice are common. They may also be subjected to unnecessary procedures like caesarean sections or sterilisation. Additionally, healthcare providers often violate privacy and confidentiality by obtaining medical information without consent or gossiping about patients.

On the demand side, individuals' ability to engage with and benefit from SRH services is key. Here we see that girls and women with disabilities face limitations in engaging with their care due to their dependence on personal assistance or escorts. This necessity forces them to disclose confidential information, discourages them from seeking care, or leads to them foregoing treatment when no one is available to accompany them. During health visits, they may feel uncomfortable or concerned about the information being exchanged, leading to a lack of full disclosure to healthcare providers.

The type of impairment also impacts engagement, with individuals with hearing impairments struggling the most with communication due to a lack of staff proficiency in sign language. Those with visual or physical impairments are more likely to depend on escorts, further inhibiting their ability to engage by compromising privacy and confidentiality. Breaking down Barriers SRH barriers for girls and women with disabilities in Sub-Saharan Africa: a literature review

CONCLUSIONS AND RECOMMENDATIONS

Women with disabilities face significant barriers to accessing and utilising SRH services, stemming from both supply and demand sides. Supply-side challenges include the exclusion from SRH programs, inaccessible sexual health information, derogatory treatment by healthcare providers, inadequate infrastructure, high service costs, and a lack of competence in addressing their specific needs. On the demand side, women with disabilities often struggle with perceiving their care needs due to reliance on informal health information sources. Furthermore, they face societal stigma and self-stigma, encounter transportation difficulties, and have financial constraints that limit their ability to pay for services. Intersectional factors such as type of impairment, education level, socioeconomic status, gender roles, and rurality further exacerbate these challenges, making it harder for them to seek, reach, and engage in appropriate SRH care.

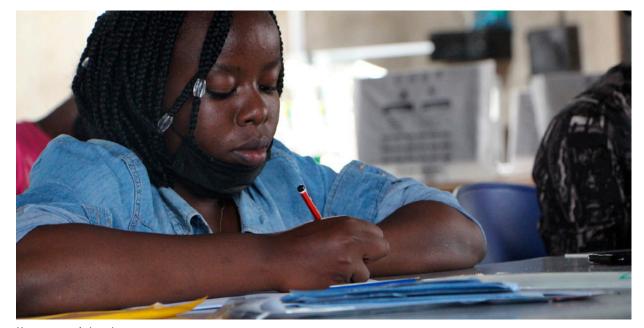
From these findings, the following recommendations emerge for governments:

- Policy integration: Integrate SRH needs of women with disabilities into national health policies and enforce accessibility standards.
- **2. Training programs:** Implement mandatory training programs for healthcare providers on disability-sensitive care and communication techniques.
- **3. Inclusive education:** Incorporate inclusive SRH education into school curricula and community outreach programs using accessible materials.
- 4. Financial assistance: Provide subsidies or financial support mechanisms to make SRH services affordable for women with disabilities.
- **5. Monitoring and compliance:** Establish regular monitoring and audits of healthcare facilities to ensure compliance with accessibility standards and respectful treatment.

- 6.Infrastructure investment: Allocate funds for improving infrastructure at SRH facilities to enhance accessibility for women with disabilities.
- 7. Collaborative partnerships: Foster partnerships with disability organisations to seek expertise and guidance on SRH needs and experiences of girls and women with disabilities.

RECOMMENDATIONS FOR NGOS:

- 1. **Training:** Train healthcare providers on disability inclusion and best practices in SRH care.
- **2.Community engagement:** Establish support groups and community networks to empower women with disabilities and facilitate access to SRH information and services.
- **3. Legal support services:** Offer legal aid and advocacy services to assist women with disabilities in asserting their SRH rights and combating discrimination.
- 4. Research and data collection: Conduct research studies to gather data on SRH barriers and outcomes for women with disabilities, informing evidence-based advocacy efforts.
- Awareness raising: Conduct advocacy campaigns to raise awareness about SRH rights and challenges faced by women with disabilities.
- 6. Policy influence: Engage in policy dialogue and partnerships with government agencies to influence inclusive SRH policy formulation and implementation.
- **7. Capacity strengthening:** Strengthen advocacy groups' capacity to advocate for the SRH needs of women with disabilities and monitor policy implementation.



Young woman in her classroom. PHOTO: CHIARA BELTRAMINI

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Young woman is looking forward to starting her medical studies. PHOTO: CEDRIC MUSENGE KANGWA

Credits

Picture on the front page: CHIARA BELTRAMINI

Further reading

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