



International Community
of Women Living with HIV
Eastern Africa (ICWEA)

SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS VIOLATIONS AGAINST WOMEN WITH DISABILITIES

*Experiences and Perspectives from Gulu, Masaka
and Mbale Districts in Uganda*



August 2020

With funding support from:



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ACKNOWLEDGEMENTS

The International Community of Women Living with HIV East Africa (ICWEA) applauds the indispensable financial and technical support that we received from partners that made this study possible ICWEA is grateful to everyone who contributed to the success of this study.

We are particularly indebted to the networks of persons with disabilities (PWD) in Gulu, Masaka and Mbale; the community development and social services departments; and the in-charges of health facilities that accorded the study team generous reception and provided invaluable support.

This study would not have been successful without the respondents, particularly the women with disabilities who voluntarily and willingly accepted to participate in the study, as well as the representatives of PWD networks, PWD leaders, sexual and reproductive health and rights (SRHR) program managers, and health providers at the health facilities reached in Gulu, Masaka and Mbale districts,

The research team was led by Lillian Mworeko as Principal Investigator, supported by Dorothy Namutamba as Co-Investigator and Richard Hasunira as Consultant. ICWEA is thankful to the research assistants, Christopher Ogwang, Irene Ochwo and Patience Nabwami; as well as to the field team that supported data collection and entry, including mobilizers and sign language interpreters and the guides and caregivers who supported the respondents in this study.

ICWEA is also grateful to the invaluable support from the ICWEA secretariat staff and resource persons who reviewed the initial drafts of this report and provided valuable input and guidance to the study team.

The financial support from Open Society Initiative for Eastern Africa that facilitated the carrying out of this research is highly appreciated.

Lillian Mworeko
Executive Director,

LIST OF ACRONYMS

CESR	Center for Economic and Social Rights
CRPD	Convention on the Rights of Persons with Disabilities
CDO	Community development office
CSO	Civil society organizations
DHT	District health team
EmOC	Emergency obstetric care
FGD	Focus group discussion
GBV	Gender-based violence
HUMC	Health unit management committee
ICWEA	International Community of Women Living with HIV East Africa
MCH	Mother and child health
NUWODU	National Union of Women with Disabilities of Uganda
OPD	Out-patient department
PrEP	Pre-exposure prophylaxis
PWD	Persons with disability
RRH	Regional referral hospital
SRH	Sexual and reproductive health

SRHR	Sexual and reproductive health and rights
STI	Sexually transmitted infection
UBOS	Uganda Bureau of Statistics
UNCST	Uganda National Council for Science and Technology
UNFPA	United Nations Population Fund

DEFINITION OF THE KEY TERMS

“Disability” is defined as a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation.¹ The United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.²

“Sexual health” is a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.³

“Sexual rights” refer to specific norms that emerge when existing human rights are applied to sexuality. These rights include freedom, equality, privacy, autonomy, integrity and dignity of all people; principles recognized in many international instruments that are particularly relevant to sexuality.⁴

“Reproductive health” is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. Reproductive health implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Men and women, including women with disability, have a right to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice, as well as other methods of their choice for the regulation of fertility which are not against the law, and the right of access to appropriate health-care services that will enable them to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy child.⁵

“Reproductive rights” refer to the rights of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. They also include the right of all to make decisions concerning reproduction free of discrimination, coercion and violence.⁶

“Violence” refers to the intentional use of physical force or power – threatened or actual – against oneself, another person, or against a group or community, which either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment, or deprivation.⁷

¹ Persons with Disabilities Act, Article 2 “Interpretation”

²CRPD, Preamble (e).

³ WHO: Sexual health. https://www.who.int/topics/sexual_health/en/

⁴ IPPF, 2008. Sexual rights: an IPPF declaration. https://www.ippf.org/sites/default/files/sexualrightsippfdeclaration_1.pdf

⁵ United Nations 1994 International Conference on Population and Development (ICPD)

⁶ WHO. Gender and reproductive rights. <https://web.archive.org/web/20090726150133/http://www.who.int//reproductive-health/gender/index.html>

⁷ WHO, 2002. World Report on Violence and Health. <https://bit.ly/3jxo6z5>

“Sexual violence” is defined as any sexual act, attempt to obtain a sexual act, unwanted sexual comments or advances, or acts to traffic, or otherwise directed, against a person’s sexuality using coercion, by any person regardless of their relationship to the victim, in any setting, including but not limited to home and work.⁸

“Informed consent” is a process of communication between health care providers and patients to ensure that consent for a medical procedure is given voluntarily, without threats or inducements, after the patient has been fully counseled on the risks and benefits of the procedure, as well as possible alternatives, in a language and form that is understandable to the patient.⁹ The patient must be competent to make a voluntary decision about whether to undergo the procedure or intervention. Informed consent is both an ethical and legal obligation of medical practitioners.

⁸ WHO, 2002. World Report on Violence and Health. <https://bit.ly/3jxo6z5>

⁹ Center for Reproductive Rights and UNFPA. Reproductive Rights: A Tool for Monitoring State Obligations. https://www.reproductiverights.org/sites/crr.civicaactions.net/files/documents/crr_Monitoring_Tool_State_Obligations.pdf

EXECUTIVE SUMMARY

Under the United Nations Convention on the Rights of Persons with Disabilities, Uganda and other state parties have committed to uphold the rights of women and girl with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education, as well as other sexual and reproductive health rights (SRHR). These commitments have been reiterated in the domestic disability legislation and policy, including the Uganda Constitution of 1995, the Persons with Disabilities Act of 2006, National Policy on Disability of 2006, and others.

This study documented and assessed the SRHR violations that women with disabilities of reproductive age face in community and clinical settings in three districts of Uganda - Gulu, Masaka and Mbale. The study takes a human rights approach to disability and assesses the experiences of women with disabilities, documenting violations against women and girls with disabilities in clinical and community settings.

A desk review of policy and legal frameworks, and other relevant literature found that while the international and regional laws as established in several treats, particularly the Convention on the Rights of Persons with Disabilities (CRPD) and the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol), layout a strong legal framework for the SRHR of women with disabilities, these have not been translated into the national legal framework. Uganda's reservation on Article 14 of the Maputo Protocol which stipulates the SRHR of women in Africa, undermines advocacy for the SRHR of vulnerable women such as women with disabilities.

On its part, the policy framework is more generic in its provisions and strategies to promote the SRHR of the population, and only makes mention of women with disabilities as one of the vulnerable groups without making specific strategies to reach them.

From the field data, the study found SRHR violations within programming, but in clinical and community settings as well. In terms of programming, a wide range of SRHR services are provided at public health facilities that were reached in this study, especially at the regional referral hospitals, but the findings show that SRHR programming is not inclusive of women with disabilities. Service providers are generally poorly equipped to provide SRHR services to women with disabilities. Health facilities at the different levels report that they do not have any standard provisions or written guidelines for meeting the special needs of women with disabilities.

None of the lower health facilities reached has an adjustable bed that is designed to make access by women with physical disabilities easy. Only Gulu and Masaka regional referral hospitals reported to have adjustable delivery beds. Only two of the 12 health facilities reached in this study - Masaka RRH and Mbale RRH - had at least one health worker who had been trained in sign language. Health workers cited several challenges in providing SRHR services to women with disabilities, including referral of women who cannot afford transport to higher health facilities; helping girls and women with disabilities who have been sexually assaulted; attending to pregnant women who have unaccompanied by care givers or partners, and dealing with relatives who do not appreciate the rights of PWD, among others.

The findings further that women with disabilities are aware of their SRHR but are powerless and unable to claim them. Almost all women participating in the FGDs report some unpleasant experience, either at a health facility, in the family, in their community, or at all three levels. They feel that they are treated as women who are "not normal"; who are not able to look after children and should therefore not have children or should have fewer children; who are likely to give birth to children with abnormalities; who cannot have a normal delivery, need more specialized attendance during childbirth, among other biases.

In the clinical setting, the findings indicate that due to stigmatization and discrimination, uptake of SRHR services by women with disabilities is low. The responses from women with disabilities indicate that health facilities are a major

source of stigma for women with disabilities seeking SRHR services. They report being ignored, demeaned, embarrassed, under-served and insulted.

Several health facilities visited indicated that they usually “help” women with disabilities when necessary. However, women with disabilities denied that they get any special attention when they go to health facilities for SRHR services. They report outright discrimination in access to information and services, as well as negative attitudes among health workers.

Even where there has been well-meaning “help” from health workers, it has ended up stigmatizing or discriminating women with disabilities. Women participating in FGDs reported that when they go for family planning, health workers insist on giving them permanent methods reportedly to “save them the burden” of having children. They cited cases of being subjected to unnecessary cesarean surgery even when they felt that they could push babies. Women with disability report service providers being “surprised” by their request for contraceptives.

Several health workers felt that women with disabilities should have fewer children, and reported that they had provided contraception to women with disabilities upon the request of relatives. Women with disabilities cited many cases where girls with disabilities were forced to abort, to take a contraceptive or to be sterilized altogether by relatives in connivance with health workers.

At the community level, the commonest SRHR-related violations against women and girls with disabilities include stigmatization, sexual assault, forced marriages, psychological harassment, outright discrimination and forced sterilization, being victimized for HIV infection of spouses, and lack of access to justice for SRHR violations.

The study recommends:

- 1) **Ministry of Health and Parliament** should develop policies and laws that guarantee women with disabilities access to SRHR services that are sensitive to their needs; prioritize investments that make health facilities disability friendly; mainstream sign language in the medical school curriculum and build the capacity of, and strengthen, existing grievance redress mechanisms and structures at the facility and community levels.
- 2) Ministry of Gender, Labor and Social Development should scale up services for PWD generally, and give special attention to women with disability.
- 3) **Human Rights organizations, PWD networks and local governments:** Train SRHR service providers in the HRBA; and sensitize and empower women and girls with disabilities on SRHR to be able to speak out, defend and demand their rights; work together to improve coordination of disability interventions of state and non-state actors in community and clinical settings; and should involve PWDs in planning and advocacy spaces such as HUMCs and service committees to improve SRH services.
- 4) **Human rights organizations and monitoring agencies** should establish a participatory monitoring and evaluation mechanism to track the implementation of policies and programs on access to SRHR by women with disabilities.

1. BACKGROUND

1.1 INTRODUCTION

The International Community of Women living with HIV Eastern Africa (ICWEA) is a legally registered regional advocacy network. It is a membership-based organization founded in 2005. It exists to give visibility to, and promote women's collective voices to advocate for, and claim their rights. It mobilizes, mentors, creates safe spaces for, and builds the capacities of, women. The organization undertakes research on issues critical to HIV policies and programs. It builds bridges, opens dialogues, monitors political commitments and proposes improvements in policy and law.

ICWEA is conceptualized and organized around sexual and reproductive health and rights (SRHR) movement-building. As women cannot wait for their rights to be fulfilled charitably, ICWEA brings together the community of women living with HIV through intensive mobilization and capacity-building to act. It builds knowledge through community-based research and training on advocacy and human rights. It supports engagement with policy and decision-makers as well as with other stakeholders, initiating or building key coalitions as needed.

ICWEA's vision is a world where all women living with HIV have respected and meaningful involvement at all political levels where decisions that affect their lives are made; have full access to care and treatment services and fully enjoy their rights, particularly their SRHR. ICWEA's mission is to promote all women's voices and to advocate for changes that improve their lives. ICWEA's mandate is premised on the fact that gender and gender-related inequalities and vulnerabilities are at the heart of the abuses and violations that marginalized women and girls endure, including abuses and violations of their SRHR. Many women are isolated, stigmatized and discriminated for different reasons.

In pursuit of its mission and mandate, ICWEA, with funding from Open Society Institute in Eastern Africa (OSIEA), is implementing an SRHR advocacy project aimed at putting an end to SRHR violations against women, especially marginalized women, and to advocate for the elimination all forms of forced and/or coerced sterilization of women in Uganda. As part of this project, ICWEA undertook this study on violations of SRHR of women and girls with disability within the clinical and community settings. The purpose of the study was to generate evidence to inform advocacy at community, service implementation and policy levels. This document summarizes the main findings of the study.

1.2 CONTEXT

Persons with disability (PWD) constitute a substantial proportion of the population of Uganda. In 2014, Uganda Bureau of Statistics (UBOS) estimated that about 4,781,250 people – equivalent to 13.6% of the total population – had disabilities of different forms.¹⁰ The commonest forms of disability were: physical disability (lost/limited use of limbs), 35%; serious spine problems, 22%; hearing impairments, 15%; visual impairment, 6.7%; speech impairment, 3.9%; mental retardation, 3.6%; mental illness, 3.6%; other disabilities, 9.6%. Persons with physical, visual and hearing/speech impairments constitute an estimated 92.6% of PWDs in Uganda.

For a variety of reasons, PWD in Uganda, as in most developing countries, face extreme conditions of poverty, have limited opportunities for accessing education, health, and suitable housing and employment opportunities.¹¹ It has been estimated that 80% of PWD are living in conditions of long-term poverty with limited access to education,

¹⁰UBOS, 2014. National Housing and Population Census

¹¹International Labor Organization (ILO, 2009). Inclusion of people with disabilities in Uganda: Decent work for people with disabilities. *Fact Sheet*. https://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_115099.pdf

health facilities, sustainable housing and employment.¹² In addition, PWD-headed households in Uganda have been found to be 38% more likely to be poor than those headed by nondisabled persons.¹³

The 2014 national census revealed that disability is higher among women (14.5%), than among men (10%). Evidence suggests that more PWD suffer abuse than persons without disability¹⁴; that the incidence of maltreatment and abuse of women with disability far exceeds that of women without disability¹⁵; and that there is a higher rate of violence against women with disability than against men with disability¹⁶. PWD often are considered by society to be “not completely human and of less value”, leading to a lack of remorse or conscience by their abusers.¹⁷

People frequently react to the presence of PWD with fear, pity, patronization, intrusive gazes, revulsion, or disregard. These reactions can, and often do, exclude persons with disabilities from accessing social spaces along with the benefits and resources these spaces provide.¹⁸ The CRPD differentiates two kinds of disability intersection: race-disability intersection and gender-disability intersection.¹⁹

Women with disability suffer multiple vulnerabilities associated with their gender as well as those associated with their disability. Evidence shows that PWD are at a significant risk of becoming HIV infected because all risk factors associated with HIV are increased for PWD.²⁰ For instance, one study has estimated that 38% of women and 35% of men with disability had a sexually transmitted infection (STI) at one time, raising concerns about PWD vulnerability to HIV, given the high correlation between STI and HIV risk.²¹ Gender and disability-based discrimination and exclusion result into a high risk of violence against girls and women with disabilities.²²

The clinical setting is a particular source of abuses against PWD.^{23,24} Medical treatments of an intrusive and irreversible nature, enforced or administered without the free and informed consent of the person concerned, that are

¹²Lwanga-Ntale (2003:1)

¹³Hoogeveen, J.G., 2005. Measuring welfare for small but vulnerable groups: Poverty and disability in Uganda', *Journal of African Economies* 14(4), 603-631. <http://dx.doi.org/10.1093/jae/eji020>

¹⁴European Disability Forum (1999). *Report on violence and discrimination against disabled people* [Doc EDF 99/5 EN]. <http://cms.horus.be/files/99909/MediaArchive/EDF%2099-5-violence%20and%20discr-EN.pdf>

¹⁵Iglesias, M. (1998). *Violence and women with disability*. Vedras, Spain: AIES;The Swedish Research Institute for Disability Policy, HANDU AB. (2007). Men's violence against women with disabilities. *Synskadades Riksförbund*, The Report Series, 2007(1). <http://www.wwda.org.au/swedishstudy1.pdf>

¹⁶Department of Justice, Office of Justice Programs. (2009). *Crime Against People with Disabilities, 2007*. Bureau of Justice Statistics, Special Report. <http://bjs.ojp.usdoj.gov/content/pub/pdf/capd07.pdf>

¹⁷Iglesias, M. (2004). The nature of violence against disabled people. <http://www.nda.ie/cntmgmtnew.nsf/0/BE967D49F3E2CD488025707B004C4016?OpenDocument>

¹⁸Reeve, D. (2004) 'Psycho-emotional dimensions of disability and the social model', in C. Barnes and G. Mercer (eds). *Implementing the Social Model of Disability: Theory and Research*, Leeds: The Disability Press, pp. 83-100. <http://domareeve.co.uk/wp-content/uploads/2014/03/ReeveChapter2004b.pdf>

¹⁹Anna Lawson (2016). *European Union Non-Discrimination Law and Intersectionality*

²⁰Groce, Nora. 2004. HIV/AIDS and disability: Capturing hidden voices. World Bank. <http://documents.worldbank.org/curated/en/520371468140965858/HIV-AIDS-and-disability-capturing-hidden-voices>

²¹Groce, Nora (2004). Ibid

²²Human Rights Watch, 2010. As if we weren't human: Discrimination and violence against women with disabilities in northern Uganda. <https://www.hrw.org/report/2010/08/26/if-we-werent-human/discrimination-and-violence-against-women-disabilities-northern>

²³Young M., Nosek M., Howland C., Chanpong G., and Rintala D. (1997).Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*,78(Supplement), S34–8.

aimed at correcting or alleviating a disability or that lack a therapeutic purpose constitutes torture or ill-treatment of PWD.²⁵ These kinds of actions include forced abortion and sterilization.²⁶

Appallingly, many women with disability consider their plight normal or acceptable, particularly in contexts where abuses are sanctioned by law, policy or social norms.^{27,28} It is possible that inability to perform the roles of a mother, or even of the perceived roles of a woman in society, undermines not only their self-esteem, but also their valuation by society. Perpetrators are more likely to assume that their actions are defensible, will not be discovered, or that victims have no ability to report violations.²⁹ Women with disabilities often are dependent on other people for care, physically, materially or financially.³⁰ Under such circumstances, they may fear to report abuse as it could result in breaking the dependency bonds and loss of the care that sustains them.

1.3 PROBLEM STATEMENT

The rights of PWD are recognized in national and international law, including the rights to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education, as well as other sexual and reproductive health and rights (SRHR).³¹ SRHR is the concept of human rights applied to sexuality and reproduction, encompassing sexual health, sexual rights, reproductive health and reproductive rights.

The CRPD (Article 12) specifies that PWD enjoy legal capacity on an equal basis with others, have the right to marry and found a family and retain their fertility (Article 23), and have access to sexual and reproductive health care (Article 25). Uganda ratified the CRPD and its Optional Protocol on 25 September 2008 without reservations. By so doing, the country committed itself to accord the same rights to PWD (including women with disability) like the rest of the citizens.³²

Under the CRPD, Uganda and other states parties have acknowledged that women and girls with disability are subject to multiple discrimination, and have accordingly committed to take measures to ensure their full and equal enjoyment of all human rights and fundamental freedoms. These commitments have been reiterated in the domestic disability legislation and policy, including the national Constitution of 1995, PWD Act of 2006, the National Policy on

²⁴Interim report of the Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment, (2008). UN Doc. A/63/175.<http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N08/440/75/PDF/N0844075.pdf?OpenElement>

²⁵Interim report of the Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment. (2008).

²⁶ Minkowitz, T. (2007). The UN CRPD and the Right to be free from non-consensual psychiatric interventions. *Syracuse Journal of International Law and Commerce*, 32(2), 405-428. <http://www.chrusp.org/home/resources>

²⁷Burstow, B. (2006). Electroshock as a form of violence against women. *Violence Against Women*, 12(4), 372-392.

²⁸Burstow, B. (2006). Understanding and ending ECT: A feminist perspective. *Canadian Woman Studies*, 25(1,2), 115-123.

²⁹Women with Disabilities Australia (2004).

³⁰Women with Disabilities Australia (2004).

³¹The Constitution, Persons with Disability Act, and the Convention on the Rights of Persons with Disabilities (Article 23).

³²Government of Uganda: UN Convention on the Rights of Persons with Disabilities: Uganda's initial status report 2010

Disability of 2006, and others. Accordingly, Uganda has been praised as one of the champions of PWD rights in sub-Saharan Africa.³³

In spite of this progress, women and girls with disability face barriers to access to maternal health care³⁴, and continue to be vulnerable to violence.³⁵ The UN Population Fund (UNFPA) estimates that PWD are up to three times more susceptible to physical and sexual abuse and rape, and that women and children with disabilities are more likely to be victims of violence than their male counterparts.³⁶

In addition, it is not clear to what extent these interventions and commitments are enabling women to realize their SRHR. PWD have the same sexual and reproductive health (SRH) needs as other people, yet they often face barriers to information and services. The negative attitudes of society and individuals, including health-care providers, raise most of the barriers – not the disabilities themselves.³⁷ There is evidence showing that PWD continue to experience poorer health outcomes than those without disability and that they are still left behind – the common barriers to health care being health-service providers’ attitudes, knowledge and skills.³⁸ Unfortunately, many women and girls with disability consider their plight normal or acceptable, particularly in contexts where abuses are sanctioned by law, policy or social norms.³⁹

1.4 OBJECTIVES OF THE STUDY

The main objective of the study was to investigate SRHR violations against women of reproductive age living with disability within clinical and community settings in Gulu, Masaka and Mbale districts in Uganda.

The specific objectives are:

- 1) To examine the existing laws and policies that relate to the SRHR needs of women living with disability;
- 2) To identify existing interventions and practices at clinical and community levels that influence the realization of SRHR by women living with disability;
- 3) To understand the experiences of women living with disability in their reproductive ages with a focus on SRHR violations that take place in the clinical and community settings.

³³Abimanyi-Ochom, J. and Mannan, H., 2014. Uganda’s disability journey: Progress and challenges.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5443041/>

³⁴Innocent Najjumba Mulindwa, 2003. Study on reproductive health and HIV/AIDS among persons with disabilities in Kampala, Katakwi and Rakai districts. Disabled Women’s Network and Resource Organization (DWNRO)

³⁵Human Rights Watch, 2010. As If We Weren’t Human: Discrimination and Violence against Women with Disabilities in Northern Uganda. <https://www.hrw.org/report/2010/08/26/if-we-werent-human/discrimination-and-violence-against-women-disabilities-northern>

³⁶Secretariat for CRPD, UNFPA & Wellesley Centers for Women, 2008. Disability Rights, Gender and Development: A Resource Tool for Action. www.un.org/disabilities/documents/Publication/UNWCW%20MANUAL.pdf

³⁷World Health Organization, 2009. Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA guidance note

³⁸World Health Organization, 2011. World report on disability 2011

³⁹Burstow, B. (2006). Electroshock as a form of violence against women. *Violence Against Women*, 12(4), 372-392.

2. METHODOLOGY

2.1 STUDY DESIGN

This study employed a qualitative methodology and an explorative phenomenological study design. Phenomenological designs are effective at bringing to the fore the experiences and perspectives of individuals from their own perspectives. The qualitative approach has enabled an in-depth exploration of the SRHR experiences of women with disability in community and clinical settings. The research also involved a desk review of the relevant policy and legal framework, and a field-based inquiry conducted through personal interviews and focus group discussions (FGDs).

2.2 STUDY AREA

The study was conducted in Gulu, Masaka and Mbale districts. The three districts were selected through a structured approach to represent different regions of Uganda (Gulu in the North, Mbale in the East, and Masaka in Central). They were also selected because they each have a regional referral hospital which is expected to provide a full range of SRHR services; and have active district-based networks of persons with disabilities to facilitate mobilization of respondents, particularly women with disabilities, for focus group discussions and interviews, and to participate in the study.

Gulu district is located in Acholi sub-region in the northern region, with an estimated population of 315,077 (2019). The district's public health sector has a regional referral hospital, one Health Centre IV, 11 Health Centre IIIs, and 19 Health Centre IIs with an average staffing of 80.4%.⁴⁰

Masaka district is located in central Uganda, with an estimated population of 307,900 (UBOS, 2015/16 est.) The district public health sector consists of 12 Health Center IIs, nine Health Center IIIs, three Health Center IVs, and a referral hospital. On its part, Mbale is a district in the eastern region. Each of the three study districts has a regional referral hospital, which ideally has the capacity to provide the full range of SRH information, commodities and services, including permanent surgical family planning methods.

2.3 STUDY POPULATION

The study population consisted of women with disability aged 15-49 years, SRHR service providers, program managers, district leaders and CSOs working on disability rights. The study targeted women with either of three disabilities – physical, visual and hearing/speech disabilities – who were purposively selected, approached and consented to participate in this study. The study conducted key informant interviews with selected district leaders who included community development officers at the sub county and district levels; district health teams (DHTs), local government-level disability focal persons; mother and child health (MCH) service providers; local government-level TB/HIV focal persons.

2.3 CONCEPTUAL FRAMEWORK

This study takes a human rights approach to disability as articulated by the UN Office of the High Commissioner for Human Rights (OHCHR).^{41,42} The human rights approach to disability acknowledges PWD as equal human beings with

⁴⁰ Gulu district local government.

https://www.gulu.go.ug/sites/files/GULU%20DISTRICT%20PROFILE%202019_0.pdf#:~:text=DISTRICT%20PROFILE%20GULU%20DISTRICT%20PROFILE%20General%20Information%20Total,2019%29%20Number%20of%20Sub-Counties12%20Number%20of%20division%204

⁴¹UN OHCHR, 2014. The Convention on the Rights of Persons with Disabilities: Training Guide. *Professional Training Series No.19*

rights and freedoms to make their own choices and to determine their own destiny, and the State and its agents as having responsibilities to respect, protect and fulfill those rights and freedoms⁴³ to make their own choices and to determine their own destiny, and the State and its agents as having responsibilities to respect, protect and fulfill those rights and freedoms. This approach treats any barriers in society as discriminatory and provides avenues for PWD to complain when they are aggrieved. This approach is based on the three main principles of disability inclusion, which require that PWD are:

- 1) Engaged, consulted, represented and listened to at all levels of decision-making and as leaders;
- 2) Empowered as powerful and active agents of change to challenge discrimination;
- 3) Able to exercise and enjoy their fundamental rights and freedoms on an equal basis with others.

This approach is binding on Uganda and all other states that have ratified the CRPD, and requires state parties to eliminate and prevent discrimination; to involve PWD in the design of all policies and laws; and to mainstream disability into all aspects of political action. No “special” policies should be designed for PWD, notwithstanding the particularities needed to comply with the principle of full participation.

Using this approach, this study is focusing specifically on the SRHR of women with disability in their reproductive age (15-45 years). This study attempts to assess progress on SRHR-related human rights obligations under the CRPD, the Constitution of 1995, the PWD Act 2006 and the National Policy on Disability of 2006.

Specifically, the study focuses on the following rights:

- 1) The right to equality and non-discrimination.
- 2) The right to autonomy and bodily integrity.
- 3) The right to be free from torture and cruel, inhuman, and degrading treatment or punishment.
- 4) The right to be free from all forms of violence and coercion.
- 5) The right to the highest attainable standard of health, including sexual health; with the possibility of pleasurable, satisfying, and safe sexual experiences.
- 6) The right to information.
- 7) The right to enter, form and dissolve marriage and similar types of relationships based on equality and full and free consent.
- 8) The right to decide whether to have children, the number and spacing of children, and to have the information and the means to do so.
- 9) The right to participation in public and political life.

⁴² Human rights are values or standards that allow people to live with dignity and *all* people are entitled to them regardless of race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status, including disability.

⁴³ Human rights are values or standards that allow people to live with dignity and *all* people are entitled to them regardless of race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status, including disability.

10) The right to access justice, remedies, and redress.

11) Right to privacy of person, home and other property.

2.4 SAMPLING PROCEDURES AND DATA SOURCES

The study has documented the SRHR experiences of women with disability in the community and clinical settings, in Gulu, Masaka and Mbale districts. The selection of respondents was largely purposive, targeting women with disability within the reproductive age (15-49 years), SRHR providers, policy makers, program managers, district leaders and representatives of CSOs working on disability rights. The study targeted women with either of three disabilities – physical, visual and hearing disabilities.

In each of these districts, 36 women were identified and reached to participate in FGDs and personal interviews, giving a total of 108 women. In each of the three districts, three FGDs were held with 12 women in each of the three focus categories of disabilities. Women with disabilities were identified through district based PWD networks from the community.

In addition, in-depth interviews were then conducted with selected women in each of the disability categories in each of the districts, giving a total of nine respondents in this category – three per district. The respondents in the in-depth interviews were selected from among the FGD participants, and were the participants who shared striking experiences. Personal interviews were held to give them an opportunity to share additional information about their experiences, which have been documented as vignettes/cases.

Summary of respondent categories

District	Women with disability (FGDs)	Women with disability (FGDs and interviews)	PWD networks/activists	District/subcounty program managers	SRHR service providers
Gulu	36	3	4	4	6
Masaka	36	3	3	3	4
Mbale	36	3	2	3	3

Note: The program managers included assistant district health officer/MCH focal person, community development officers, PWD focal persons, HIV focal person, district health educator.

2.5 DATA COLLECTION METHODS

Primary data were collected using FGDs, key informant interviews, in-depth interviews using FGD and interview guides, respectively. These were used to capture socioeconomic and demographic characteristics; household data; experiences with SRHR service utilization; sexual relationships; participation in health governance; SRHR enjoyment and violations; and other relevant variables. FGDs were held with women with disabilities. A total of nine focus group discussions, three per district using prepared FGD guides. In each district, separate FGDs were held with women with physical, hearing and visual disabilities, at a convenient venue within the community, the premises of PWD organizations or at a health facility. In-depth interviews were held with women with disability who have experienced SRHR violations in community or clinical settings to capture their personal stories as vignettes/cases. The respondents were identified amongst FGD participants.

Relevant laws, policies, reports and records were reviewed following a checklist. This involved a comprehensive review of the relevant policy and legal framework, as well as the literature on SRHR of women with disability in community and clinical settings. Literature from both published and grey material were reviewed.

2.6 ETHICAL CONSIDERATIONS

Throughout the research process, the investigators and research staff have protected research participants in line with fundamental ethical values/norms. All participation in the study was voluntary. Participants were taken through an informed consent process, involving an explanation of the study details, its objectives and procedures before being given an opportunity to freely decide whether to participate in the study. Respondents were free to withdraw from an FGD, or stop an interview at any time, or to decline to respond to any of the questions.

This study targeted the 15-49 age-group, which includes those that are yet to attain the legal age of majority, which is 18 years in Uganda's case. Hence, respondents who had not attained the age of majority (15-17 years) included only those with capacity to consent, i.e. emancipated minors – those that are married, have had a child, are pregnant or are in charge of their livelihood. These were taken through the same informed consent process as the rest of the respondents in line with research ethics guidelines. Due to the sensitivity of certain data, respondent names have not been written in this report, and only pseudonyms have been used in vignettes.

Ethical approval of the study protocol was sought and obtained from the Makerere University School of Biomedical Sciences Higher Degrees Research and Ethics Committee, which is accredited by Uganda National Council for Science and Technology (UNCST) as an institutional review board/research ethics committee.

2.7 Study limitation

This study was conducted in only three of the country's rapidly increasing number of district (134 at the time of this study), and only three of disability categories – physical, visual and hearing/speech disabilities. The study was also limited to the reproductive age-group of 15-49 years, yet women with disability outside this age-group may be suffering SRHR-related violations that need to be researched to inform advocacy.

3. THE LEGAL AND POLICY FRAMEWORK FOR SRHR AND WOMEN WITH DISABILITY

3.1 THE LEGAL FRAMEWORK FOR SRHR AND WOMEN WITH DISABILITY

Persons with disabilities (PWD) are not listed among the groups explicitly protected against discrimination in the human rights instruments that make up the international bill of rights, including the Universal Declaration of Human Rights (UDHR, 1948), the International Covenant on Civil and Political Rights (ICCPR, 1966) and the International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966). These instruments address PWD rights only via non-discrimination clauses and do not pay sufficient attention to the promotion and protection of the rights of PWD. For instance, all three instruments oblige States to guarantee human rights without distinction of any kind, including race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. In 2009, the Committee on Economic, Social and Cultural Rights included disability among the grounds covered by “other status”.⁴⁴

The Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol were adopted on 13 December 2006 and entered into force on 3 May 2008, becoming the first international, legally binding instrument setting minimum standards for rights of PWD. The CRPD recognizes the rights of PWD – these being the same rights for everyone else – but reaffirms that PWD must also enjoy them, while guaranteeing additional rights that specifically apply to PWD and the corresponding obligations on States to promote, protect and ensure them.

The CRPD is the first international treaty to require States to take steps to ensure the accessibility of the physical environment and services for PWD (Article 9), and to raise awareness regarding PWD – including fostering respect and combating stereotypes (Article 8). It guarantees the right to independent living (Article 19) – the first such right of its kind; the right to liberty and security (Article 14); freedom from torture and cruel, inhuman or degrading treatment and punishment (Article 15); the right to respect for physical and mental integrity of the person (Article 17); the right to health (Article 25); the right to access to justice (Article 13); and equal recognition before the law (Article 12). In establishing a mechanism for complaints, the Convention’s Optional Protocol ensures that persons with disabilities have an equal right to redress for violations of the rights enshrined in the Convention.

Under Article 25, the CRPD guarantees PWD for the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. It requires State Parties to take all appropriate measures to ensure access for PWD to health services that are gender-sensitive, including health-related rehabilitation. Specifically, States Parties are required to:

- (a) Provide PWD with the same range, quality and standard of free or affordable health care and programs as provided to other persons, including in the area of *sexual and reproductive health* and population-based public health programs;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people’s own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to PWD as to others, including on the basis of free and informed consent by, *inter alia*, raising awareness of the human rights, dignity, autonomy and needs of PWD through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against PWD in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

⁴⁴ General Comment No.20

- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

The reproductive rights of PWD are covered under Article 23. This Article requires States Parties to take effective and appropriate measures to eliminate discrimination against PWD in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

- (a) The right of all PWD who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
- (b) The rights of PWD to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
- (c) PWD retain their fertility on an equal basis with others.

The special vulnerabilities of women with disabilities are addressed by Article 6, under which States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. The Article further requires States Parties to take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the Convention.

One area where women and girls are vulnerable is gender-based violence (GBV). The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) is the specialized human rights treaty on women's rights, establishing an agenda of action for putting an end to sex-based discrimination. Together with the CRPD, it spells out the responsibilities of States to prevent discrimination and promote equality for women with disability. The Convention was adopted by the UN General Assembly in 1979 and is one of the core UN human rights instruments⁴⁵.

Under article 11 (1) (f), the Convention requires States Parties to take all appropriate measures to eliminate discrimination against women in the enjoyment of "the right to protection of health and to safety in the working conditions, including the safeguarding of the function of reproduction."

In General Recommendation No.24, the CEDAW Committee calls on states to give special attention to the health care needs of vulnerable and disadvantaged groups, including women with disabilities. The Committee recognizes that women with disability often have difficulties with physical access to health facilities and recommends that states "take appropriate measures to ensure that health services are sensitive to the needs of women with disabilities and are respectful of their human rights and dignity."

General Recommendation No.18 of the CEDAW Committee addresses the double discrimination affecting women with disability – as women and as PWD – and recommends that States Parties provide information on women with disability in their periodic reports and on measures taken to deal with their particular situation, including special measures to ensure that they have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life. This General Recommendation, however, does not directly address the SRHR issues of women with disability.

⁴⁵ There are nine core international human rights instruments: International Convention on the Elimination of All Forms of Racial Discrimination; International Covenant on Civil and Political Rights; International Covenant on Economic, Social and Cultural Rights; Convention on the Elimination of All Forms of Discrimination against Women; Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; Convention on the Rights of the Child; International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families; International Convention for the Protection of All Persons from Enforced Disappearance; Convention on the Rights of Persons with Disabilities.

At the continental level, the African Charter on Human and Peoples' Rights (ACHPR) provides that every individual has the right to enjoy the best attainable state of physical and mental health (Article 16). Adopted in 1981, the Charter requires States Parties to ensure the elimination of every discrimination against women and also ensure the protection of the rights of the woman and the child as stipulated in international declarations and conventions (Article 18(3)). It further provides that "the aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs (Article 18(4)).

In 2003, the African Union adopted the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol), as a supplementary instrument to the ACHPR. The Protocol is one of the most progressive legal instruments providing a comprehensive set of human rights for women in Africa. It guarantees comprehensive rights to women including improved autonomy in their reproductive health decisions.

The Protocol requires States Parties to ensure that the right to health of women, including sexual and reproductive health is respected and promoted. However, this right is provided for under Article 14 on which Uganda has a reservation. The Article requires States Parties to, among others, "protect the reproductive rights of women by authorizing medical abortion in cases of sexual assault, rape, incest, and where the continued pregnancy endangers the mental and physical health of the mother or the life of the mother or the fetus."

Under Article 23, the Protocol requires States Parties to provide special protection to women with disability, to take specific measures commensurate with their physical, economic and social needs to facilitate their access to employment, professional and vocational training as well as their participation in decision-making; and to ensure the right of women with disabilities to freedom from violence, including sexual abuse, discrimination based on disability and the right to be treated with dignity.

At the national level, the Constitution states among the social and economic objectives that the State shall ensure that all Ugandans enjoy rights and opportunities and access to education, health services, clean and safe water, work, decent shelter, adequate clothing, food, security, pension and retirement benefits. The Constitution provides for the rights of women as well as the rights of PWD. Under Article 33, it states that women shall be accorded full and equal dignity of the person with men; that the State shall protect women and their rights, taking into account their unique status and natural maternal functions in society; and that women shall have the right to affirmative action for the purpose of redressing the imbalances created by history, tradition or custom.

Under Article 35, the Constitution provides that persons with disabilities have a right to respect and human dignity and the State and society shall take appropriate measures to ensure that they realize their full mental and physical potential. It further states that Parliament shall enact laws appropriate for the protection of persons with disabilities.

The Persons with Disabilities Act 2019 provides that PWD shall enjoy the fundamental and other human rights and freedoms enshrined in the Constitution. Section 7 provides for non-discrimination in the provision of health services. It provides that a health unit discriminates against a person with a disability where it is not accessible by PWD; or where the health unit does not provide accessible labor beds, examination tables or wheelchairs for PWD. Hence the Act requires health units to provide wheelchairs and accessible examination tables for PWD, and to provide labor beds for expectant women with disability.

The Act provides that a person with a disability has a right to a home, to found a family, and is entitled to have sexual and other intimate relationships; and equal rights at and in marriage, during marriage and at its dissolution (Sec.4). It further provides that PWD shall not without their free and informed consent be subjected to forced sterilization (Sec.5).

The National Council for Disability Act 2003 sets up disability councils at national, district and subcounty levels to act as a channel through which the needs, problems, concerns, potentials and abilities of PWD can be communicated to

government and its agencies for action (Section 5), and to investigate violations of the rights of PWDs and non-compliance with laws relating to disabilities (Section 6(f)). However, less than half of Uganda's districts actually have a disability council (Human Rights Watch, 2010).

3.2 THE POLICY FRAMEWORK FOR SRHR AND WOMEN WITH DISABILITY

The theme of the 2030 Agenda for Sustainable Development, also known as the Sustainable Development Goals (SDGs), is to leave no one behind, including PWD and other disadvantaged groups. The Agenda has seven targets and 11 indicators explicitly making reference to PWD, covering access to education and employment, availability of disability-sensitive schools, inclusion and empowerment of PWD, accessible transport, accessible public and green spaces, and building the capacity of countries to disaggregate data by disability. In addition, the Agenda recognizes disability as a cross-cutting issue, to be considered in the implementation of all the 17 SDGs.

Goal 3 (Ensure healthy lives and promote well-being for all at all ages) and Goal 5 (Achieve gender equality and empower all women and girls) are particularly relevant to the SRHR of women with disability. Women with disability are implicitly included in the pledge to ensure *universal* access to sexual and reproductive health-care services, including family planning, information and education, and the integration of reproductive health into national strategies and programs; and to end all forms of discrimination against *all* women and girls everywhere.

Under the Program of Action of the International Conference on Population and Development (ICPD), governments set out an ambitious agenda to deliver inclusive, equitable and sustainable global development. The Program of Action, which is the steering document for the UN Population Fund (UNFPA), affirms sexual and reproductive health as a fundamental human right and emphasizes that empowering women and girls is key to ensuring the well-being of individuals, families, nations and the world. It recognizes the rights of PWD concerning, among others, reproductive health, including family planning, sexual health, HIV/AIDS, information, education and communication, and calls on governments to eliminate specific forms of discrimination that PWD may face with regard to reproductive rights, and household and family formation. However, these are stated as “needs” rather than rights. The ICPD25 summit, held in Nairobi in November 2019, reinforced these commitments with an ambitious target to end all maternal deaths, unmet need for family planning and gender-based violence (GBV) and harmful practices against women and girls by 2030.

The World Program of Action Concerning Disabled Persons, adopted by the UN General Assembly on 3 December 1982, is a global strategy to enhance disability prevention, rehabilitation and equalization of opportunities, which pertains to full participation of PWD in social life and national development. The World Program of Action recognizes the diminished chances of women with disability in developing countries to overcome their disablement, making it difficult for them to take part in community life. However, the World Program of Action does not explicitly use the human rights language, with disability largely viewed as a social protection and welfare issue. The policy document does not focus on defending the rights of PWD and makes no specific reference to the SRHR of women with disability.

The overall mandate of the World Health Organization (WHO) is to prevent health conditions that may result in death, morbidity or *disability*.⁴⁶ In line with this mandate, WHO recognizes disability as a global public health issue, a human rights issue and a development priority. The WHO Disability Action Plan 2014-2021, which aims at achieving better health for all PWD, is directed at improving the health, functioning and well-being of PWD. One of the Action Plan's key objectives is to remove barriers and improve access to health services and programs.

The Action Plan proposes several actions for member states, international and national partners, and the secretariat, including generating conditions in which each PWD can enjoy the highest attainable standard of health, including provision of health services on the basis of free and informed consent. One of the key actions is the removal of barriers to service delivery (including impediments to physical access, information and communication, and

⁴⁶ WHO global disability action plan 2014-2021

coordination) across all health care programs, including those on sexual and reproductive health, health promotion and other population-based public health initiatives. The Action Plan recommends the adoption of national accessibility standards in line with universal design principles, and the integration of disability into relevant undergraduate curricula and continuing education for service providers.

At the national level, Vision 2040 states that Ugandans aspire for a future in which men, women, youth, children and PWD are empowered to participate as equal partners in development. Vision 2040 is the country's long-term development masterplan for achieving the national vision statement, "A transformed Ugandan society from a peasant to a modern and prosperous country within 30 years". The Vision highlights the mainstreaming of disability alongside gender and human rights as a core part of the national planning process.

However, while Vision 2040 recognizes PWD among vulnerable population groups, it does not explicitly state that they have a right to participate in development of the country, stating instead that "the state recognizes the need to provide assistance" to them. In addition, the third National Development Plan (NDP III) 2020/21-2024/25, part of the series intended to guide the country to deliver the aspirations articulated in Uganda Vision 2040, has little mention of PWD beyond a simple acknowledgement that disability is highly prevalent in Uganda. The NDP III falls short of its theme of "Sustainable industrialization for inclusive growth, employment and sustainable wealth creation". It maintains a welfare approach as stated in Vision 2040. PWD appear in only one indicator, in which the target combined coverage of social protection/social assistance to vulnerable groups, including PWD, orphans and vulnerable children (OVC), the elderly and the poor, is set at 50%.

On its part, the National Policy on Disability (2006) aims to promote effective, friendly service delivery to PWD and their caregivers, and to ensure that the capacity of PWD and their care-givers to access essential services is enhanced, among other objectives. The Policy has eight stated principles, among which is the human rights-based approach to programming. To this end, the policy provides that promotion and protection of the rights of PWD will be upheld at all times by service providers. The Policy commits to minimize stigmatization and discrimination which it acknowledges as barriers to PWD access to service.

The National Policy on Disability also takes note of the problem of accessibility. The policy defines what it calls "policy priorities" to include accessibility. It points out that in Uganda, PWD face difficulties in accessing health, education and sports facilities, and places of employment, cultural sites and other physical infrastructure; they are denied access to most buildings such as schools, hospitals, courts of law and stadiums as many such facilities do not have facilities such as ramps and lifts. It points out that the existing lifts in buildings do not have audio devices to enable persons with visual impairment to access information. It further points out that PWD are most times unable to access information provided by both electronic and print media. The National Policy on Disability takes note of the fact that due to their vulnerability, PWD have inadequate access to services, information, resources as well as limited participation in the development process.

The Policy acknowledges that disability affects men and women differently, but impacts more on females than males due to their social and cultural roles. Discriminatory cultural practices on property inheritance and property ownership affect the livelihoods of women with disability more adversely than men with disability. This is compounded by the inadequacy of programs that focus on women with disability during service delivery, which makes it even more difficult for them to improve their livelihoods.

The Policy strategies to achieve its objectives include:

- Advocating for the strengthening of positive cultural values that foster understanding, care and support for the protection of PWD;
- Strengthening and empowerment of PWD and their caregivers;
- Capacity building and enhancing skills development and social support systems so that PWD participate in, and effectively contribute to, socio-economic development;

- Ensuring participation of PWD in the planning, implementation, monitoring and evaluation of all relevant initiatives;
- Implementing interventions through communities, local authorities, CSOs, the private sector networks and other actors so as to enhance capacity and increase the outreach;
- Promoting awareness about different impacts of the same disability on male and female PWD;
- Developing and implementing media and communications strategy to enhance awareness on PWD issues, including gender concerns;

The policy framework at both national and international levels has progressive aspirations in as far as it advocates a human rights-based approach to health service provision with regard to PWD but also to women with disability in particular. Generally, the policy and legal environment is progressive. It upholds the rights of women with disability and outlaws discrimination. However, a reservation on the article that guarantees abortion rights of women in the Maputo Protocol remains a major dent on the realization of the SRHR of women and girls generally, and of women and girls with disability in particular. And while the special challenges of women with disability are well-recognized in the national laws and policies, they are largely considered to have “needs” for which they need “assistance” rather than having rights that they are entitled to, and which the State has an obligation to respect, protect and fulfill.

4. FIELD FINDINGS

This section presents the main findings from the field data. It has three main subsections: Women with disability SRHR programming; experiences of women with disabilities with SRHR services (clinical setting); and SRHR-related experiences of women with disabilities at the community level (community setting).

4.1 WOMEN WITH DISABILITY SRHR PROGRAMMING

This study sought to establish the range of SRHR services that are available at public health facilities in the study area. Availability of a range of SRHR services and commodities was explored, including SRHR information, family planning and contraception, breast and cervical cancer screening, HPV vaccination, HIV testing and counselling, condoms, sex lubricants, HIV pre-exposure prophylaxis (PrEP), HIV care and treatment, screening and treatment of sexually transmitted infections (STIs), antenatal care (ANC), safe delivery (including delivery by caesarean section and emergency obstetric care), postnatal care, infant feeding counseling, safe abortion, post-abortion care, infertility treatment, and management of survivors of sexual violence.

A wide range of SRHR services are provided at public health facilities that were reached in this study, especially at the regional referral hospitals. As expected, the service range increases with the level of the facility. Service providers at the regional referral hospitals report that they deal with almost all simple and complicated conditions affecting the reproductive system as well as with conditions that may affect sexual and reproductive health broadly, such as anemia, malaria and others. However, safe abortion services are only provided on “medical grounds” due to legal restrictions, and sex lubricants were mostly out of stock. Lower health facilities (Health Center III and below) do not provide delivery by Caesarean section and they refer the cases to the higher-level facilities referral hospitals. Mbale RRH, a higher-level facility, conducts between 230-250 cesarean deliveries per month, which is roughly one third of all the deliveries the hospital handles. Most cesarean cases are caused by obstructed labor, according to the departmental in-charge. Cases of infertility are not handled by the hospital but are referred to a private facility, which the in-charge agrees may not be affordable to an average woman with disability.

The study further explored the provisions in place to ensure that women with disabilities access these and other SRHR services. The findings indicate that SRHR programming is not inclusive of women with disabilities. This includes both onsite and offsite services, and services provided by the government as well as the non-government sectors. Women with disabilities report that, in the non-government sector, service providers such as Marie Stopes, PACE and others that conduct community outreaches for family planning, often do not go along with sign language interpreters. For onsite services, signage and information, education and communication (IEC) materials such as posters are not disability friendly. For instance, both service providers and consumers report that signs directing clients to the maternity wing, the HIV clinic, the laboratory and other departments that provide SRHR services do not have visual illustrations.

In the government sector, service providers are generally poorly equipped to provide SRHR services to women with disabilities. Health facilities at the different levels report that they do not have any standard provisions or written guidelines for meeting the special needs of women with disabilities. Instead, health workers report that they “help” them where there is need, such as lifting those with physical disability to the examination bed or delivery bed. Others report that they give women with disabilities “special care” because they have stigma, while others report that they “give them priority” during antenatal care if they are identified during triage.

“To be sincere with you, persons with disabilities have been left aside when it comes to accessing SRH services. We have had several discussions with community development officers in different sub counties to help improve the situation but progress is still slow. There is no special treatment for these people in the facilities that even if it means accessing services, they have to line up with the other ‘normal’ people.” – PWD focal person, Mbale district

None of the lower health facilities (Health Center IIIs) reached has an adjustable bed that is designed to make access by women with physical disabilities easy, including Angaya HC III and Bar-Dege HC III in Gulu; Nyendo HC III and Masaka Municipal Medical Center in Masaka; and Nakaloke HC III in Mbale. Only Gulu and Masaka regional referral hospitals reported to have adjustable delivery beds. At the time of the study, Masaka district had two adjustable delivery beds for women with physical disabilities. Even then, Gulu RRH had just acquired the only two adjustable delivery beds that the hospital has, as a donation from Voluntary Service Overseas (VSO), an international development organization, along with 10 wheel chairs in the gynecology and maternity wards. Masaka RRH has only one adjustable delivery bed, while Mbale RRH has none. Up to six health facilities out of the 12 visited did not have ramps to facilitate access to the out-patient department (OPD) by wheelchair. Women with disability report that even where ramps are, they are not safe for them because they are too steep.

These under-investments in the SRHR programming for women with disabilities mirrors the general under-funding of disability interventions in the country. Government, through Ministry of Gender, Labor and Social Development (MGLSD) started giving out a Special Grant to PWD groups in FY 2009/10 to support income generating activities. While allocations to this fund has increased over the years, it remains small and insufficient – approximately UGX3 billion per annum.⁴⁷ Responses indicated that the allocation to the PWD special grants program is insufficient to support viable income-generating activities. For instance, the entire Masaka district gets just Ushs 15 million per year for disability grants. The community-based department reported that it had just delivered Ushs 1.5 million to one PWD group of 30 members in Kabonera sub county, who did not have a joint investment and ended up each taking home a paltry Ushs 50,000. As a result, CDOs are not fully involved in activities of PWD because of limited facilitation.

“We had the money, but we did not have the logistics to deliver it. The money itself was very little because on average each person got only 50,000 (Ushs). Remember people used transport to come to the venue, and some even had guides, and (given that) we reached there a bit late, those that came early spent additional money on eats as they waited. In the end, our help was even much less than it seems... What can a person really do with that money?” - key informant, Masaka district local government

Responses suggest that local governments are not keen on PWD work. For instance, while the District Development Plan of Mbale considers PWD, its implementation is poor, because the PWD budget is funded from “local revenues” expenditure line which is unpredictable and rarely realized. Local government leaders report lack of adequate information and records about PWDs to facilitate proper planning and budgeting for their special needs. PWDs report that they are not even represented on health unit management committees (HUMCs), which oversee health facilities in the community.

“[The representation of PWDs on HUMCs] is something we have never thought about [but it is something] we can do in the new guidelines... to constitute the new HUMC with PWDs. This can greatly improve access for reproductive services by persons with disabilities. We need to involve them in the management of health facilities to ensure that their issues are catered for, since most of them can only access services in the lower level facilities.” - key informant, district health team, Gulu

“We don’t have records about these people. For example, if you visited a health facility and asked for a record of clients with disabilities that have visited the facility for SRHR services, in a quarter you find none or just two if you’re lucky. Do you agree that there are no disabled people out there in the community that need services... (such as) family planning and others?” - community development officer, key informant, Mbale

“We should deliberately put their budget under the District Discretionary Equalization Grant. This is not equal at all. There is a serious budget disparity, Disability only has one million yet other areas have over 10 million

⁴⁷ Increase budget for PWDs, MPs ask Government. 27 November 2019.

<https://www.parliament.go.ug/news/3896/increase-budget-pwds-mps-ask-gov%E2%80%99t>

shillings. Politicians responsible for allocation of budgets and resources don't consider PLWD because they are not able to mobilize votes for them.” - Key informant, Mbale district local government

Health workers cited several challenges that they face in providing services to women with disabilities. They include challenges in dealing with a diversity of disabilities; communicating with women with hearing impairment; dealing with women who are unaccompanied by their spouses or other caregivers; inability of women with disabilities to return to the facility for review; referral of women who cannot afford transport to higher health facilities; handling girls and women with disabilities who have been sexually assaulted; handling pregnant women who have no idea about the responsible person; lack or shortage of adjustable delivery beds; dealing with relatives who do not appreciate the rights of persons with disabilities; shortages and stock-outs of essential medicines and supplies; understaffing; and lack of skills in handling clients with disabilities, among others.

“Some patients with disabilities come by themselves and others may be brought by police which is a challenge to the hospital because they come without caregivers. Nurses have to find a way of caring for them, and sometimes it is the caretakers of other patients who help out,” - Midwife, Nyendo HCIII, Masaka

Program managers report that they have a big challenge in skilling health workers to deal with clients of different disabilities. They report that this problem is compounded by the fact that the staffing levels are low. Even health workers that have been trained in sign language report that their training was insufficient. None of the health workers who participated in this study received training in handling women with disabilities beyond the hearing impairment.

Only two of the 12 health facilities reached in this study - Masaka RRH and Mbale RRH - had at least one health worker who had been trained in sign language. At Masaka RRH, a number of health workers were trained in sign language basics in three weekly sessions spread over a three-month period. The training was sponsored and conducted by Sign Language Uganda (SLU) and Masaka Deaf Association about seven months prior to the visit by the study team. The challenge however, is that several of those trained were student nurses and have since left, leaving behind only one. At Mbale RRH, only one counselor had attended sign language training only two months prior to the visit of the study team. Gulu RRH does not have even a single health worker trained in sign language.

Even then, sign language is taught in English, meaning that women and girls who are not schooled in the English language will not be able to communicate with health workers who have been trained in sign language. In differentiated HIV service delivery, peers rely on short messaging to reach persons with hearing disability.

However, Masaka RRH and Mbale RRH each has only one health worker with sign language skills, and none of them is able to work effectively in the different departments, let alone work 24 hours a day, seven days a week. One health worker related a case of a woman who was hard-of-hearing, and she had to shout on top of her voice to communicate with her. Elsewhere health workers reported that they depended on clients with hearing impairments coming along with their own sign language interpreters, and those with visual impairment coming along with their own guides. The other option is for the health worker and the client to communicate through writing. But this only works for the literate clients and is time consuming.

Health workers seem less comfortable delivering expectant mothers with disabilities. Responses from health workers at lower and higher health facilities indicate that lower health facilities tend to refer women with physical disabilities to higher facilities for fear that they may not be able to deliver them safely, competently handle potential complications - or even for the sheer fear that they may not be able to deliver safely. Health workers have negative attitudes towards expectant mothers with disabilities, which further stigmatizes women with disabilities. None of the health facilities reached had a focal person for PWD clients to guide them and help them navigate particularly the large health facilities at the regional referral level.

4.2 EXPERIENCES OF WOMEN WITH DISABILITIES WITH SRHR SERVICES

The study explored awareness of SRHR among women with disabilities, as a proxy for their capacity to identify violations when they happen. Women were also asked what SRHR services they needed to realize good sexual and reproductive health, as a way of gauging their expectation.

Most women are aware of their SRHR but are powerless and unable to claim them. They cited their rights to have children and to be treated with dignity. Overall, however, the findings indicate that women with disabilities are resigned to their plight. A few women participating in FGDs feel they are not equal to women without disabilities, let alone men. The findings indicate that the SRHR decisions are often made between health workers and relatives, denying women with disabilities the right of informed consent and autonomy. SRHR providers report that they have ever received caregivers who have come to their facility to ask health workers to give women and girls with disabilities contraception.

Almost all women participating in the FGDs report some unpleasant experience, either at a health facility, in the family, in their community, or at all three levels. They feel that they are treated as women who are “not normal”; who are not able to look after children and should therefore not have children or should have fewer children; who are likely to give birth to children with abnormalities; who cannot have a normal delivery, need more specialized attendance during childbirth, and should be “assisted” with cesarean surgery; who consume more time with health workers, do not understand “their situation” and are therefore getting pregnant, are irresponsible and inconsiderate to their already “burdened” caregivers who must extend their magnanimity to their children; and who are weak and need “help” from everyone around them.

“[Health workers] ignore you, shout at you... they ask you embarrassing questions why you want family planning, why you are pregnant all the time, and where your husband is; they think we don’t have sexual feelings.” - woman with physical disability, Gulu

“The first time I went to the hospital, I went for antenatal care but the questions were too many... They asked me a lot of questions... where is your husband? Is he ‘normal’? How comes he is not the one who ‘brought you’? Will he look after that child? How are you related to this one (the caregiver)? Will you be able to ‘push’? A lot of questions, as if you are not human.” – woman with physical disability, Masaka

“There is a midwife I know in one of the health facilities who is so rude. She keeps asking women why they can’t climb a delivery bed when they managed to climb the bed for sex.” – woman with physical disability, Mbale

The findings indicate that due to stigmatization and discrimination, uptake of SRHR services by women with disabilities is low. For example, among the women participating in the group discussions, only about one third report to have ever used a modern family planning method, and about two in every three report to have delivered their last child in a health facility. Many of the women report having delivered their last child either at home or at a traditional birth attendant.

The responses from women with disabilities indicate that health facilities are a major source of stigma for women with disabilities seeking SRHR services. They report being ignored, demeaned, embarrassed, under-served and insulted. One woman in Gulu and another in Masaka reported to have lost their babies due to alleged negligence of health workers. They believe they were not given good care because of their disability. Another narrated how a health worker at Lacor Hospital was “shocked” to see her arriving in labor for a second time in “a short time”. “Again, you are coming to have another baby, what is wrong with you?” the health worker reportedly quizzed. At Masaka RRH, midwives were reportedly “shocked” to see a blind woman give birth to healthy twins.

“In Mulago, they couldn’t allow my caregiver to take me to the labor ward yet I can’t walk on my own. The midwife even went ahead to insult me and asked me how I was able to climb onto a man’s bed... The next time they loudly wondered if I was a rabbit just because I had gone there to deliver another child. I can never go back to Mulago.” – woman with physical disability, Masaka.

Several SRHR service providers indicated that they usually “help” women with disabilities when necessary. Indeed, a few women with disabilities report that they have been forced to seek SRHR services from more distant health facilities that have more friendly health workers. Health workers report giving “help” especially to women with disabilities that come to the facility without necessities (for instance supplies needed to assist in childbirth), women in desperate condition, victims of sexual assault, and those without a caregiver. Women with disabilities that have no caregiver are reportedly delivered to facilities by well-wishers or police – none of whom is willing to take responsibility.

Mbale RRH reports that in cases where women with disabilities are “helpless”, there is a provision to utilize the hospital’s emergency stocks of supplies to enable them have smooth childbirth. At times it can go beyond the emergency supplies. In one case, health workers reportedly had to tear-up maternity fabric to cover a newborn of an expectant mother with disability who did not have a caregiver.

However, while the health workers reported that they give special attention to clients with disabilities, women with disabilities denied that they any special attention when they go to health facilities for SRHR services. Women report outright discrimination in access to information and services, as well as negative attitudes among health workers.

“There is little special treatment given to us as we have to stay in the same line with those without disabilities and worst of all, using the same beds that the ‘normal people’ use. These beds are highly raised which gives us a problem to climb when the time comes,” – woman with physical disability, Mbale

“Health workers are rude to us; they ask as silly questions and mock us... you are saying you can’t climb this bed, how did you climb it when you are going to have sex. They don’t know that many of us often got pregnant because men force us not necessarily by choice.” – woman with physical disability, Mbale

“In hospital, our books are packed last claiming that we need more time.” – woman with hearing/speech disability, Gulu

Even where there has been well-meaning “help” from health workers, it has ended up stigmatizing or discriminating women with disabilities. Women participating in FGDs reported that when they go for family planning, health workers insist on giving them permanent methods reportedly to “save them the burden” of having children. They cited cases of being subjected to unnecessary cesarean surgery even when they felt that they could push babies. Most of the women felt that the unnecessary medical procedures are deliberate violations by the health workers; some felt that it is due to “genuine” sympathy with their situation, while a few felt that it is due to failure of the health workers to understand women with disabilities, their health needs and to communicate effectively with them.

“I went to hospital to try to get family planning. I went alone because my sister who usually accompanies me and helps communicate with health workers was not around. I tried to signal to the midwife but she could not understand me well. She gave me a pen and paper to write what I want but I don’t know how to write. She decided to give me pills, which I did not like.” - woman with hearing and speech disabilities, 29, Masaka

“The health workers asked me if I wanted to have a normal delivery or by surgery (C-section), and I told them that I wanted to push (normal delivery) but the midwife decided that I should be cut (C-section). They don’t think that we can decide for ourselves.” – woman with physical disability, Masaka

From the responses of women with disabilities who have accessed SRHR services at public health facilities, there is a feeling among some health workers that women with disabilities do not have the same SRHR as women without disabilities. Women with disabilities are widely considered not to have the capacity to look after children, and hence less deserving of sexual rights. Women with disability report service providers being “surprised” by their request for contraceptives. A number of health workers felt that women with disabilities should have fewer children that they can “manage”, and reported that they had provided contraception to women with disabilities upon the request of relatives.

“Health workers think we do not have feelings... that it is improper for us to engage in sexual intercourse. One time I went to a health center and asked for a family planning injection, and the health worker asked me, ‘In your state, do you really need want family planning?’” – woman with physical disability, Gulu

“A married neighbor impregnated a girl with physical disability but denied responsibility. The girl became pregnant a second time and still there was no known father. When she delivered the relatives took her to Masaka hospital and they instructed the health workers to give her family planning. She was given a coil.” – woman with physical disability, Masaka

4.3 EXPERIENCES OF WOMEN WITH DISABILITIES AT THE COMMUNITY LEVEL

Women and girls with disabilities report receiving different forms of support from their families, relatives and community members. This support has been helpful towards the realization of their SRHR. Relatives have been supportive as caretakers both in hospitals and in homes. Accompanying women with speech impairment to health facilities has particularly been helpful in communication with health workers, many of whom do not have sign language skills. Women with physical and visual disabilities have relied on health workers, family members and relatives as care takers in health facilities but also in homes. The guides for women and girls with visual impairment are usually family members and relatives.

Responses indicate that families of women and girls with disabilities are more supportive than those of spouses and often even spouses themselves, and that they generally tend to receive more support from females than from males, including their own spouses. Their spouses rarely accompany them to health facilities, mostly because of stigma but also because the spouses also have disabilities and need support themselves. This study found very isolated cases of women with disability who reported having been accompanied to a health facility by their spouse, and having agreed with their spouse on the use of family planning and other SRHR services. This finding was corroborated by health workers participating in this study.

Overall, relatives from the family of the woman tend to be more supportive than those from the family of the man. Women with disability report receiving care, including care toward their SRHR, mostly from sisters, mothers and other female relatives.

“I had a boyfriend who I was living with in Kampala. One time I fell sick and when I went to hospital they found that I was HIV-positive. My boyfriend lost interest in me and I had to come back to the village... Here, my mother has given me a lot of help. She took me to hospital where I started getting medicines (ARVs), and every time I go for medicines, I go with her.” – 22 year old young woman with hearing disability, in , Masaka

However, women and girls with disabilities, health workers and program managers report SRHR violations against women and girls with disabilities at family level and within the community. These include stigmatization, sexual assault, forced marriages, psychological harassment, outright discrimination and forced sterilization. They report being victimized for HIV and other health conditions, and being sexually harassment by relatives, including instances where women with hearing/speech impairments are unable to identify relatives or clanmates in choosing sexual partners. At the community level, hooligans normally harass women by hissing at them to attract their attention, and by throwing objects at those with hearing disability.

“There has been a lot of reports in my office about sexual assault. In fact, sexual violence is rampant among women and girls with disabilities. These people are frequently raped. They often suffer gender-based violence by their husbands. For example, yesterday I received a case of an epileptic young girl who was taken to work as a maid in one of the homes here in Mbale town. When the wife was not around, the man came back home and raped this poor girl.” – PWD focal person, Mbale

I just got disabled due to an accident that I lost my sight but I feel the discrimination even when I can't see. Even if a man loved you, the community will discourage him and, in the end, he will leave you. Community discrimination

starts with the family members. My parents discriminated me right from childhood, and when I became pregnant my mother even cried wondering who had given the family the ‘problem’ of impregnating me and how they would suffer helping me through the pregnancy to childbirth. But I surprised them when I gave birth normally, from home.” – woman with visual disability, Mbale

“The community believes that women who are deaf are very fertile so you find that they are the most sexually abused group. We get few women with disabilities here, but among those few you find that dumb girls are the majority. It’s common to find relatives brining their dumb daughters here that they want to stop them producing and they ask for permanent methods,” – Health worker, Masaka RRH

Women with disabilities also report being mistreated by the family members of their spouses, and being stigmatized by community members. Appallingly, this also affects women that have partners with disabilities. Women with disabilities are rarely accompanied by their partners to health facilities. The reasons given were that some women with disabilities have partners who also have disability, and that men who do not have disabilities do not want to be seen in public with partners who have a disability. Many women with disabilities report being rejected by the families of men without disabilities, and that men without disability tend to “use” them and later dump them, which has forced many women with disabilities to avoid men without disability.

“I once got a man who had no disability but his family asked him whether I was ‘the only woman left in the world’. They told him to find a ‘normal’ woman and he left me. Fortunately, later I got a man who is like me... he understands me and his family has accepted me.” - woman with speech/hearing disability, 29 years, Masaka

“The family members don’t like the daughter in law who has a disability. They think you will not be helpful. Even when you produce a child, they will never like your child because your child is an additional burden. No one loves a woman with disability” – woman with visual disability, Gulu

Another woman in Gulu, with a physical disability following surviving a landmine, reported being blamed for the death of her partner because she **AND** her partner were HIV-positive and the partner has since passed on. The partner had long stopped providing for the family, and abandoned her when she went to hospital to deliver their second child. However, the husband’s family continue to provide support for her children even when they reportedly hate her.

Disability remains a highly stigmatizing condition within communities. The findings indicate a high prevalence of self-stigma as well. Many women with disabilities were of the view that it is a favor for a man to propose to a woman with a disability, and that men also feel that when they propose to a woman with a disability, they are doing them a favor. This widespread perception seems to perpetuate violence against women with disabilities – and a tendency of women with disabilities as well as society generally to consider such violence to be normal.

“If you have a disability, it is difficult to get a man who will appreciate you. So, whoever comes along you will accept and once he has used you, he will start to abuse you or even abandon you... And if a man approaches you and you turn him down, he will mock you about your disability... sometimes he can resort to force... and what can you do as a ‘lame’ woman?” – woman with physical disability, Masaka

“For me it was a great honor when a man who did not have any disability proposed to me genuinely and showed that he was serious and he even went and men my parents. Even though he later left me, I didn’t find it a problem because he left me with children and he continues to look after them... when they grow up, they will take care of me.” – woman with physical disability, Gulu

Only a few women reported having a spouse who was proud of them and appreciated them with their disability. Many reported having “night husbands”, which is the epitome of the stigma associated with relating with women with disability in the study communities. Many “respectable” men in the community are reportedly shameful to be seen to

have sexual relations with women with disability. Respondents in Gulu narrated the case of a prominent businessman in Gulu town who sired three children with a street woman with a physical disability and over a long time gave the impression he was only being helpful to her by buying her lunch.

“If you have a disability, only expect your sexual partners in the night; they don’t want to identify with you during the day. You don’t expect a serious man to propose to you in the dark or to relate with you without his friends and family knowing about it. Men take us for granted.” – woman with physical disability, Gulu

“As a woman, I should be able to leave my father’s home and find a man to marry me, give birth to children and take good care of them. However, that is not the case for us who have disabilities. What happens is, a man will admire you during the day but waits for the night, grabs you, forces you into sex with you and the next thing will be a pregnancy. He will not want to associate with you because actually most of such men are married men. You will struggle with the pregnancy till giving birth. You shouldn’t be surprised by the fact that most mothers with disabilities are single mothers,” – woman with disability, Mbale

Women with visual impairment report that men have a tendency to take advantage of them because of their inability to recognize their abusers. They report that crooks creep onto them in the night faking the identity of their partners just to have sexual intercourse with them. This has reportedly created a challenge for women with visual disability to identify the true fathers of their children. They further report that their partners tend to have multiple partners just because women with visual impairment are unable to see what they do. None of the women participating in FGDs reported having a spouse who was proud of them. One woman with visual impairment who was taken by her prospective spouse to introduce her to his parents reported her would-be in-laws asking her who her guide would be.

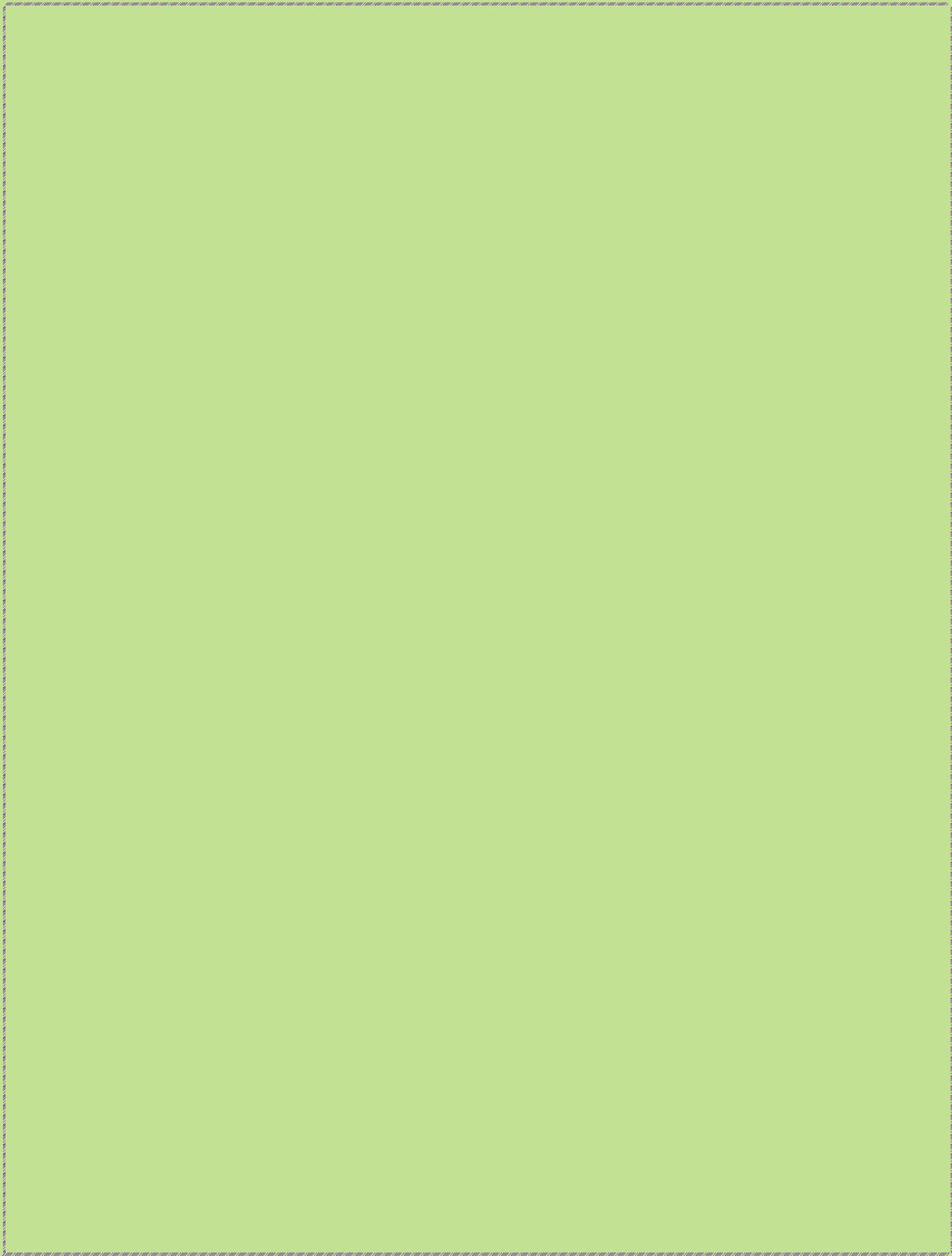
The responses indicated that women with speech/hearing impairments tend to be sexually abused most often because of the challenges they face in reporting their abusers to police, other authorities and relatives. The difficulty they face in communication many times means that they are unable to give evidence. When they are caught up by the law, women with speech disability are often harassed and tortured by police who most times assume that they are pretending to be unable to speak to avoid prosecution. In most instances, women with speech/hearing impairments are resigned to their fate and consider the violations “normal”. In one case in Masaka for instance, one 25-year old respondent was at the time of the research carrying her third pregnancy from rape, but she had never reported any of the incidents to police and she only receives support from sympathizers as she has no family.

Women with disability report relatives among people who tend to oppose their wish to have children, arguing that children create an additional burden to them as caregivers. While health providers denied ever undertaking any procedures against the wishes of clients, respondents among women with disabilities cited many cases where girls with disabilities were forced to abort, to take a contraceptive or to be sterilized altogether by relatives in connivance with health workers.

“I had three children who were boys, and I wanted to have a girl who would look after me when I am sick. My mother and sisters were very opposed to the idea because they thought I already had many children who they were helping me to look after and I have HIV. But when the health workers tested by CD4 and found that it was ok, I went ahead and conceived. Lucky enough I got a baby girl who has now started school,” – woman with physical disability, Gulu

“One girl was forced to have an abortion by parents because she was blind and the family didn’t want her to give them an additional burden. She was sterilized so she could not have children.” – woman with physical disability, Masaka

“There was a girl who was made pregnant several times by unidentified men and after the fourth child, the parents took her to hospital and they stopped her from getting pregnant again (sterilized her).” – woman with physical disability, Masaka



5. DISCUSSION AND EMERGING ISSUES

The international legal framework as established by the CRPD represents the modern approach to disability. The Convention and its Optional Protocol establish an empowering human rights-based approach to disability, and forms a strong basis for the protection and promotion of the SRHR of women and girls with disabilities. The national legal framework as established by the Disability Act 2006 too, recognizes the rights of PWD but falls short of laying down the legal mechanism for realizing these rights, including the right to health generally and SRHR in particular.

From the findings, HRBA has not been fully applied in SRHR programming and service delivery. Access to SRHR information, commodities and services requires that health facilities, goods and services be within safe physical reach for all population groups, especially vulnerable and marginalized groups such as PWD. While the range of SRHR services provided at public health facilities is broad, some of the services that are ordinarily provided are not readily available as indicated in the findings. For instance, the management of infertility in private facilities is costly and is out of the reach of ordinary women with disabilities, and yet this is where public health facilities refer clients. It is underwhelming that Gulu RRH refers clients for diagnostic services to Lacor Hospital, which is not only a lower facility but also a non-public facility.

One of the core principles of international law on accessibility to health services is that of non-discrimination, especially for the most vulnerable or marginalized sections of the population. The findings indicate that women with disabilities are discriminated at health facilities where their special SRHR needs are not catered for, and their SRHR violated by service providers due to lack of awareness of their SRHR among health providers, lack of capacity and skills to attend to them, structural gaps in the health system, and misconceptions at both facility and community levels that PWD are not sexually active. For instance, the health system does not have standard guidelines for handling women with disabilities.

Well-meaning attempts by individual health facilities and health workers to support expectant mothers with disabilities have ended up undermining rather than upholding their dignity, privacy and autonomy. These attempts have been a major source of stigma and other violations. A typical example has been in situations where health workers have lent women with disabilities help and felt they are doing them a favor to them rather than view it as an obligation on their part to fulfil the sexual and reproductive health rights of women with disabilities.

The findings of this study indicate that some health workers do not feel as comfortable attending to women with disabilities as they do when attending to those without disabilities, as evidenced by the tendency of lower health facilities (Health Center IIIs) to refer women with physical disabilities to higher health facilities (Health Center IVs and hospitals). There are isolated cases of outright resentment, and several health workers admit that attending to some categories women with disabilities consumes more time than those without disabilities, and hence face a challenge in giving them sufficient time among overwhelming patient numbers. While they deny forcing women with disabilities to take contraception, a few agreed that they had advised some women with disabilities to limit the number of children given their condition.

The SRHR needs of women with disabilities have not been prioritized by the public health system. The same applies to the continued failure to ensure that health workers are able to effectively communicate with persons with hearing impairment. Government investment in assistive devices, rehabilitation interventions and disability programs has been inadequate. The gender and community-based services departments which are in charge of disability interventions are grossly underfunded in the three district local governments reached in this study. In Mbale, the local government budget-line for disability interventions is placed under local revenue, which is unpredictable and often under-performs, leading to some disability interventions not being implemented. In Masaka, the district community-based services department reported to have recently delivered a government disability grant of Ushs 1.5 million to a group of 30 PWD in Kabonera sub county who did not have a joint investment and ended up taking a paltry Ushs 50,000 each.

Out of the 12 health facilities reached in this study, only two regional referral hospitals had adjustable delivery beds for women with physical disability. Even then, the two beds and 10 wheelchairs in Gulu RRH are a recent donation from VSO, a foreign NGO. Hence, it is clear that adjustable beds are neither in the procurement plans of the health sector nor in its budget. Where some health workers have received some training in sign language, it has been sponsored by NGOs or PWD organizations - not by the Government of Uganda.

Negative perceptions of health workers continue to be a major barrier to the provision of disability-friendly services and to responding to the health needs of women with disability. The negative perceptions of some service providers were evident in their use of exclusive characterizations, such as “those women” in reference to women with disabilities while comparing them to “normal women” (without disabilities).

While many of the SRHR violations that women with disabilities experience in clinical settings are systemic, some are linked to, and are perpetrated by, negative social norms, practices, myths and perceptions about PWD generally, and women with disabilities in particular, within their communities. The “Social Model of Disability”⁴⁸ considers the issue of disability as a socially created problem and a matter of the full integration of individuals into society. Consistent with this model, the findings in this study show that SRHR violations against women and girls with disabilities have been initiated, exacerbated or compounded by family members, relatives and community members where they live.

The trend has been for development programs to target women generally, including in the health sector but without special consideration of those with disability. As a result, women with disabilities continue to be subjected to double discrimination due to their gender and disability status and continue to be at a disadvantage in most spheres of socio-economic development broadly, and to post poorer health outcomes and to lag behind in health status.

PWD have equal needs to access SRHR as those without disabilities and have similar requirements for family planning and childbirth. Without access to SRHR services and with widespread violations of their SRHR, women with disabilities are at higher risk of unwanted pregnancies, STIs including HIV/AIDS and gender-based violence (GBV).

Amid all the violations against women with disabilities, this study did not find an effective grievance redress mechanism whether that the facility or community level that aggrieved women were using to find justice. They report that the local council system is composed of people who are biased against women with disabilities, and that the justice system does not favor women with disabilities who for various reasons are unable to adduce evidence against their abusers as often is the case. At the facility level, the immediate mechanism for grievance redress, the health unit management committees, are largely unknown to women with disabilities, have limited capacity to hold health workers accountable, or non-functional.

6. RECOMMENDATIONS

- 1) Ministry of Health and Parliament should develop national policies and laws that guarantee women with disabilities access to SRHR services that are sensitive to their needs as women, as persons with disability and as rights holders. The national budget should prioritize investments that make health facilities disability friendly, by building the skills of health workers in sign language, providing IEC materials and signage in accessible formats; and enhancing physical accessibility, among others.
- 2) Ministry of Health should work with Human Rights organizations, PWD networks and local governments to train SRHR service providers in the HRBA, to enable them appreciate the human rights of women with disabilities and their responsibility in respecting, protecting, fulfilling and promoting them.

⁴⁸ Langtree (2010)

- 3) Ministry of Gender, Labor and Social Development should scale up services for PWD generally, and give special attention to women with disability. This should include skilling, to empower them for independent livelihoods, as well as strengthening community-level support structures for PWDs.
- 4) Human rights organizations and PWD networks should sensitize and empower women and girls with disabilities on SRHR to be able to speak out, fend and demand their rights
- 5) Human rights organizations and monitoring agencies should establish a participatory monitoring and evaluation mechanism to track the implementation of policies and programs on access to SRHR by women with disabilities.
- 6) The district local governments should work more closely with the PWD networks for improved coordination of disability interventions of state and non-state actors in the community and clinical settings.
- 7) Build the capacity of, and strengthen, existing grievance redress mechanisms and structures at the facility and community levels, including health unit management committees and local councils.
- 8) District and lower local governments should involve and include PWDs into planning and advocacy spaces such as HUMCs and service committees to improve SRH services in the Lower health facilities where most of them can access.

REFERENCES

- Abimanyi-Ochom, J. and Mannan, H., 2014. Uganda's disability journey: Progress and challenges. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5443041/>
- Anna Lawson (2016). *European Union Non-Discrimination Law and Intersectionality*
- Burstow, B. (2006). Electroshock as a form of violence against women. *Violence Against Women*, 12(4), 372-392
- Department of Justice, Office of Justice Programs. (2009). *Crime Against People with Disabilities, 2007*. Bureau of Justice Statistics, Special Report. <http://bjs.ojp.usdoj.gov/content/pub/pdf/capd07.pdf>
- European Disability Forum (1999). *Report on violence and discrimination against disabled people* [Doc EDF 99/5 EN]. <http://cms.horus.be/files/99909/MediaArchive/EDF%2099-5-violence%20and%20discr-EN.pdf>
- Government of Uganda: UN Convention on the Rights of Persons with Disabilities: Uganda's initial status report 2010
- Groce, Nora. 2004. HIV/AIDS and disability: Capturing hidden voices. World Bank. <http://documents.worldbank.org/curated/en/520371468140965858/HIV-AIDS-and-disability-capturing-hidden-voices>
- Hoogeveen, J.G., 2005. Measuring welfare for small but vulnerable groups: Poverty and disability in Uganda', *Journal of African Economies* 14(4), 603-631. <http://dx.doi.org/10.1093/jae/eji020>
- Human Rights Watch, 2010. As If We Weren't Human: Discrimination and Violence against Women with Disabilities in Northern Uganda. <https://www.hrw.org/report/2010/08/26/if-we-werent-human/discrimination-and-violence-against-women-disabilities-northern>
- Iglesias, M. (1998). *Violence and women with disability*. Vedras, Spain: AIES;The Swedish Research Institute for Disability Policy, HANDU AB. (2007). Men's violence against women with disabilities. *Synskadades Riksförbund*, The Report Series, 2007(1). <http://www.wwda.org.au/swedishstudy1.pdf>
- Innocent Najjumba Mulindwa, 2003. Study on reproductive health and HIV/AIDS among persons with disabilities in Kampala, Katakwi and Rakai districts. Disabled Women's Network and Resource Organization (DWNRO)
- Interim report of the Special Rapporteur on the question of torture and other cruel, inhuman or degrading treatment or punishment, (2008). UN Doc. A/63/175. <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N08/440/75/PDF/N0844075.pdf?OpenElement>
- International Labor Organization (ILO, 2009). Inclusion of people with disabilities in Uganda: Decent work for people with disabilities. *Fact Sheet*. https://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_115099.pdf
- Minkowitz, T. (2007). The UN CRPD and the Right to be free from non-consensual psychiatric interventions. *Syracuse Journal of International Law and Commerce*, 32(2), 405-428. <http://www.chrusp.org/home/resources>
- Reeve, D. (2004) 'Psycho-emotional dimensions of disability and the social model', in C. Barnes and G. Mercer (eds). *Implementing the Social Model of Disability: Theory and Research*, Leeds: The Disability Press, pp. 83-100. <http://donnareeve.co.uk/wp-content/uploads/2014/03/ReeveChapter2004b.pdf>
- Secretariat for CRPD, UNFPA & Wellesley Centers for Women, 2008. Disability Rights, Gender and Development: A Resource Tool for Action. www.un.org/disabilities/documents/Publication/UNWCW%20MANUAL.pdf

UBOS, 2014. National Housing and Population Census

UN OHCHR, 2014. The Convention on the Rights of Persons with Disabilities: Training Guide. *Professional Training Series No.19*

WHO global disability action plan 2014-2021

World Health Organization, 2011. World report on disability 2011

Young M., Nosek M., Howland C., Chanpong G., and Rintala D. (1997). Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*,78(Supplement), S34–8