Women with Disabilities and Reproductive Rights

A brief illustration of the picture in Uganda

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Contents

ABSTRACT

This paper explores the complex roles played by the state, primary caregivers, health workers and community residents who are key players in the assurance of sexual and reproductive health rights for women and girls with disabilities in Uganda. women's sexual and reproductive health and rights are internationally acknowledged as fundamental human rights and the violation of the same is a barrier to gender equality. Disproportionate discrimination and violation in the security of these rights trouble women and girls with disabilities. Intersectionality exposes the innumerable oppressions undermining sexual and reproductive health and rights for women and girls with disabilities. Intersections of disability on other social injustices simultaneously work with the key players to augment the fluid inequities tackled by women and girls with disabilities. These fluid inequities exhibited through the experiences of women and girls with disabilities prove that the right to sexual and reproductive health rights is yet to be secured for this section of women.

Key words: sexual and reproductive health rights, women and girls with disabilities, Uganda

INTRODUCTION

Health inequities have emerged as the lead obstacle to the fulfilment of gender equality initiatives between men and women. Within these inequities lie the violation of sexual and reproductive rights for women and girls more so those with disabilities.

The World Health Organisation (2014) takes it that sexual and reproductive health rights in its context and services means the right of all persons to seek, receive, and impart information related to sexuality, receive sexuality education, have respect for bodily integrity, choose their partner, decide to be sexually active or not, have consensual sexual relations, have consensual marriage, decide whether or not and when, to have children and pursue a satisfying, safe, and pleasurable sexual life.

Universally acknowledged as fundamental inalienable rights by the United Nations Convention on the Rights of Persons with Disabilities (UN, 2008) and the (ICPD, 1995), women's sexual and reproductive rights emerged as one of the lead challenges to gender equality between men and women. A challenge sustained by the inequalities not only between men and women but within women themselves. On top of discrimination as a result of disability, women and girls with disabilities suffer all forms of gender based discrimination in the area of sexual and reproductive health rights (Habib, 2010).

Whitehead (1990) asserts that equity in health ideally implies that everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that no one should be disadvantaged from achieving this potential. In that regard, women and girls with disabilities have the right to equal access to quality health services irrespective of gender and disability.

This right is enshrined in the existing human rights frameworks mainly the United Nations Convention on the Rights of Persons with Disabilities (UN, 2008). Article 6 directly speaks to women with disabilities, appeals to State Parties for the recognition of the multiple forms of discrimination against them, and need for actions that make certain they fully and equally enjoy all human and fundamental freedoms (UN, 2008). Whereas Article 25 specifically indicates that States Parties recognise that persons with disabilities have a right to the enjoyment of the highest attainable standard of health without discrimination based on disability (UN, 2008). These Articles are underscored by Sustainable Development Goals (SDGS, 2015) 3 Good health and wellbeing and 5 Gender equality.

It is indisputable that persons discriminated against the above are liable to suffer unfavourable health outcomes, comprising lesser contacts with health providers and decreased access to health care and information (Khadidiatou, Krieger, Warren, Hecht, & Kola, 2008). A situation women and girls with disabilities in Uganda find themselves in, yet Articles 33 rights of women and 34 rights of children in Chapter Four of the 1995 Constitution of the Republic of Uganda recognises them as rights holders.

The aim of this paper is to ascertain the myriad of discrimination and oppression that women and girls with disabilities in Uganda confront during attempts to secure their sexual and reproductive health rights. As a black, middle-class woman with a disability privileged with the power of education from Uganda. I am fully aware of the importance of agency for women and girls with disabilities in sexuality and reproductive rights. But I lack understanding on what it means to be a woman with a disability from the rural area seeking sexual and reproductive health rights. I wanted to know more of what women and girls with disabilities from the rural areas experienced, how the different intersections on disability affect access to sexual and reproductive health rights.

I will first discuss the theoretical framework of intersectionality (Crenshaw, 1989) and explain how disability intersects with multiple forms of discrimination to shape the lives of women and girls with disabilities in Uganda. Next, I will provide stories on the experiences of women and girls with disabilities in relation to reproductive health drawn from my experience as an advocate for reproductive rights of women and girls with disabilities. Then I will proceed to the discussion and conclude by determining whether Uganda has done enough in guaranteeing their sexual and reproductive health rights.

THEORETICAL FRAMEWORK

Intersectionality

It is often assumed that persons with disabilities hold similar views, experiences, priorities, regardless of gender, age, cultural background, sexual orientation, socio-economic status, religion, and other classifications of diversity. This assumption gives supremacy to disability and often results into the neglect of interactions among other key elements that work toward aiding the discrimination of persons with disabilities from services and society alike (Goethals, De Schauwer, & Van Hove, 2015, p. 75). Although the term is taken to refer to a single population, it encompasses a diverse group of people with differing disability needs. With the implication that two people with a similar disability can be affected in very different ways, (Centers for Disease Control and Prevention (CDC), 2019).

Developed in feminist scholarship, intersectionality as a critical feminist approach has been spread to research pertaining to the experiences of individuals including those with disability. The approach suggests that a person with several oppressed identities will live completely different experiences than somebody who shares only one, or a few of those oppressed identities (Crenshaw, 1989). It seeks to shed light on various interacting factors that affect human lives and attempts to distinguish how these different systemic conditions varying in location, time and situation work together to repeat conditions of inequality (Goethals et al., 2015).

The identification of these interlocking forms of oppression from past feminists like Sojourner Truth who had long before argued for equal rights and stressed the different oppressions between black and white women, propelled Kimberle Crenshaw (1989), to coin the term 'Intersectionality'. The feminist approach offered the world insight on the intersections between different power dynamics on marginalised groups like women and girls.

Premised on the fact that not all women are the same and are affected differently by the social positions they occupy, intersectionality as a critical feminist approach shall help us understand the multiple forms of discrimination exposed to women and girls with disabilities in Uganda. This chapter shall explore the intersections of disability on gender, sexuality, socio-economic status, and location and how they affect their access to sexual and reproductive health rights and services.

Disability and Gender

Gender has yet to be seen and acknowledged as intersecting other elements that define the opportunities people have in life (Habib, 2010), like gender/sex roles. The socially accepted definitive tenets of womanhood that is daughter, mother, wife which follow women through their lifespan are denied women and girls with disabilities. With their bodies perceived incapable, consequently women and girls with disabilities are given very low social standards to become wives and lovers

(Othelia Lee & Oh, 2005). When it comes to the male gaze, the internalisation of ableism that seeks to refute disableism in women and girls with disabilities so as to appear not “too” disabled to able-bodied men (Flores, 2018) weakens an already low self-image. They either fight twice as hard as non-disabled women to prove their capability for marriage (Inderjeet, 2018), or undergo non-consensual medical procedures like forced sterilization and abortion by doctors under instructions of care-givers. Care-givers take these extreme measures out of belief “they would be the actual parents of their child’s offspring, and that sterilization is a prerequisite for their child’s well-being and sexual blossoming” (Desjardines, 2012, p. 82). This cheats women and girls with disabilities subscription to gender/sex roles that persist on being society’s measure of a woman’s success.

Entrenched in the parental preference of the male child with a disability is the undervaluation of the girl child with a disability. His potential to carry the lineage forward accrues him all the opportunities for growth, development, and sustainability like education while relegating the female child with a disability to traditional roles befitting her gender. Statistics from the (Uganda Bureau of Statistics (UBOS), 2019) have it that the attainment of tertiary education for males with disabilities in the rural areas is two times higher than that of females with disabilities at 5.2.% and 2.6% respectively. Acute refusal to offer the girl-child with disabilities similar prospects for empowerment like education disadvantages the pursuit of her sexual and reproductive health right to education and information on sexual and reproductive health.

Parental preference of the male child with a disability sustains the perpetuation of sexism and its oppressions on women and girls with disabilities. They are prevented from being the main decision makers concerning their bodies and reproductive health since men hold the upper hand in both the public and private spheres of women’s lives. It is indicated that only 0.2% of married women with disabilities have the power to independently make decisions on their own health (Uganda Demographic and Health Survey (UDHS), 2016), implying that majority lack the authority to make decisions on their health and lack control over their bodies. While non-disabled women hold considerable agency when it comes to partner choice and control over their bodies, women and girls with disabilities fall prey to a gender that controls not only their bodies but also when, how and who to have sex with. This lack of agency when it comes to choice of sexual partners and consent to sex makes them liable to HIV/AIDS (Bhana, Morrell, Hearn, & Moletsane, 2007) and places sexual autonomy beyond their reach. It is therefore justifiable that women and girls with disabilities face double discrimination on the grounds of both their gender and their impairments, (Dutch Coalition on Disability and Disability Development (DCDD), 2013).

Disability and Sexuality

The upbringing between a girl with a disability and one without could not be any more disparate nor reflective of the inherent cultural beliefs against disability within the African traditional mindset. Even with the low value attached to her sex as female, the girl without a disability has the chance to flourish in her environment, learn social skills and gain community recognition. Unlike the girl with a disability who is either brought up in secrecy, “Indeed, many blind and lame children were hidden by their families from society; they were a source of shame and embarrassment to their families” (Ndlovu, 2016, p. 35), or killed at birth as a “mercy killing”. Parents of children with disabilities deliberately allow them to die through starvation or deny them medical attention under the belief that the children are better off dead than having to endure a painful and incurable disability (Bareebe & Dewulf, 2018). Considering these circumstances, the girl with a disability is denied social inclusion, community acceptance and recognition, and forced to grow up on the fringes of society. Social exclusion from childhood spreads to adulthood and is further enforced in the exclusion from community health drives on sexual and reproductive health.

Transitioning from puberty to adulthood is a period filled with sexual discovery and exploration for both men and women. With the practice of sexuality prohibited to on one except women and girls with disabilities. While it is very common to see disabled men married to non-disabled women (Habib, 2010). Women and girls with disabilities have to grapple with feminine ideals of beauty which magnify the differences between them and non-disabled women (Titchkosky, 2003). This diminishes the delicate outlook on self-image, body image, desirability, and participation in intimate partnerships. Amidst efforts to call for the appreciation of the sexual needs of women, women and girls with disabilities are romantically disadvantaged because of the view that they are flawed sexual partners (Othelia Lee & Oh, 2005).

Being viewed as flawed sexual partners compounds their lack of agency that is often exercised by non-disabled women in choice of partner for intimate relationships and incites their susceptibility to sexual violation from men. In comparison to their non-disabled peers, women and girls with disabilities have their first date and sexual experience later in life (Othelia Lee & Oh, 2005). For women and girls with disabilities, disability is a cause for segregation from the exploration of femininity, companionship, active sexuality and the denial of maternity prospects (Addlakha, Price, & Heidari, 2017).

Sexual discovery and exploration in women and girls with disabilities is constrained by the societal misconception that they are asexual. The misconception holds the implication that women and girls with disabilities do not have sexual feelings, yet they are not only sexual (have sexual feelings) but have a right to free sexual association. This emerges as a foundation for their denial of necessary information and reproductive health services, (United Nations Population Fund (UNFPA), 2009). In its situational analysis of 2009, UNFPA showed that myths and misconceptions on disability and sexuality place women and girls with disabilities in an unfortunate situation. Women and girls with disabilities are left out on sexual and reproductive health related information putting their lives in danger.

Also, they are left uninformed and ignorant about the health services provided even within their communities for example, the information is hard to access for women and with visual impairment because it is neither brailed nor in large print and lack of information on the location of health facilities hindered their access (Casebolt, 2020). These misconceptions not only hide violence and abuse against them but also cement the deep-seated stigma and shame connected to both disability and sexuality, (DCDD, 2013).

Existence and performance of non-consensual medical procedures like forced sterilisation, forced abortion and pre-natal diagnoses that seek to prevent the continuation of disability in society have made their way to contemporary discourse. Pregnant women choose pre-natal screening due to pressure from their doctors or undertake testing as part of “routine” treatment without the knowledge of choices to be made (Liamputtong, 2003). Normalisation of mercy killings for children with disabilities, instil fear in persons with disabilities (Citizen, 1997) and make it impossible to distinguish denial of disease and disability from attitudes towards individuals who are sick or disabled. Disability and disease act as the antithesis of health which is considered a norm of orientation (Hechler, 2017). The negative portrayal of disability as a “"tragedy" or "problems" of disability, as well as "victims and sufferers" of disability in the media” (Mills, 2012) nurtures society’s view of disability as problematic. Not forgetting the ableist point of view that sees disability as a source of curiosity and a times pity, shapes intercorporeal emotions in abled-disabled encounters for it invalidates the disabled body and affirms its own validity at the same time (Costa, Hughes, & Menezes, 2013) to sustain the social construction of ableism.

Disability and Socio-economic status

The feminization of poverty notwithstanding, women and girls with disabilities are inexplicably likely to be among the very poor because of their dependence on subsistence farming as a sole source of income for survival. In Uganda 80% of households headed by persons with disabilities and 79% of households with persons with disabilities depend on subsistence farming as their main source of livelihood compared to households without persons with disabilities, (UBOS, 2019). The socio-economic disparity between women and girls with disabilities and those without disability supports their association with abject poverty and low rank on the socio-economic status. In addition, the presence of disability and the related disability costs such as assistive devices, routine medication for those with psychosocial disabilities, personal assistants/helpers and guides strains already overstretched resources. Resulting into women and girls with disabilities becoming lifelong economic dependents to their families. This makes some families feel burdened and impacts women and girls with disabilities' desire for independent living.

Moreover, prejudices against persons with disabilities, particularly women and girls are fuelled by the social hierarchy that magnifies the class distinctions between and within genders. The status of disabled women and men in the social hierarchy differs substantially in most, if not all, societies (Habib, 2010). Even though men with disabilities may be impaired by able-bodied societal constructions, they are able to profit from male privilege (Gerschick, 2000). Unlike women and girls with disabilities whose socio-economic status and disability aids in widening the division within their own gender. This division is witnessed through the exclusion of women and girls with disabilities from community health initiatives pertaining to sexual and reproductive health, and low prioritisation of their unique disability needs by both the state and families (Habib, 2010).

Disability and Geography of Inequalities

In Uganda, the greatest population of disability lives in the rural areas, yet majority of services especially better health services are concentrated in urban areas. The (National Housing and Population Census (NHPC), 2014) indicates that the prevalence rate for disability is higher among those living in the rural areas compared to those in the urban areas. Although there is a health centre three in every sub-county to provide services such as laboratory testing, antenatal care, general treatment, immunisation, and family planning, the distances involved to get to the services remains a challenge for women and girls with disabilities. This incongruence in location of services and physical location of women and girls with disabilities makes sexual and reproductive health services inaccessible.

Many women and girls with disabilities live in remote areas with limited access to services including sexual and reproductive health since some of the health centres are located 2 kilometres away from some of their residences (Mudoola, 2013). This intensifies their vulnerability to multiple kinds of discrimination as women and persons with disabilities for they cannot access these services because of the journeys involved. Because they lack assistive devices like wheelchairs, some women, and girls with disabilities either crawl to the health centre or use public transport since they cannot afford private transportation. They are also incapable of paying for standard postdelivery medical attention (Othelia Lee & Oh, 2005).

The inability to afford private transportation which is of vital importance for persons with disabilities, (UBOS, 2019), and hand-to-mouth lifestyle that comes with subsistence farming compounds this geography of inequalities. Girls with disabilities in the rural areas gain access to contraceptives between 18.6 to 24 years compared to their non-disabled counterparts who access it between 17.4 to 21 years, (UDHS, 2016). They choose to forego the services unlike non-disabled men and women whose non-disabled state and proximity to services facilitates their access to sexual and reproductive health services.

Inaccessibility to the physical environment and communication linger as barriers for women and girls with disabilities due to the ableist construction of society, that separates human beings into disabled and normal, whose determination relates primarily to capabilities (Hechler, 2017). The separation between disabled and normal decides the ways in which services may be rendered for women and girls with disabilities. Access to the physical environment especially in public spaces like hospitals and health centres is an area of negotiation in terms of cost. They largely depend on the financial assistance of family members to cover transport and service costs (lee, et al., 2015).

Presence of structural obstacles like staircases, inflexible medical equipment and high examination beds (Othelia Lee & Oh, 2005) built to suit non-disabled persons dissuade women and girls with mobility difficulties from accessing sexual and reproductive health services. In addition; the lack of inclusive communication service providers like Sign Language Interpreters for those with hearing impairments, and information on sexual and reproductive health in accessible formats for example in Braille and large print for the visually impaired negates their right of access to this information.

Disability and the Policy environment

In 2009, the WHO and UNFPA developed a guidance note on promoting sexual and reproductive health for persons with disabilities. This note explicitly speaks to issues of sexual and reproductive health for persons with disabilities with intended users being sexual and reproductive health experts, advocates within UNFPA and WHO, and other development organisations and partners with an interest in sexual and reproductive health. The guidance note is premised on the consideration that as much as sexual and reproductive health rights for persons with disabilities are as important for non-disabled persons, they are more critical for the former due to their increased vulnerability to abuse (WHO & UNFPA, 2009).

On that note, Uganda is currently implementing the National Policy and Service Standards on Sexual and Reproductive Health Rights, third edition, 2012 (Ministry of Health, 2012). But the generic design of the policy which translates into generic programs and actions is a test to women and girls with disabilities. The policy is under the assumption that all women are homogenous, therefore provides for generic needs of all women. It does not consider the unique needs of women and girls with disabilities whose needs differ according to types of disability. Most of the trials faced by women and girls with disabilities in accessing their sexual and reproductive health rights stem for example from policy formulation. These include but not limited to structural barriers such as poorly laid stairwells to buildings (hospitals and health centres), inaccessible medical equipment which limits women with mobility difficulties to access breast and cervical cancer screening because the examination tables are not height adjustable and use of mammography equipment that only accommodates women who are able to stand, poor signage, narrow doorways etc., (UBOS, 2012).

For developing countries like Uganda, policies are to blame for the invisibility of women and girls with disabilities and their struggle to access sexual and reproductive health services. Women and girls with disabilities not only remain underrepresented but excluded, (UNFPA, 2009).

Even though all women face challenges in access to sexual and reproductive health rights, women and girls with disabilities encounter a combination of complex, intersecting and simultaneous challenges that reduce their access to sexual and reproductive health and rights. They face stigma and discrimination consistently throughout their lives and thus lead desperate lives.

In the next chapter, the lived experiences of women and girls with disabilities in accessing their sexual and reproductive health rights and services shall help me explore the complex roles played by the state, primary caregivers, health workers and community residents in violating their sexual and reproductive health rights. Their personal experiences shall also highlight a multitude of other factors that have limited their equal access to quality sexual and reproductive health services.

EXPERIENCES OF WOMEN AND GIRLS WITH DISABILITIES

It is estimated that 15% of the world's population is disabled and the prevalence is higher for developing countries, The World Bank (The World Bank, 2020). In Uganda, 12.4% of the population is considered to have disabilities, (NHPC, 2014), and are listed as the most "at risk" and socially excluded groups in the community. Data differentials based on sex and geographical location reveal that disability is high among women than men. Disability prevalence rate was higher among those living in the rural areas compared to those in the urban areas (NHPC, 2014).

To ascent with the directives of the ICPD (1995) and UN (2008); Uganda put in place its National Policy Guidelines and Service Standards for Sexual and Reproductive Health and Rights, third edition, 2012 (Ministry of Health, 2012). From the year of implementation, the policy has seen to a decline in the practice of female genital mutilation from 1.4% in 2011 to 0.3% by 2016 (Byaruhanga, 2019). Led to a remarkable drop in the total fertility rate in non- disabled women and girls from 6.9 children per woman in 2000-01 to 5.4 children in 2016, (UDHS, 2016). However, women and girls with disabilities remain invisible when it comes to the safeguarding of their sexual and reproductive health rights. They are met with disproportionate discrimination during the security and exercise of their rights increasing their susceptibility to sexual abuse, sexual isolation, unwanted pregnancies, girl-child marriages, denial of consent and choice over body autonomy and integrity, and right to privacy (Ahumuza, Matovu, Ddamulira, & Muhanguzi, 2014; Ruhogo & Maphosa, 2017).

Sexual and reproductive health rights of persons with disabilities especially women and girls have been overlooked by both the disability community and those working on sexual and reproductive health services (SRHS). Women and girls with disabilities have greater needs for sexual and reproductive health education than any other person because of their magnified vulnerability to abuse.

Although women and men with disabilities share common experiences of devaluation, alienation, marginalization and prejudice, their fortunes diverge significantly. Throughout the lives of women and girls with disabilities, two stigmatized statuses intersect, further weakening their already devalued gender status (Gershick, 2000, p. 1265) to boost the unmitigated violation of their sexual and reproductive health and rights from the State, primary caregivers, health workers and community residents.

Stories from Women and Girls with Disabilities in Uganda

These are some of the lived experiences of women and girls with disabilities in accessing their sexual and reproductive health rights and services. A brief illustration of the picture in Uganda.

*The stories are a work of fiction but based on my work experience with women and girls.

Maggie's Story

Maggie is a 26-year-old woman with a physical disability. She suffered from poliomyelitis at eight years old that left her legs weak and necessitated the use of crutches and callipers. Her education as a girl with a disability was not without struggle given the financial status of her parents that would affect her regularity at school, her mobility difficulties and relentless mocking from fellow children over her walking style. The community nicknamed her "Kalema[1]", a term that followed her to adulthood. The first day she had menstruation, she thought she had got a disease and she cried a lot. She refused to go back to school the following days because blood had gone through her school uniform and boys had seen it. Days later; she went back to school and was able to complete her high school education despite the difficulties faced along the way.

Maggie was happily staying at her parents' house after completing high school until they started complaining about her lack of work and told her to get married. She found work as a volunteer and while there gained the interest of a married man that eventually impregnated her. The man did not acknowledge her pregnancy and later abandoned her. Maggie tried to go for antenatal care at the recommended times but every-time she went, the nurse on duty would ask her how she could get pregnant as a "kalema", and the Boda-Boda[2] men on the road would also shout, "[3]Mama, nawe olya ebintu?". She gave up on the services and waited for her due date.

On the day she was to deliver; Maggie requested her neighbour to take her to the health-centre. And with her help, she carefully negotiated the well of stairs leading to the premises of the facility. The mid wife on duty told her to find herself a bed she could easily climb on without assistance, but it proved to be a challenge. Most of the beds were filled and the available ones were in corners she was unable to reach because of her disability. When she found one that she could navigate towards without any problems, trying to get atop it on her own put her disabled and pregnant state in a more precarious position. She called for the midwife to assist her only to hear, "how did you get in this condition if you cannot even climb the examination bed?" Maggie silently tolerated the comments and waited for assistance. She was later delivered of a bouncing baby boy to the joy of her parents.

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[1] Essentially means 'disabled' but used as a derogatory term on children with disabilities in Uganda

[2] Local term for the motorcyclists that use motorcycles as a form of transportation in Uganda

[3] loosely translated to disbelief over her having sex because she is disabled

Commentary

Although the circumstances of her pregnancy are less than idealistic, Maggie is the woman with a disability that many women and girls with disabilities aspire to be when it comes to their sexual and reproductive health rights. She is privileged because of her education, has the support of her parents but is oppressed because of her gender and disability. Despite the negative disposition of the nurses and midwife that pose significant problems at health centres (Tanabe, Nagujjah, Nirmal, Bukania, & Krause, 2015), she did not let the difficulties of her disability stop her from accessing her right to safe motherhood.

Because of her education, Maggie is in position to go after her rights regardless of the structural barriers at the health centre. For some women and girls with mobility difficulties, access to health services and the physical environment is impeded by the unavailability of ramps, assistive mobility aides like wheelchairs and the unfriendly medical equipment in form of the high unmodifiable delivery bed that was hard for Maggie to get on to.

Attitudes of midwives towards expectant women and girls with disabilities often bar them from gaining expert sexual and reproductive health services, pushing them to obtain services of conventional birth attendants (New Vision, 2011; Mudoola, 2013), and Maggie is no exception. In her decision to not continue with the antenatal care visits due to the negative remarks from the nurses and midwives, Maggie joined the 249,000 adolescent women that do not obtain the requisite number of antenatal care visits (Guttmacher Institute, 2019). She put her life and that of her unborn child at risk.

In some cases, the inability of women and girls with mobility difficulties to access different service points at health facilities like examination rooms, laboratories and consultation points forbids their right to privacy. Women and girls with disabilities are forced to give private and confidential information in public spaces such as general wards, corridors and even compounds of health facilities. This level of dehumanisation deprives them of the right to confidentiality and discourages them from seeking medical services.

Maggie's privilege as an educated woman with a disability does not save her from the oppressions of gender, classism, disability, and socio-economic status that seem to shape her experience as a woman with a disability.

Rita’s Story

Rita is 18 years old with multiple disabilities that is partial visual impairment and limb deficiency in her left arm. At 16 years old, Rita was sexually abused by her Uncle while her Aunt June attended a friend’s burial and every time she went away, the violation continued. As a result, Rita became pregnant. While the community was shocked to see her growing belly, Rita’s aunt grew suspicious of her and took her to the health centre. Rita was not certain of what was going on but recalls the hushed conversation between her aunt and the health-worker and being called upon to enter the examination room.

The health-worker examined her to know the stage of the pregnancy and sent her out of the room. He called her aunt into the room and showed her the results of the examination. Her aunt and the health-worker took longer than she expected. They later left the health-centre with a prescription and directions for use known solely by her aunt.

Rita kept wondering what the health-worker had told Aunt June and if it at all had anything to do with the child growing inside her. She knew she was having a baby. One of her friends had been like her and had a baby afterwards. The thought of having a baby excited her but she could not express it. Her aunt kept looking at her in disapproval and so did uncle.

It was quite late when they reached their grass thatched house; Aunt June gave Rita two tablets and told her to swallow them immediately and go to bed. Rita did not have supper that night. A few nights later, Rita suffered a painful stomach-ache that drove her from the floor that was her bed, felt her way around the room until she got to pit latrine a few metres from the house.
Later, Rita realised that the feeling of constant fullness that came with being pregnant had left her. She wondered if it had anything to do with the pills Aunt June had given her a week ago.

Commentary

Rita was excited at the thought of having a baby and be like her friend who is non-disabled, but her aunt robbed her of that chance. In her conference with the health-worker and consenting to the forceful abortion of Rita’s baby, Aunt June not only violated Rita’s right to body autonomy, consent, and choice. She renounced Rita’s right to confidentiality and privacy that is the norm between patients and doctors.

As a woman with a disability, Rita is divested of the little power she had to make decisions over her own body even though she is cognizant of thought. Instead of addressing the results of the examination to her, it is Aunt June that is spoken to and handed the prescription. It is rare that women and girls with disabilities are spoken to by health workers, it is more common for them to choose to communicate to the primary caregiver irrespective of the women and girls with disabilities ability to speak (Casebolt, 2020). Communication of personal information through third parties restricts the engagement of women and girls with disabilities in sexual and reproductive health and services. They are not in position to ask questions regarding their health due to the presence of a third party (Casebolt, 2020).

By not asking Rita if she wants to keep her child or not, nor telling her that they are aborting displays the infantilization of Rita by both her primary caregiver and health-worker. Sometimes, persons with disabilities are treated like children with decisions made on their behalf with neither consent nor choice because caregivers assume what they are doing is in the interest of the child.

The shocked reaction of the community towards Rita's growing belly endorses society's misconception that women and girls with disabilities are asexual and harbour no sexual desire. These misconceptions have made women and girls with disabilities vulnerable to sexual predators who believe that the sexual inactivity – virginity of a girl with a disability can cure HIV/AIDS (Groce, 2004), fostered their exclusion from sex education as teachers do not think they need to know about it (The Economist, 2020).

Age, disability, and gender come together to build Rita's experience as a girl with a disability. She suffered several violations with the abuse. Her agency taken away by her aunt because of her teenage pregnancy and disability.

Jane's Story

Jane is a 17-year-old girl with a hearing impairment. Her mother goes to the community meetings for sexual and reproductive health information at a community school with other women and the older girls. She used to go without her, yet other parents would go with girls older than her and some of her age to the meetings. Her friend Lizabeti had the same challenge. Her mother was also not taking her.

Jane and her friend Lizabeti used to follow their mother to the community meetings without their knowledge. They would wait at Jane's house for her mother to leave before following her. Lizabeti's mother did not attend regularly like Jane's mother because she did not agree with what the health-workers were teaching the women. She said only God can stop her from having children.

When Jane asked her mother why she did not take her to the meetings, her mother's response would be that Jane was young and would not understand because of her hearing impairment. One day; she and her friend followed her to the community meetings and saw the women and older girls seated in a circle with the health-worker in the centre. In his hand was a banana, and he was trying to put a polythene bag on top of the banana. Jane saw the various reactions from the ladies in the groups from laughter to shock and shyness. One of the older girls put up her hand to speak but Jane could not hear what she said because of her impairment. The health-worker put up some medicines and the senior woman of the village passed the medicine around for the women and older girls to see.

Reeling from confusion over what she had witnessed and failed to comprehend, Jane decided to leave without Lizabeti. '"Why did the women and older girls react like that? What was the health-worker doing in putting a polythene bag over a banana?", were questions she could not make sense of. She was however not surprised at seeing the health-worker for she had seen him before on a visit to the health-centre with her mother.

Two weeks later, Lizabeti went to play with her. Jane took the time to ask her about the women and older girls' reactions and she replied that the health worker was showing them how to use protection to avoid having babies. She then put her hand behind her back, pushed her stomach in front, in imitation of the pregnant women they had seen going to the community meetings. Rita found the imitation funny because the aunties always had big stomach's like her mother's friend whose children stopped playing with her.

Her mother's friend has children that often visit with. They used to play with Jane sometimes but not anymore because they were boys and her mother's friend did not like it when she saw Jane playing with them. She kept saying Rita wears a dress and the boys wear shorts. Jane did not understand it but stopped after the boys chased her away whenever she went to play with them.

Commentary

From this scenario, it is easy to see that Jane and her friend Lizabeti are curious about the community meetings their mothers and older girls attend. Jane's desire for knowledge and curiosity over the happenings at the community meetings is understandable of young girls especially those going through puberty. However, she is burdened by her lack of education which is not uncommon for girls with disabilities in the rural areas considering the fact that tertiary education for males with disabilities is twice higher at 5.2.% in comparison to 2.6% of females with disabilities, (UDHS, 2016).

Jane's mother is a traditional woman who strongly believes in culture and its stand on sex and reproductive health. In some African cultures like Uganda, the treatment of sex as a taboo topic prohibits the conversation between parents and children (Wamoyi, Fenwick, & Urassa, 2010) due to the certainty that discussing sex could promote premarital sexual intercourse (Alomair, Alageel, Davies, & Bailey, 2020). Hence her evasive responses to Jane when she enquires about the community meetings. Similarly, the cultural belief explains Jane's lack of education. Some African parents do not believe in the education of females with disabilities because of disability.

Culture aside, Jane has an unmet desire for sexual and reproductive health information but the hindrance in communication between her and the health-worker forbids her right to this information. Her disability needs are overlooked by the lack of provision of Sign Language

Interpretation services that would bridge the communication divide between Jane and the health-worker at the community meetings. Even though her friend Lizabeti communicates to her with physical demonstrations, sign language interpretation is paramount (Adubango & Okello, 2015) for hearing impaired women and girls with disabilities. The lack of which poses as a point of exclusion for Jane.

Lizabeti's mother's religious beliefs present another form of oppression that continues to restrain the achievement of sexual and reproductive health rights programs in some communities. Religion can influence attitudes and behaviours in sexual and reproductive health services (Hall, Moreau, & Trussell, 2012). Religious views on contraception have affected the attitude of women towards family planning, (Alomair et al., 2020), as witnessed by Lizabeti's mother. She is of the belief that God shall stop her from having children and as such does not consider the community meetings useful.

Women with hearing impairments have been reported as particularly at risk of sexual harassment, (Tanabe et al., 2015). As a member of the community and citizen of Uganda, Jane is entitled to information regarding sexual and reproductive health but without the inclusive communication service providers, many hearing-impaired women and girls with disabilities like Jane are left out of sexual and reproductive health services in this manner. This bears the implication that the inclusion of women and girls with disabilities especially those with hearing impairment in sexual and reproductive health services information and outreach is a problem (Casebolt, 2020).

Jane's story has underpinnings of gender norms exhibited through the separation between her and the sons to her mother's friend. She is stopped from playing with them because she is an adolescent now and her mother's friend does not like to see her playing with the boys. It also depicts the intersections of age, gender, culture, and religion in shaping her experience as a girl with a disability.

Pauline's Story

Pauline is a 25-year-old girl with an intellectual disability. She is in a loving relationship with John, the man she met through her brothers as a young girl. Pauline wanted to have a child with John but discovered that she was unable to. She grew up in the confines of her home and was not allowed to go to school or play outside like her two brothers. She stayed home with her mother and did the household chores around the house. Never allowed to go fetch firewood or water. The one time her mother went with her to the well, the women at the well started whispering among themselves. One of the women asked her mother why she was proudly walking around with a cursed child? The few women that used to visit her mother stopped going to see her. Whenever her mother's friend went to visit her, her mother would lock Pauline inside the house until the visit was over.

When her mother was not around, Pauline would play with her brothers and their friends. Sometimes, they taught her how to read, write, speak and easy lessons they picked from school. It is through them that she learnt how to speak. One fateful day, while her mother took long to return from the well, Pauline heard the door lock being broken. Thinking her mother had returned, Pauline thought nothing of it until she saw a man open the door and forcibly carried her to the plantation next to their home. He started by undressing her and then himself, at which point, Pauline kicked and screamed but he was too powerful for her. He put his hand on her face and pushed her head and body into the ground…

The memories of her assault may be sketchy but Pauline clearly remembers her mother taking her to the health centre and the conversation that took place between her mother and the doctor before being taken to the operating room, “I cannot keep her safe if you do not go through with it. It is the only way I know of to protect her.” The midwife then took her to the operating room.

After that day, life became a little stricter for Pauline. Her mother never left her out of her sight and when she had to fetch water or firewood, she insisted on her brothers hanging around the home to watch over Pauline. That is how John and she became friends. He used to visit her brothers when they could not go to him and he made sure to include her in all their games. Pauline’s brothers grew to trust him in that they would even let him stay with her when they needed to go elsewhere in their mother’s absence. On her 18th birthday, John informed Pauline’s brothers that he wanted to marry her.

Her mother agreed to the marriage on condition that Pauline and John do not stay further from her. Pauline expressed her desire to have children with John, but her mother told her she could not. That is was not possible for her and never explained why. She talked to John and he took her to the health centre for a check-up. It is then that they discovered Pauline had been sterilised as a young girl. That is the day the conversation she had overheard between her mother and the doctor as a young child made sense.

Commentary

Like many mothers of children with disabilities in the rural setting, Pauline’s mother is involuntarily hiding her child from society. The African belief that children with disabilities are curses is inherent in their community. Pauline’s mother is not only dealing with community ostracism for taking her child with a disability about but utter rejection for having a child with a disability as seen from the disappearance of her friends. This enforces the social exclusion of women and girls with disabilities from community health drives that would be of benefit to them.

Faced with societal rejection for having a disability, Pauline manages to have a semblance of a good childhood. She has the love of her parent, her brothers, and their friend John. Finding love with John bred the desire to cement that love with a child but was unable to. Pauline underwent non-consensual sterilisation after sexual violation out of her mother's fear of the consequences and belief that she is protecting her.

Forced sterilisation of women and girls with disabilities is a topic of contention in today's discourse because it cheats them of their right to bodily integrity. Doctors take it upon themselves to recommend it to expectant mothers with disabilities over the assumption of unforeseen complications (Casebolt, 2020) and mothers of children with disabilities as a justification for reduction on the family burden (Casebolt, 2020). Sterilization of women carried out without their consent or without any reasonable choice is to be viewed not only as physical violence but also as a form of violence against their person (Björnsdóttir, Stefánsdóttir, & Stefánsdóttir, 2017). And when a sterilized woman is raped it is easier to conceal (Hild, 2018).

Women and girls with intellectual disabilities are most exposed to forced sterilization (Hild, 2018), endangering them to sexual violence. Whereas primary caregivers and doctors may think of involuntary sterilisation as a small price to pay in prevention of extra family burdens that may arise out of the sexual violation (Holnes, 2013), and discontinuity of disability in society (Hechler, 2017), it embraces lifelong consequences for women and girls with disabilities such as painful periods, heart problems and stress (Hild, 2018).

Involuntary sterilisation takes away their gender/sex roles, rights to motherhood, family ownership and belonging. The tenets of womanhood are basically stripped away from women and girls with intellectual disabilities at a young age with neither consent nor awareness of the cost until the desire for a child and family materialises.

In Pauline's story, intersections between ableism, disability, culture, and social stratification of her mother, work together to shape her experience as a woman with a disability.

DISCUSSION

Sexual and reproductive health rights continue to elude women and girls with disabilities in Uganda because of the violation brought on by the state, primary caregivers, health workers and community residents. These violations are broadened by the continuous and disproportionate discrimination centred on gender, disability itself, geographical environment, sexuality, socio-economic status, and the policies in place. Inasmuch as reducing fertility calls for promotion of access to comprehensive, reliable sexual and reproductive health services (Byarugaba, 2018), it is a futile attempt to address individual problems in isolation from others that cannot contribute to fundamental and lasting change in social systems and relationships that systematically exploit and marginalise groups of people (Liasidou, 2013).

Fear of disability

The magnified nature of disability has generated a lot of fear from primary caregivers, health-workers, and community residents who in reaction tend to draw to harmful practices to either protect themselves or the women and girls with disabilities. This unabating fright over disability and consequent negative attitudes within communities and families of persons with disabilities (Kasozi, 2014), and expectant women and girls with disabilities has forced them to shun use of expert services for safe motherhood in favour of delivery under trees (Sabano, 2019). Presence of ableist practices like “mercy killings”, involuntary sterilisation and abortion in the community coupled with societal attitudes towards disability have infused fear in women and girls with disabilities. Disability might not necessarily hinder one’s emotional development, although other people’s biases and fears can hinder our professional or academic development (Mohler, 2018). Limiting standards can be detrimental because many persons with disabilities tend to accept these misperceptions and see themselves as unable to achieve their goals (Mohler, 2018). It is this fear of disability that has limited women and girls with disabilities from pursuing and exploiting their sexual and reproductive health and rights.

Unequal opportunities

Over the years, the Government of Uganda has created plenty of programs geared towards poverty alleviation including Women Empowerment Program, Youth Livelihood program, Operation Wealth Creation, and the Special Grant specifically for the economic development of persons with disabilities. The entry point to economic empowerment for persons with disabilities is to create an environment that encourages them to develop self-confidence and interact openly with fellow community members (Delfyna, 2019). The disparities in provisions for persons with disabilities and those without are implicative of the stringent measures in effect to gain access to these programs. Persons with disabilities often miss out on the existing programs because they live in isolated rural communities and seldom acquire the requisite information for application (Delfyna, 2019). The Special Grant itself is challenged by limited funds, unclear guidelines for entry and use, complicated requirements to access the grant and misappropriation of funds at district level, (National Council for Disability (NCD), 2018). Lack of disability inclusion in design and planning (Daily Monitor, 2020) incapacitate the intent of the programs for persons with disabilities. Imposition of stringent measures has opposed women and girls with disabilities shifting from subsistence farming to income generating activities availed by the programs. Engagement of organisations for persons with disabilities in the designing and planning of livelihood programs would encourage the inclusion of women and girls with disabilities in livelihood programs since programs would be designed to suit their needs, simplify social inclusion and lead to participation in community health drives.

Inaccessibility

In accessibility in terms of the physical environment and communication work together to become points of exclusion from access to sexual and reproductive health, rights and services for women and girls with disabilities. The state's failure to put in force the Building Control Act 2013 (Odeng, 2017) that would lead to the availability of features like ramps at buildings (Kasozi, 2014) and ease the access of health centres for women and girls with disabilities has constrained them from pursuing their human rights. Besides that information on sexual and reproductive health is rarely available and in the case that it is, the information is hard to access for women and girls with visual impairment because it is neither brailed nor in large print (Casebolt, 2020). For women and girls with hearing impairments, communication barriers are cause for violation of their sexual and reproductive health and rights because they "can't express themselves" (Adubango & Okello, 2015). Denial of access to the physical environment and inclusive communication is in direct violation of the UNCRPD that mandates all member countries to observe the rights of persons with disabilities. Enforcing the Building Control Act, 2013, would ease the movement and access to sexual and reproductive health services for women and girls with disabilities while provision of inclusive communication at health centres and community health drives would empower them into becoming rights defenders.

Gender Norms

The patriarchal structure of Uganda's society has played a role in the violation of sexual and reproductive health and rights for women and girls with disabilities. They are denied the right to information and education on relevant reproductive health products and services because of the superiority of the male child. Negligence of the education of the female child impacts their awareness and knowledge of their sexual and reproductive rights for it leaves them disempowered to become rights protectors and change agents. It is for this matter that there is a 6.3% high fertility rate in women with disabilities of reproductive age in comparison to 5.8% of non-disabled women

(UBOS, 2019), and within heterosexual relationships, the gendered nature of their positions and their relative inability to discuss sex and sexuality put gender problems at the core of the HIV/ AIDS pandemic, (Bhana et al., 2007). Availing similar opportunities to the girl-child through education would lead to a decrease in teenage pregnancies, school retention and reduction in girl-child marriages because of the awareness on her sexual and reproductive health rights.

State conflict between priorities and policy

Conflict between the state's priorities and performance of the policies entrusted with guaranteeing sexual and reproductive health rights for women and girls with disabilities serve to violate rather than guarantee these rights. The sector in charge of overseeing gender equality receives 1% of the national budget (Ministry of Finance, Planning and Economic Development (MOF), 2017) which is shared with other special interest groups for instance children, youth and the elderly. Passivity of key sectors such as health in Gender Responsive Budgeting (Walusimbi, 2019) and government's inability to enforce laws which affect the dignity and integrity of individuals is the greatest failure of Uganda's legal system (Okiror, 2019). State and non-state actors in sexual and reproductive health are operating under the third edition of Uganda's National Policy Guidelines and Service Standards for Sexual and Reproductive Health and Rights which was last reviewed in 2012. As an outdated policy, it lacks the amendments made to the Mental Health Act 2014 and Persons with Disabilities Bill 2018 (Parliament of the Republic of Uganda, 2019) that would oversee the provision of inclusive services for women and girls with disabilities in sexual and reproductive health rights as well as the judicial system. There is a clear need for policy review to include amendments that would protect the sexual and reproductive health rights of women and girls with disabilities as well as an increment in the budgetary allocation for the sector in charge of gender equality. A positive turnaround from both would ensure better service provision and access to women and girls with disabilities.

Actors in sexual and reproductive health and rights

Working hand in hand with the Government of Uganda, Reproductive Health Uganda, Reach A Hand Uganda, and Marie Stopes Uganda are some of the organisations in Uganda doing credible work around sexual and reproductive health rights. However, while persons with disabilities especially women and girls are listed as beneficiaries of these projects, they are often left out of awareness raising trainings by mainstream sexual and reproductive health actors. In instances of inclusion, the lack of initiative to learn about disability and the unique needs that come with it elevates issues of inaccessibility that usually go unaccommodated during interactions with persons with disabilities. The United Nations Development Programme (UNDP, 2018) notes that those who are disadvantaged, unable to understand their rights and have restrictions on their prospects in society relative to others are at risk of being left behind. Such is the case for women and girls with disabilities whose exclusion from mainstream sexual and reproductive health rights programs places their rights beyond reach.

Sexual and reproductive health rights affect all women and men. Inclusion of persons with disabilities in sexual and reproductive health initiatives by different actors besides organisations for persons with disabilities would ensure a wider reach of services and acquisition of knowledge that would enable them exercise their right to reproduce when they wish and make informed decisions pertaining to their bodies without coercion.

Scarcity of data

Service providers in sexual and reproductive health have expressed lack of reliable data on disability prevalence within communities and evidence based research to the sexual and reproductive health needs of women with disability (lee, et al., 2015) as an impediment to inclusive services. A valid concern given that the lack of data on violence against women and girls with disabilities has disguised the practice against them in Uganda and aggravated their exclusion. ‘Violence against women and girls with disabilities is not just a subset of gender-based violence - it is an intersectional category dealing with gender-based and disability-based violence’ (Akina Mama Wa Afrika, 2017). Uganda’s population has grown since the national population census of 2014 that estimated persons with disabilities at 12.4%. The enactment of sexual and reproductive health initiatives in the absence of reliable data on disability pre-empts the success of some initiatives for women and girls with disabilities. Provision of sex and disability disaggregated data would lead to better policy formulation, planning and development of interventions geared towards violence against women and girls with disabilities.

CONCLUSION

Basing on the above; Uganda has not done much to guarantee the sexual and reproductive health and rights of women and girls with disabilities as evidenced by their experiences. Several factors such as gender, socio-economic status, ableism, and location work concurrently to undermine their attempts at championing their human rights. At the core of the violation lies discrimination, stigma attached to disability and lack of knowledge on disability by the primary caregivers, health-workers, and community residents. Institutionalisation of policies like the Sustainable Development Goals and Uganda's National Sexual and Reproductive Health and Rights Service Guidelines and Standards, third edition, 2012, that deny the marginality and heterogeneity of different users discourage the mandates of the policies and by-laws. Furthermore, the lack of awareness on the legal instruments certifying human rights like sexual and reproductive health and rights by women and girl with disabilities compounds the ineffectiveness of these legal instruments towards the people they are to protect. While the empowerment of women sits atop the global agenda, the consistent inequities faced by women and girls with disabilities in achieving their fundamental freedoms of sexual and reproductive health and rights stand to thwart gender equality and achievement of vision 2030 for Uganda. Since Uganda ratified the United Nations Convention on the Rights of Persons with Disabilities, it is imperative that the government of Uganda ensure equitable access to sexual and reproductive health and rights for women and girls with disabilities.

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