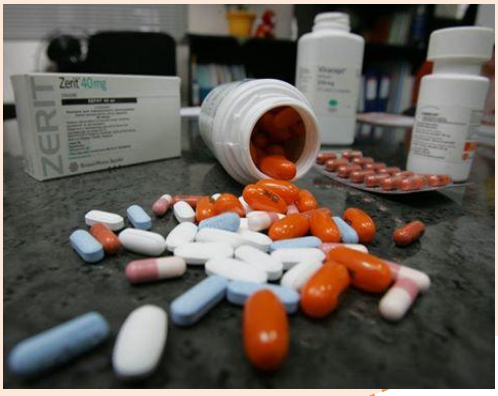
**ACCESSIBILITY AND AVAILABILITY OF SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS (SRHR) SERVICES OF ADOLESCENT WITH DISABILITIES IN MONGU DISTRICT, WESTERN PROVINCE, ZAMBIA.**




Maboshe Memorial Centre - MMC is working towards rural/remote areas in Western province, Zambia in which all adolescences with disabilities are fully included as equal members of society and are able to achieve their full potential.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## Acknowledgements

This report was written, reviewed and edited by Ms. Namukolo Mulumeui, Acting Executive Director, Maboshe Memorial Centre (MMC). The report is based on survey study conducted by Maboshe Memorial Centre - MMC team of community health volunteers on the accessibility and availability of Sexual and Reproductive Health and Rights (SRHR) services of adolescent with disabilities in Mongu district, western province, Zambia.

The programme aimed at advocating for Sexual and Reproductive Health and Rights (SRHR) services on adolescent girls with disabilities and young sex workers in Western province, Zambia.

Maboshe Memorial Centre - MMC team of community health volunteers and staff we would like to express its sincere gratitude to all those involved. To be precise, we would like to appreciate the Maboshe Small Village Bank Fund (MSVBF) a department of Maboshe Memorial Centre - MMC for valuable and unreserved funding in the development of survey study.

We would like also to thank the data enumerators MMC community health volunteers) for their durable work and professional skills exhibited during questionnaire translation from English to Silozi, data collection and data transcribing.

Our gratitude further goes to the Mongu District adolescent girls with disabilities and young sex workers participants of this survey study in Siwa, Simulima, Kembi, Sefula Musindi and Simulumbe areas for their participation whose consent and contributions made this study possible. We sincerely hope their stories and experiences will contribute greatly in creating a supportive Sexual and Reproductive Health and Rights (SRHR) response.

Finally, we intend that the results of the study will give all key stakeholders understand clearer picture on the current Sexual and Reproductive Health and Rights (SRHR) services situation under Siwa, Simulima, Kembi, Sefula Musindi and Simulumbe areas and be able to make informed decision towards improving the status quo.

"I'm a human being who has feelings…People say how did you become positive when you are blind? They should understand that HIV does not spare the disabled."
—Sibeso. S. a blind, Mongu district,

We are too shy to go to the shops to get condoms…even to the clinic" because of the fear of what members of the community will say when people with disabilities are seen getting condoms—
Monde. S. a Zambian woman with a physical disability, Mongu district.

The problem is that deaf people have no detailed information on SRHR/HIV prevention services. We can go to any health centre but there is no sign language…The deaf do not know about adherence to medication and it can be a killer.
— Susana. M., a Zambian woman who is deaf and has received training to be a counselor for HIV testing and counseling, Mongu district.

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Health workers expressed negative and stigmatizing attitudes toward pregnant women with disabilities. "If you go for pregnancy care, they counsel you publicly as if you have done something wrong and everyone is free to make comments…'Why should you become pregnant?' Everyone gets shocked. – Lungowe. M. Mongu district.

People in my village do say why should you get involved in sex if you are disabled. You don't even feel sorry for yourself.'…But we have a right to have sex. – Nalishebo. M. Mongu district.

**Acronyms**

| | |
|---|---|
| CIDRZ | Centre for Infectious Disease Research in Zambia |
| CLTS | Community Led Total Sanitation |
| DEBS | District Education Board Secretary |
| MMC | Maboshe Memorial Centre |
| MHM | Menstrual Hygiene Management |
| MoE | Ministry of Education |
| MOH | Ministry of Health |
| MLGH | Ministry of Local Government and Housing |
| MOGE | Ministry of Education General Education |
| O&M | Operations and Maintenance |
| PPP | Public Private Partnership |
| PTA | Parent Teacher Association |
| RWSSP | Rural Water Supply and Sanitation Programme |
| SRHR | Sexual And Reproductive Health And Rights |
| SLTS | School Led Total Sanitation |
| UNICEF | United Nations Children's Fund |
| UNESCO | United Nations Educational, Scientific and Cultural Organization |
| UNPFA | United Nations Population Fund |
| USAID | United States Agency for International Development |
| WASH | Water Sanitation and Hygiene |
| WHO | World Health Organisation |
| WinS | Water Sanitation and Hygiene in Schools |
| FGD/s | Focus Group Discussion/s |
| KII/s | Key Informant interview/s |
| IDI/s | In-depth Interview/ |

Persons with disabilities are often called by denigrating and stigmatizing names. For example, individuals with psychosocial and intellectual disabilities are called "Simumu" (one who doesn't understand) – Nyambe.M. Mongu district.

People think that people with disabilities can't have boyfriends or girlfriends…They can't feel sex…They must be just staying at home as a disabled – Limpo .N. a single mother with physical disability, Mongu district.

## FOREWORD

According to the Zambia National Disability Survey (2015), as estimated 7.7% of the population are persons with disability, with prevalence among young people (2–17 years) estimated at 4.4%, including adolescent girls. Girls with disabilities often face key barriers that prevent them from accessing essential health information and services, including sexual and reproductive health services. This situation remains a huge challenge particularly for girls in rural and underserved communities, many of whom remain unware of their rights and thus denying them the power to make informed choices about their own lives.

Zambia has made important progress in scaling-up sexual and reproductive health and rights (SRHR) services over the past decade. However, more than 1 in 10 adults in Zambia are living with HIV and 46 thousand adults and more than 9,000 children are infected with HIV every year. There are nearly two million persons with disabilities in Zambia, and like any other Zambian, they face a high risk of HIV infection. Yet, adults and children with disabilities have been systematically left behind in the national HIV response, with limited access to SRHR and HIV prevention services information and significant barriers to HIV testing and treatment.

Our programmes support the Ministry of Health of the republic of Zambia's strategic goal of ending preventable maternal, newborn and child death in accessing sexual and reproductive health and rights SRHR services in health centres.

MMC is working to ensure that accurate information is provided to adolescences and young women with disabilities of reproductive age and pregnant disabilities women on infection precautions, potential risks and how to seek timely medical care.

"We must stand together in solidarity, fight stigma and discrimination, and ensure that adolescences and young women with disabilities get the information and services they need, especially pregnant and lactating adolescences and young women with disabilities." Sexual and reproductive health is a significant public health issue during epidemics, and safe pregnancy and childbirth depends on functioning health systems and strict adherence to infection precautions.

Maboshe Memorial Centre - MMC will work with the government and other partners to create an enabling legal and policy environment where adolescences and young women with disabilities can access services with no barriers most importantly by considering sexual reproductive health as a human right

Patrick Maboshe,
Executive Director
Maboshe Memorial Centre - MMC

## INTRODUCTION

Adolescent with disabilities in Zambia face numerous challenges in accessing sexual and reproductive health. Cultural belief still regards them as not sexually active. The government has also failed to promote policies that facilitate access to sexual and reproductive services by adolescent with disabilities.

There is a need for more sensitization on preventive methods for adolescent with disabilities, especially for the deaf and hearing impaired. Due to stigmatization and discrimination they are often left out, especially in times of crisis as it happens now. Due to challenges in communication, not many people know sign language, there is a lack of understanding of what is happening and what can and should be done.

In Western province, Zambia, in the absence of reliable census data, adolescent with disabilities, we can't estimate the population of them but majority are among the poorest part of the population. Vulnerable adolescent with disabilities face various physical, attitudinal and institutional barriers to access food, health, shelter and protection on an equal basis with others. They also face disability-based discrimination, which is exacerbated in situations of crisis, and when it intersects with other factors, such as poverty, gender or age.

Maboshe Memorial Centre - MMC clearly identified adolescent with disabilities as one of the particularly adolescent with disabilities in Mongu district, Zambia express concern about the deterioration of their psychosocial and socio-economic wellbeing. To make sure persons with different types of disabilities are included in any sexual and reproductive health and rights SRHR services, they need to be consulted and their specific needs and equal rights accounted for.

Maboshe Memorial Centre - MMC is one rural organization of adolescent with disabilities exists in different locations of Western province, Zambia. Specific risks faced by adolescent with disabilities:

- Adolescent with disabilities, face increased risks of HIV infection and complications due to underlying health conditions and socio-economic inequalities, including poor access to health care. These risks are compounded by numerous barriers in the preparedness and response including:
    I. Lack of meaningful consultation of adolescent with disabilities.
    II. Lack of access to sexual and reproductive health and rights (SRHR) in public health, increased stigma on the basis of disability and other intersecting factors.
    III. Inadequate accessibility of the WASH and health infrastructure.
    IV. Lack of inclusive surveillance mechanisms, contingency plans, preparedness and response plans.
- Adolescent with disabilities, especially persons with psychosocial disability and/or intellectual disabilities may at higher risk of being deprioritised or denied access to treatment for sexual and reproductive health and rights (SRHR) based on the wrong assumption that their chances of survival are less compared to those without disabilities.
- Physical distancing, movement restrictions and/or separation from care givers may impose disruption of medical, social and/or rehabilitation care and/or individual support affecting their health status and heighten exposure.
- Lack of protection and social support mechanisms for adolescent with disabilities lead to increased vulnerability, affect physical and psychosocial wellbeing, reduce autonomy, increase risk of violence and difficulty in accessing specific requirements (dietary requirements, medicines, etc).

Many adolescent with disabilities have pre-existing health conditions that make them more susceptible to contracting the virus, experiencing more severe symptoms upon infection, leading to elevated levels of death.

Adolescent with disabilities who are dependent on support for their daily living of selling sex may find themselves isolated and unable to survive during lockdown measures.

Barriers for adolescent with disabilities in accessing health services and information are intensified; adolescent with disabilities will continue to face discrimination and other barriers in accessing sexual and reproductive health and rights (SRHR) in health centres, livelihood and income support and protection from violence.

## Chapter 1

### PERVASIVE STIGMA AND DISCRIMINATION

In Zambia, disability is often considered a curse or punishment caused by evil spirits or as a result of witchcraft, for example in response to the actions of family members. Taboos regarding their sexuality result in a lack of respect for the sexual and reproductive rights of persons with disabilities. Individuals with different disabilities, they are often viewed as being a sexual and are confronted with negative attitudes about their right to marry and have children. As a result, persons with disabilities sometimes do not have access to HIV prevention, testing, or treatment services.

Many deaf people are discriminated against in schools, communities, health centers and by their own families. All deaf people are locked in a world where they can't communicate their ideas, they can't ask for help or ideas, information or advice.

Maboshe Memorial Centre - MMC discovered it is not easy for deaf people to get information, for the blind they can hear information on the radio but they still need written records. They need information in Braille so they can revisit the information when they need to.

All persons living with HIV experience stigma and discrimination. However, persons with disabilities face "double" stigma because of their disabilities and HIV status, perpetuating their social isolation, hampering the linkage and adherence to treatment, and limiting their ability to form intimate relationships. This increased stigma further inhibits disclosure of their positive status in the community and even within their family and circle of peers.

### METHODOLOGY

This study is based on desk research and interviews with 10 young deaf women, 30 young sex workers with disabilities and 10 persons with sensory or physical disabilities conducted in July, 2020 in Mongu district Western province, Zambia.

The study utilised qualitative methods using focus group discussions (FGD) with 10 young deaf women, 30 young sex workers with disabilities, key informant interviews (KII) with 10 persons with sensory or physical disabilities, to collect data. Data were collected in five (5) areas named: - Siwa, Simulima, Kembi, Sefula Musindi and Simulumbe areas in Mongu district. The selection criteria included young disabled women areas and their caregvers in order to investigate the different challenges faced by them. Structured observation forms were used to conduct the Sexual and Reproductive Health and Rights (SRHR) assessment

This study was a purely qualitative study and was conducted in seven areas named: - Siwa, Simulima, Kembi, Sefula Musindi and Simulumbe areas in Mongu district.

Qualitative data was collected using a Focus Group Discussion (FGD) guide. A checklist was further used to capture data on the existing SRHR services. Recorded data was transcribed and entered in NVIVO to facilitate data analysis.

Convergence between data collected using a checklist and focus group discussion was done during the reporting stage.

### ASSESSMENT BACKGROUND

This report examines the barriers faced by young women with disabilities in accessing SRHR and HIV prevention services in local health centres in Mongu district, including HIV prevention information, family planning, condoms, testing, treatment and long-term support for adherence. It also examines the exposure of girls and young women with disabilities to significant risk factors for SRHR in five (5) areas named: - Siwa, Simulima, Kembi, Sefula Musindi and Simulumbe areas in Mongu district.

The purpose of this research was to investigate factors that influence the management of SRHR among adolescent girls with disabilities and young sex workers. This report presents the study findings that bring to light various challenges and determinants among adolescent girls with disabilities and young sex workers. The reader will also find interesting among adolescences and young women with disabilities voice impacts on the challenges they face. Lastly, it discusses the practical steps that should be taken to ensure appropriate sexual and reproductive health services interventions are promoted in Mongu district.

### OBJECTIVE

- To explore the challenges faced by adolescent girls with disabilities and young sex workers in accessing sexual and reproductive health in Zambia.
- To scale up and strengthen the health service delivery system through addressing critical areas for efficient and effective scale up of linkages between sexual and reproductive health and rights SRHR services.
- Educating adolescent girls with disabilities and young sex workers on issues of SRHR services and gender based violence.
- To increase knowledge and uptake of sexual reproductive health services were low among adolescent girls with disabilities and young sex workers
- Bring awareness of SRHR services impact on adolescent girls with disabilities and young sex workers and their sexual and reproductive health and rights (SRHR).
- Identify key actions and other stakeholders on SRHR services
- Provide needed resources for provision of SRHR services responses of adolescent girls with disabilities and young sex workers.

**STUDY POPULATION**

Many of the areas visited have a population of more than 50 adolescent girls with disabilities and young sex workers (adolescent girls with disabilities 10-19 years of age, youth: 15-24 years of age and young people: 10-24 years of age).

**STUDY SITES**

The survey was conducted in Mongu district of Western province in Zambia. The focus areas being five (5) areas named: - Siwa, Simulima, Kembi, Sefula Musindi and Simulumbe areas in Mongu district.

**DATA COLLECTION TOOLS AND PROCEDURES**

In order for the survey to meet its intended objectives, different data collection methods were used.

This allowed data to be triangulated from different sources. Qualitative data was collected using a Focus Group Discussion (FGD) guide. Observational study was also used to collect data on key indicators of the project. A checklist was further used to capture data on the existing sexual and reproductive health services.

The survey data was also collected from secondary data to provide analytical benchmark data on different program indicators while photos were also captured to visualize the general situation on certain indicators. However, Qualitative data captured on a structured guide was entered in NVIVO to organize the data for easy analysis.

**QUALITY ASSURANCE**

Quality assurance was a fundamental part of this survey. Therefore, quality was assured through four basic extensions:

- The first was at the recruitment stage of research enumerators, some level of effort was made to ensure that only qualified and experienced enumerators were recruited for the assignment.
- Second, extensive training of data collectors was done in order to ensure that interviewer's bias is reduced. The training also ensured that data collectors understood the objectives, processes as well as output requirements for consistency and completeness of data that was collected.
- Thirdly, close and continuous supervision of data collectors was done by the principal investigator to ensure that the study captures what it intended to capture.
- All data collection tools were checked by the field supervisor on a daily basis to ensure that collected data was consistent and complete. Data collected via focus group discussions were recorded and transcribed.

**SAMPLING TECHNIQUE AND SAMPLE SIZE DETERMINATION**

The selection of focus group participants was done using convenience sampling method. This allowed the researcher to obtain basic data and trends regarding the set indicators.

**DATA ANALYSIS**

Qualitative data was transcribed and entered in NVIVO software to facilitate data analysis. Thematic analysis was then used for the qualitative data. Convergence between data collected using a checklist and observation was done during the reporting stage. Furthermore, a comprehensive document review was done to collect all information on secondary data indicators.

## DATA DISSEMINATION

Upon completion of the study, findings were presented to Maboshe Memorial Centre - MMC and Health Project Officer. The report was then shared with project beneficiaries. In addition the report was presented in hard copy and soft copy form.

## ETHICAL CONSIDERATION

All vulnerable adolescent girls with disabilities and young sex workers (participants) were informed about the purpose of the study and their right to decline from participating as well as the right to withdraw at any stage of the study. Participants were assured that no information pertaining to their identity will be recorded during data collection and reporting stages of the study, hence ensuring confidentiality. Verbal consent was obtained before data collection.

Information on the study as well as all possible risks of participating in the study was communicated to participants in order to respect their autonomous decision on whether to participate in the study or not.

The study did not provide any direct benefits to the study participants. This was clearly indicated prior to the study to ensure that participants who were not comfortable with revealing information would be free to pull out from the study.

## RESULTS

- Negative perceptions of health personnel towards adolescent girls with disabilities and young sex workers, disability-unfriendly infrastructure at health facilities and absence of trained personnel for people with disabilities (sign language) are some of the challenges involved.
- Lack of prevalence data about adolescent girls with disabilities and young sex workers in the district and lack of technical capacity are the most widely cited reasons for not promoting inclusive and targeted HIV and sexual and reproductive health services.
- We found that adolescent girls with disabilities and young sex workers face several key barriers to SRHR services, and hence to realizing their right to the highest attainable standard of health. While some of these are the same for all people living with HIV and not only for young women with disabilities, other barriers disproportionately limit or uniquely affect adolescent girls with disabilities and young sex workers.
- Adolescent girls with disabilities under the age of 18 are almost four times more likely than are their peers without disabilities to be victims of abuse, with young persons with intellectual disabilities, especially girls, at greatest risk.
- Adolescent girls with disabilities and young sex workers are more likely to experience violence than either their male peers with disabilities or girls and young women without disabilities are.
- Adolescent girls with disabilities and young sex workers are almost without exception denied the right to make decisions for themselves about their reproductive and sexual health, increasing their risk of sexual violence, unplanned pregnancy, and sexually transmitted infection. They are more likely than their male peers to think of themselves as disabled and to hold a negative self-image. This in turn can make them more susceptible to harmful social interactions.
- Adolescent girls with disabilities and young sex workers have little knowledge about their sexual and reproductive health and rights and limited access to services.
- Adolescent girls with disabilities and young sex workers are not seen as needing information about their sexual and reproductive health and rights or capable of making their own decisions about their sexual and reproductive lives.
- Pervasive stigma and discrimination both in the community and by healthcare workers.
- Lack of access to inclusive SRHR education and information in schools, community settings, and through mass media.
- Obstacles to accessing voluntary testing and HIV treatment services.
- Lack of appropriate support for adherence to antiretroviral treatment (ART).
- Lack of effective pre- and post- HIV testing counseling because of inadequate training of healthcare workers on how to communicate with and address the concerns of adolescent girls with disabilities and young sex workers.

## WHAT IS THE IMPACT OF SEXUAL AND REPRODUCTIVE HEALTH SERVICES?

50 of the interviewed adolescent girls with disabilities and young sex workers faced major obstacles in accessing SRH information and services, including antenatal and delivery care from a skilled provider, as well as access to a variety of methods of contraception. After testing positive for HIV, individuals with disabilities face difficulty linking to ART because of stigma or fear of loss of confidentiality. The experience of stigma by persons with disabilities is not dissimilar to many people without disabilities who are living with HIV. However, adolescent girls with disabilities and young sex workers face compounded barriers because their fear of HIV related stigma is heightened by lack of accessible HIV information and negative attitudes about their sexual and reproductive lives by health workers and people in the community.

Adolescent girls with disabilities and young sex workers are unable to access SRHR information on an equal basis with other people because of lack of access to education in general. Discrimination within the family, admission barriers and lack of physical accessibility keep many young sex workers out of school where they might receive SRHR information. Even when adolescent girls with disabilities and young sex workers are able to attend school, are often excluded from programs providing SRHR information, or cannot access inclusive materials disseminated through print and mass media because of the lack of materials produced in simplified formats, braille, large print, or with sign language symbols.

Persons with sensory or physical disabilities experience difficulties in accessing and using condoms due to the lack of accessible information and peer education. Community-based sensitization activities often exclude adolescent girls with disabilities and young sex workers due to physical and communication barriers and social isolation.

Adolescent girls with disabilities and young sex workers face many challenges in accessing sexual and reproductive health and rights today – having a disability often means facing even more barriers. Adolescent girls with disabilities and young sex workers are often neglected in sexual and reproductive health policies and health care provisions, limiting their access to information and services.

Every adolescent girls with disabilities and young sex workers has the right to decide matters related to their own health, education, employment and life access to sexual and reproductive health services is a right; pandemics do not stop pregnancy or births and in no way justify violations of fundamental rights. Together, let's slow down the spread of HIV infection and now protect the health and rights of adolescent girls with disabilities and young sex workers.

Access to voluntary family planning is a human right and a critical way to give adolescent girls with disabilities and young sex workers the tools they need to be the masters of their fate and fulfill their greatest potential. Limiting access to sexual and reproductive health services makes adolescent girls with disabilities and young sex workers more vulnerable to violence. Family planning isn't just about planning families; it's about empowering women and enabling them to take charge of their lives.

## WHAT IS THE IMPACT OF SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS (SRHR) SERVICES OF ADOLESCENCES WITH DISABILITIES.

Without the usual protection of family and community, women and adolescent girls frequently become victims of sexual violence, unwanted pregnancies and sexually transmitted infections. Basic needs for safe birth, family planning and reproductive health care are rarely met when women and adolescents become separated from the lifeline of health systems.

Adolescent girls with disabilities and young sex workers are victims of physical or sexual violence during their lifetime. If Zambia will adopt lockdown measures and household tensions will increase, gender-based violence intensifies sexual and reproductive health services will be relegated to the second level by health systems that are struggling to do facing the HIV pandemic crisis.

Adolescent girls with disabilities and young sex workers are at higher risk of violence, sexual abuse, intimate partner and domestic violence particularly when isolated compared to other women, they also experience higher levels of violence than men with disabilities.

## KEY ACTIONS RECOMMENDATIONS FOR THE MABOSHE MEMORIAL CENTRE (MMC) TO IMPLEMENT.

- Establish safe spaces for adolescent girls, for mentorship platform with information on SRHR services, teenage pregnancy, child marriage and life skills.
- Produce a sign-language dictionary for sexual and reproductive health and rights SRHR services.
- Establishing sexual and reproductive health services tables at night clubs

- Advocacy campaigns for greater involvement of adolescent girls and young sex workers with disabilities in sexual and reproductive health and rights (SRHR) in public health to reduce stigma on the basis of disability and other factors.
- SRHR/HIV integration service provision: - package for integrated SRHR services, referral clients.
- Nights club mobilization campaigns to promote sexual & reproductive health services.
- Production of sexual and reproductive health and HIV prevention services IEC materials in local languages.
- Sign language interpreters and referral system to youth friendly sexual and reproductive health care facilities
- Ensure that reporting mechanisms, hotlines and other forms of assistance are accessible to and include adolescent girls with disabilities and young sex workers.
- Mass media communication will include captioning, national sign language, high contrast, large print information.
- Train behaviour change facilitators on youth friendly SRHR services sign language.
- Sensitize adolescent girls with disabilities and young sex workers in night clubs to access health care services in sexual reproductive health and HIV prevention.
- Using of sign language in youth friendly centres on SRHR services.
- Training media professionals on reproductive health services for adolescent girls with disabilities and young sex workers.
- Supporting mass media (e.g. print, radio, television, and internet) to convey messages intended to ensure positive sexual behaviors, increase awareness and knowledge, and reduce high-risk behaviors among adolescent girls with disabilities and young sex workers
- Working with youth-serving organizations to support youth-led local media to reach adolescent girls with disabilities and young sex workers, their parents, and the community.
- Establishing reporting mechanisms, hotlines and other forms of assistance are accessible to and include adolescent girls and young sex workers with disabilities.
- Develop referral system on HIV/AIDS/STI prevention testing and counseling.
- Condom distribution points night clubs.
- Establish SRHR/HIV prevention information resource centre for adolescent girls and young sex workers with disabilities.

Zambia has ratified the Convention on the Rights of Persons with Disabilities and is obligated to ensure that people with disabilities can realize their right to the highest attainable standard of health without discrimination.

**CONCLUSION**

Maboshe Memorial Centre - MMC will work with the government and other partner stakeholders in addressing challenges faced by adolescent girls with disabilities and young sex workers when accessing sexual and reproductive health services.

Maboshe Memorial Centre - MMC will consider 'youth-friendly SRHR services in the following areas: -

- Acceptable: adolescents are willing to obtain the health services that are available.
- Equitable: all adolescents, not just selected groups, are able to obtain the health services that are available.
- Appropriate: the right health services are provided to them.
- Effective: the right health services are provided in the right way, and make a positive contribution to their health.
- Accessible: adolescents are able to obtain the health services that are available.