Youth-Led Research 2023 & 2024

CONTENT

INTRODUCTION

In 2022, Liliane Fonds formed the first ever 'Regional Council of Youth with Disabilities' under the Make Way program. The council is made up of fifteen young people with disabilities across Ethiopia, Kenya, Zambia, Rwanda and Uganda. The Regional Council meets up every month for members to stay connected and discuss their Sexual and Reproductive Health and Rights (SRHR) advocacy efforts.

As part of the regional council, youth council members have also conducted their own Youth-Led Research (YLR) on the experiences of young people with disabilities of sexual and reproductive health (SRH) services. The studies explore the barriers, challenges, and opportunities in accessing SRHR services for young people with disabilities and provide recommendations to counter barriers. The YLR was conducted in 2023 and 2024 in Ethiopia, Kenya, Uganda and Zambia. The YLR in Rwanda was carried out in 2024 and 2025 due to turnover of youth council members.

Youth-led research is a powerful tool. It invites young people with disabilities to collect data and research their peers' and their own experiences. This allows for a transformative and empowering process where young people with disabilities become the researchers of their own challenges and opportunities. They create a network with young people with disabilities and other stakeholders, such as happened for example in Kenya. Furthermore, it allows for the realisation that they are not alone in their experiences. This opens the way for consciousness-raising, becoming aware that an individual problem is part of a societal process and identifying ways to change the societal system. The young researchers also used their data to inform evidence-based advocacy. In for example Zambia, the research was shared with different stakeholders in their efforts to ratify the African Disability Protocol.

Recognition goes out to the researchers Zelalem Andualem, Rahel Teshe, and Anguach Merech Teshale from Ethiopia; Vilda Atieno, Kennedy Gumba, Alfric Kioko from Kenya, Mukarusine Claudine, Tuyishime Patrick, and Ngabonziza Eric from Rwanda; Phiona Nantaba, Sabano Susan, Babirye Patience Gloria and Ndyamuhaki Sharon from Uganda; Ian Banda, Kelvin Besa, and Nsofwa Sampa from Zambia. The YLR was carried out in collaboration with Cheshire Disability Services Kenya (CDSK), Cheshire Homes Society Zambia (CHSZ), Ipas Ethiopia, Katalemwa Cheshire Home (KCH), and the National Union of Disability Organizations in Rwanda (NUDOR).

METHODOLOGY OF YOUTH-LED RESEARCH

>Inspiration Workshop organised by Liliane Fonds for Make Way in Zambia in 2024.
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The YLR was a qualitative study, in which interviews and focus group discussions using semi-structured guides have been conducted to answer research questions determined by the young people themselves. Other methods included surveys, literature reviews and observation. The selection of target groups and respondents varied per country in numbers and characteristics (see table). An effort was made to select a diverse group of respondents in types of disability, gender and geographic origin. Some researchers have also conduct interviews with other stakeholders, such as health workers, community leaders and parents. Informed consent for participation in the YLR was asked in all cases. Confidentiality of participants, data and outcomes, right to withdraw at any moment were important elements that have been guaranteed. A lot of attention has been paid to conduct the interviews in a bias-free, gender and disability sensitive way. The use of appropriate communication methods (sign language, visual aids) has been very helpful. Some of the research studies used coding for analysis of interviews and triangulated data with secondary sources, such as reports, policies, or statistics on disability and reproductive health.

2023			2024			2025			
Country	**#**	**Characteristics of respondents**	**Regions**	**#**	**Characteristics**	**Regions**	**#**	**Characteristics**	**Regions**
Kenya	66	Male, female, non-binary youth with disabilities	Counties in Kisumu, Nairobi, Siaya and Makueni	55	Young people with disabilities, different disabilities (physical disability, visual impairment, hearing impairment, intellectual disability & cerebral palsy)	Kisumu County & Makueni	n/a	n/a	n/a
Ethiopia	30	different types of impairments (physical, visual, intellectual, and hearing); different genders (male, and female) different locations (urban and rural)		20	10 youth with disabilities, 5 caregivers, and 5 health service providers	Amhara region, focusing on Debrebirhan town IDP centers,	n/a	n/a	n/a
Zambia	150	youths and adolescents with disabilities, parents of children with disabilities, church leaders, traditional leaders, neighbourhood health committees, ward councillors, and healthcare providers	Lusaka: Kanyama, Chipata, Mandevu, and Mansa central constituency township in Luapula Province.	150	Youth with disabilities (physical, hearing impairment, and albinism); Parents of YWDs; Special education teachers; Ward councilors; Church leaders; District health office leadership; Health facility in charge.	Chongwe and Mansa district	n/a	n/a	n/a
Uganda	33	People with disabilities, caretakers, Ministry of Health, OPDs, village health teams and health workers	Central Region: Mukono Nama Wakiso Kampala (Makerere Kikoni)	17	Youth with disabilities, healthcare providers and community leaders	Kampala, Wakiso and Mukono districts	n/a	n/a	n/a
Rwanda	n/a	n/a	n/a	40	Women and men with disabilities, youth without disabilities and community health workers,	Kicukiro, Gatsibo and Nyagatare	42	Deaf participants both male (42,86) and female (57,14%)	Gasabo, Kicukiro and Nyarugenge districts of Kigali

RESULTS

1. BARRIERS

Youth with disabilities face multiple barriers to accessing SRHR services. These challenges are not isolated incidents but rather a complex web of cultural, institutional, social and political obstacles that collectively hinder their ability to access the essential care and support needed for their SRH. These include physical inaccessibility of health facilities, absence accessible information, and negative attitudes from healthcare providers. In Rwanda, survey data showed that 61% of respondents felt SRHR services did not meet their needs and 68% were dissatisfied with the family planning services provided. This negatively impacted the overall health and wellbeing of 80% of the respondents in the same study, such as unintended pregnancies, limited access to contraceptives, lack of reproductive health screening and increased risk of sexually transmitted infections.

a. **Inaccessibility of healthcare services**

Often healthcare services are physically inaccessible, and this was recorded by the YLR studies in all countries. Many healthcare clinics and services are not designed to accommodate people with disabilities. Furthermore, locations can be crowded and inconvenient. The long waiting times young people with disabilities experience can also restrict obtaining timely healthcare. In Rwanda the lack of accessible facilities was noted as one of the biggest challenges. People with visual impairments in Ethiopia had difficulties navigating the facility independently. In Zambia the inaccessibility of healthcare services led young people to need to rely on others for assistance, which led to infrequent visits to health care centers.

These challenges can also intersect with other forms of marginalization. For example, in the internally displaced people (IDP) camps in Ethiopia, the study done in 2024 observed that the physical environment of the camp was not adapted to the needs of people with disabilities. They thereby face a double challenge: tackling the societal barriers that come with having a disability and navigate the necessary resources in an IDP camp. The research therefore shows that when compounded vulnerabilities are not recognized, this can severely limit access to essential services. The researchers in Uganda noted that SRHR programs often lack an intersectional lens failing to recognize the specific needs of young people with disabilities, resulting in a one-size-fits all approach.

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b. Lack of inclusive transport

According to healthcare providers interviewed in Zambia, transportation to SRH services is another significant barrier. The research team in Uganda found a lack of appropriate public transportation services, while 50% of the respondents in Kenya had to walk for at least 5 kilometers to access SRH facilities. Deaf individuals and young people with intellectual disabilities in Ethiopia also recounted how they have difficulty in public transportation due to struggling to identify the right vehicles, understanding instructions and misunderstandings about payment.

c. Financial constraints

Financial constraints pose significant barriers to accessing SRH services. Many young people with disabilities face financial limitations that hinder their access to SRHR services in Zambia. The costs associated with transportation, medical treatments and medications can act as a barrier. In Kenya, the research showed that the financial barriers of high costs of services eventually led to unplanned pregnancies and unsafe abortions. These economic constraints also lead to having fewer choices. A respondent in Kenya for example noted he would opt for a vasectomy, not because he would like it, but because of the economic situation. These financial constraints often hit people with disabilities harder as they also have to budget for their assistive devices and the services of personal assistants.

A respondent in Uganda explained: “It is not enough to know that you have a right to utilize health care during delivery, like family planning, yet you cannot afford it when you need it. For sure most of the youth with disabilities have little income and cannot afford health care; their health rights remain on paper”.

>Inspiration Workshop organised by Liliane Fonds for Make Way in Zambia IN 2024. PHOTO: CHZS - Cheshire Homes Zambia Society

d. Attitudes, beliefs and stigma

Young people with disabilities often face stigma and discrimination, deterring them from seeking SRH services due to fear of judgement and maltreatment. Cultural and religious beliefs and misconceptions about the sexuality of persons with disabilities further hinder access. The researchers in Zambia found how cultural expectations around gender can limit access to SRHR, particularly for women and gender non-conforming individuals with disabilities. A cultural emphasis on family honor and reputation can have similar effects.

In Rwanda, myths and misconceptions persist, including beliefs that youth with disabilities are asexual or unfit for parenthood. In Zambia and Uganda, parents and community leaders often underestimate the SRHR needs of youth with disabilities and their SRHR continues to be contested and not prioritized. The study conducted in the IDP camp in Debre Birhan, Ethiopia highlighted the psychological toll of this stigma and exclusion of young people with disabilities.

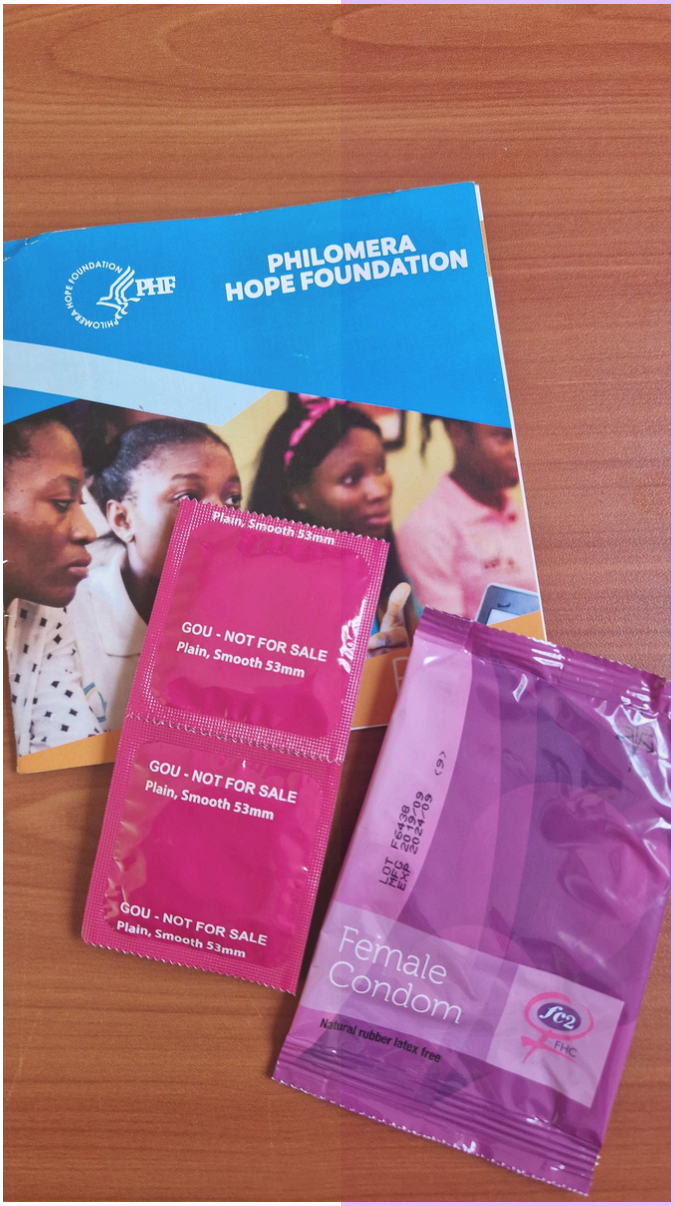
e. Negative interactions with health care providers

While some health professionals are attentive and supportive, there is a variety in the level of care provided. When accessing services, young people with disabilities in Ethiopia, Uganda and Kenya encountered unhelpful or negative attitudes from staff members. In Rwanda, this was seen by respondents as the other biggest challenges next to accessibility of health care facilities. It is therefore not surprising that 50% of respondents in this study noted that they have felt uncomfortable discussing SRH concerns with healthcare providers due to their disability. Young people in Kenya also noted that people with disabilities are handled as special clients which involves more questions and consultations. Additionally, they were afraid to be judged by community members who work at the facilities. These attitudes can cause fear of seeking SRHR services, which leaves young people with disabilities vulnerable to SRHR challenges, such as teenage pregnancies.

Some participants also perceived a lack of knowledge among health professionals. A respondent in Ethiopia from the IDP camp noted: “the health workers don’t seem to have enough training or awareness. They don’t understand the specific needs of people with disabilities”. This contributed to a low uptake of contraceptive services. The health care workers in the research done in Rwanda confirmed this and stated that they did not receive any formal training or education related to providing family planning services to adolescents with disabilities.
Another concern is the fear of health information disclosure without consent. In all countries, inadequate privacy was a problem, especially for those who are deaf or hard of hearing. In Uganda it was also observed that there is limited consultation time and poor interpersonal relationships between health care professionals and their patients. According to the research done in Zambia, young people with disabilities may face challenges in providing informed consent and exercising autonomy in their SRHR services.

f. Limited inclusive Communication

Many young people with disabilities confront barriers in communication. In the study in Rwanda done in 2024, 82% of participants indicated that communication accommodations were needed to enhance the accessibility of SRH services. For example, young people with hearing impairments often face significant communication challenges. The absence of healthcare professionals who can communicate effectively with them exacerbates the difficulties of accessing SRH services. Equally so, in Ethiopia there was a lack of interpreters and confidentiality issues with third-party interpreters. The researchers in Ethiopia found that deaf individuals are afraid, have distrust and feel insecure at health centers. These communication barriers impact how individuals seek information and navigate health services.



>Informational materials from the Philemora Hope Foundation. PHOTO: David Jagersma

"From my experience, youths and adolescents with disabilities may only visit the health center once and never return because the people to help them communicate with healthcare providers are not there especially for the deaf/mute"

- noted an NGO Representative from Zambia in 2023.

g. Limited awareness and information

There is limited information tailored to the needs of young people with disabilities, which leaves them uninformed about contraceptives and SRH. This lack of awareness contributes to a failure to seek or advocate for these services. Across Uganda, Rwanda and Zambia, youth with disabilities demonstrated limited awareness of SRHR services and rights. In Ethiopia, participants expressed varying levels of awareness regarding their reproductive rights. In Kenya, the research found that awareness was highly dependent on the level of education respondents had gotten. Lower levels of education were associated with a lack of information, which can lead to fear of accessing contraceptives and hesitancy to assert their rights.

In Kenya it was found that young people often receive SRHR information from their peers. One in five participants also received information from a religious context in which sex was being condemned. In Rwanda, most young people indicated receiving SRHR information from the government and their peers. Young people with intellectual disabilities thereby also relied heavily on parents as guides for information. Respondents in Ethiopia noted how social media can be a source of information, however they also had some concerns about privacy and sharing of information.

h. **Inaccessible SRHR information**

Often SRHR information does not come in accessible formats, such as braille or pictures. Participants in Ethiopia highlighted challenges in accessing reproductive health information through traditional tools like radio programs. Additionally, available tools are often not adequate for people with visual impairments or intellectual disabilities, noted respondents in the studies done in Ethiopia, Zambia and Kenya. A respondent in Kenya noted: “Yes we have condoms. There exists [an] instruction leaflet inside but for a visually impaired individual like me, we have never known what’s inside and learning how to use a condom. As a visually impaired person only gives an option of trusting what you got from a friend and the privileged individuals who get such information from organizations”. For these individuals, access to information such as braille, audio materials or digitally accessible content is indispensable.

i. Lack of access to justice for cases of gender-based violence

Young people with disabilities, especially those with hearing impairments and intellectual disabilities have a higher likelihood of experiencing gender-based violence (United Nations Department of Economic and Social Affairs, 2024). The research in Uganda also highlighted the sexual violence and abuse that happens at community level. The researchers observed that adolescents with disabilities might need extra information concerning sexual abuse and the right to protection from it. In Kigali, Rwanda, several factors limited young people reporting Gender Based Violence (GBV) cases, including fear of stigma, lack of trust in service providers and concerns about confidentiality.

This study, conducted among young people with hearing impairments, revealed that while awareness of GBV support services was relatively high, access remained limited due to communication barriers, lack of trust in authorities, and inadequate inclusiveness of services. Only 2.38% of respondents had accessed fully inclusive services, and 100% cited the absence of sign language interpreters as a major barrier. Many of the respondents perceive current GBV support systems as insufficiently responsive to their needs. Respondents emphasized the urgent need for more targeted support, capacity-building for healthcare providers, and enhanced collaboration with advocacy groups to address the unique vulnerabilities of youth with disabilities.

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2. ROLE OF STAKEHOLDERS

Parents, traditional leaders, religious leaders, and healthcare providers play crucial roles in facilitating young people with disabilities' access to SRH services. In Zambia, NGOs served a role as facilitators in the provision of SRH services, as they established collaborative partnerships with healthcare facilities, introduced innovative solutions, and effectively integrated SRH services with HIV-related services. They also saw how traditional leaders and healers emerged as potential advocates and change agents in addressing the challenges faced by youth and adolescents with disabilities. Other important stakeholders are community health workers who can play an important role in reaching young people with disabilities in their homes and communities. They can raise awareness around SRH and contraceptive use.

Caregivers were identified in the YLR studies as both allies and those who restrict the access of their children to SRH services. Some caregivers expressed their willingness to support and facilitate their children's access to SRH services. Many often take up the crucial logistical role of ensuring their children can access the SRH services. Others had reservations about granting their children access to SRH services. Furthermore, some parents still believe that their children are sexually inactive or immature. It is therefore clear that caregivers can play both, enabling as well as a hindering role, in access to SRH services for youth with disabilities.

3. OPPORTUNITIES

Next to barriers and the role of stakeholders, there were also several positive opportunities identified in the youth-led research, such as legal frameworks, community-based approaches, and technological solutions. Many NGOs have undertaken efforts to train healthcare providers in disability-inclusive healthcare. These trainings can be opportunities to make SRH services more accessible, acceptable and of higher quality. Organized forums, such as the inclusive coffee ceremonies that are being organized by Ethiopian Women with Disabilities National Association (EWDNA) furthermore provide a platform for open discussions on SRH and can serve as a medium to dispel myths and gain information on SRHR.

Advancements in technology can bridge the information gaps for young people with disabilities, creating easier access to health care information. An example of this was in Ethiopia, where there were voice-enabled devices at the health care clinic that provide clear instructions including contact numbers and associated costs.

Legal frameworks

All reports referenced international and national legal frameworks such as the UN Convention on the Rights of Persons with Disabilities (CRPD), Convention on the Rights of the Child, and national disability acts. For example, in Ethiopia, the legal frameworks, including the CRPD, provide a basis for advocating for improved healthcare access for young people with disabilities. Implementation and awareness, both under people with disabilities and healthcare providers, of these policies remain limited. In Rwanda, 46% of respondents were unaware of SRHR-related policies.

Communities in Zambia created by-laws specifically designed to protect and advance the rights of children with disabilities, which serve as a way to protect the rights of children with disabilities. These by-laws played an important role in ensuring that young people with disabilities are not excluded from SRHR services. Their effectiveness, however, relies heavily on proper implementation and enforcement.

RECOMMENDATIONS

- Create accessible infrastructure within healthcare facilities, ensuring that spaces are designed to accommodate the diverse needs of youth and adolescents with disabilities. Efforts should be made to address access barriers and promote inclusivity in healthcare settings to ensure that healthcare facilities accommodate the diverse needs of youths and adolescents with diverse disabilities and accessibility audits of clinics should be conducted.

- Train healthcare workers in disability inclusion and rights, communication (e.g., sign language), and informed consent for example through workshops, as part of the curricula or through orientation workshops.

- Develop and disseminate accessible SRHR information (braille, audio, visuals, easy-to-read formats).

- Provide knowledge, resources, education and support for parents and caregivers, communities and traditional and religious leaders, and other crucial stakeholders, including on the rights of young people with disabilities of SRH, informed decision-making, non-discrimination and the dispelling of misconceptions.

- Develop programs to empower economically vulnerable young persons with disabilities or provide financial support to ensure youth with disabilities can access healthcare.

- Include comprehensive sexual health education within school curricula to empower young people with disabilities with the knowledge and information they need to make informed decisions about their sexual and reproductive health and are informed about available SRH services. Where this is not possible, support the development of spaces for SRHR information, discussions and support networks for young people with disabilities, such as the safe spaces of the Make Way program, mentoring programs or peer-to-peer programs.

- Ensure community by-laws and national policies protect SRHR rights of youth with disabilities. Advocate for policy changes that prioritize the SRHR of people with disabilities and mandate healthcare providers to offer inclusive services.

- Promote further research to better understand the specific needs and challenges faced by individuals with different types of disabilities in SRHR.

- Promote the use of civic research by youth with disabilities.

CONCLUSION

Youth with disabilities in Zambia, Uganda, Ethiopia, Kenya, and Rwanda face systemic barriers to accessing SRHR services. Despite legal frameworks supporting their rights, implementation gaps persist due to inaccessible healthcare services, transportation challenges, financial constraints, inaccessible formats of SRHR information, communication barriers and attitudes, beliefs and stigma of stakeholders. These constraints cause young people to have limited awareness and knowledge about their SRHR and SRH. The challenges that young people with disabilities face in accessing SRHR services lead to a negative impact on overall health and wellbeing. Addressing these challenges requires multi-sectoral collaboration, inclusive policy-making, and community engagement.

REFERENCES

United Nations Department of Economic and Social Affairs. Disability and Development Report 2024: Accelerating the realization of the Sustainable Development Goals by, for and with persons with disabilities.

>Inspiration Workshop organised by Liliane Fonds for Make Way in Zambia in 2024. PHOTO: CHZS - Cheshire Homes Zambia Society