

**ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH OF PEOPLE WITH
INTELLECTUAL DISABILITIES IN NAIROBI CITY COUNTY**

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DECLARATION

This research project is my original work and has not been presented for examination in any other University.

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Abbreviations and Acronyms

AAIDD – American Association on Intellectual and Developmental Disabilities

AIDS – Acquired Immunodeficiency Syndrome

CRPD- Convention on the Rights of Persons with Disabilities

DARU – Disability Advocacy Resource Unit

HIV – Human Immunodeficiency Virus

ID – Intellectual Disability

IDEA – Individuals with Disabilities Education Act

IDI – In-Depth Interviews

IQ - Intellectual Quotient

KII – Key Informant Interview

KISE-Kenya Institute of Special Education

KNBS-Kenya National Bureau of Statistics

MDG- Millennium Development Goals

MoH – Ministry of Health

PWD – Person with Disability

PWID – Person with Intellectual Disability

SDG – Sustainable Development Goal

SIS – Supports Intensity Scale

SGBV – Sexual and Gender Based Violence

SRH – Sexual and Reproductive Health

SRHR – Sexual and Reproductive Health and Rights

STI – Sexually Transmitted Disease

STI – Sexually Transmitted Infection

UN – United Nations

UNFPA – United Nations Population Fund

WHO – World Health Organization

WWD – Women with disability

YPWD – Young People with Disabilities

Abstract

Sexual and reproductive health (SRH) is a human rights issue. Accessing SRH information and services provides individuals with the capacity to make informed choices regarding their SRH thus avoiding sexually transmitted infections and unwanted pregnancies. While most research on the SRH of people with disabilities focuses on women, this research employed an all-inclusive approach targeting both men and women. The study focused on identifying the specific SRH needs of people with intellectual disability (ID), and the challenges they encounter while accessing SRH information and services. The study adopted an exploratory-descriptive study design and utilized the human rights framework of understanding disability. Data was collected qualitatively through in-depth and key informant interviews. Data coding and analysis was done through Nvivo which grouped information thematically along the lines of specific objectives. The findings indicate that people with ID are not asexual as popularly believed. It further revealed that people with ID too have SRH needs and rights as stipulated by the UN Convention on the Rights of Persons with Disabilities. Access to SRH information and services was the main challenge people with ID face since they lacked reliable sources of information, and such topics were rarely discussed around them as they were considered asexual. Creating awareness of sexual and gender-based violence among people with ID was considered vital to protect them against sexual exploitation due to their vulnerability. The study recommends for capacity building among the IDs themselves as well as among the health providers to end stigmatization which was the main barrier affecting people with ID as they sought SRH services. This will enable the health workers to provide inclusive SRH services and to sensitize communities against the discrimination of people with ID in their search for SRH services.

1.0 Background to the Study

This chapter introduces the topic and highlights the various key components of access to sexual and reproductive health of people with intellectual disabilities in Nairobi City County. The section contains the specific objectives, research assumptions, study relevance as well as the scope and limitations.

1.1 Introduction

In 2020, it was anticipated that over a billion people were disabled all over the world. This translates to over 15% of the world's population with about 190 million people who are 15 years and above facing significant challenges in functionality thus requiring the utilization of health services (Cieza et al., 2020). Due to the ageing society, the number of people with disability is increasing (Cieza et al., 2020). Globally in 2021, people with disabilities face discrimination and marginalization due to the structure of ableism within societies. According to WHO (2011), this marginalization affects individuals with disabilities in a variety of ways: they have poor clinical outcomes, educational outcomes, financial opportunities, and increased levels of poverty as compared to other individuals in society.

Intellectual Disability (ID) is described as a condition typified by significant deficits in cognitive and adaptive capacities (Schalock, 2010) it begins before an individual is 18 years of age. According to Special Olympics International (2021), globally between 1% and 3% of people of around 200 million suffer from intellectual disability. An estimated 1 to 3% of the population living in the West have an intellectual disability. Mild disabilities might continue without being detected until years later, making it impossible to pinpoint the exact time of occurrence. The

prevalence of intellectual disability in males is 1.5 times more likely than in females between 10 to 14 years of age (Maulik et al., 2011).

According to Harris (2006) and Maulik et al. (2011), low-income nations have the highest prevalence (16.41/1000 people), while middle- and high-income nations have 15.94/1000 and 9.21/1000 people, respectively. Furthermore, compared to an adult population (4.94/1000), the frequency of ID is higher in the young adolescent population (18.30/1000).

Person with Intellectual Disability (PWID) are even more disadvantaged since evidence from epidemiological studies suggests that they are also more susceptible to mental and physical illnesses than the general population (UNFPA, 2021). ID is associated with a variety of neurodevelopmental, psychological, and medical issues, including epilepsy, communication impairments, learning difficulties, cerebral palsy, and a variety of genetically transmitted diseases (APA, 2013).

Individuals with intellectual disability are frequently stereotyped as asexual, oversexed, infantile, or sexually inappropriate (Frawley and Wilson, 2016). As a result of this cultural perception, people who work with individuals with intellectual disability frequently are inclined to a more 'protective' attitude when dealing with them, which then leads to an invasion of their privacy or their ability to act autonomously (Chappell et al., 2018). A study from Sweden shows the difficulty in establishing an equilibrium between caring and protecting, versus ensuring their rights to sexuality (Lukkerz, 2014). World Health Organization (2009) highlights that the access to Sexual and Reproductive Health and Rights (SRHR) services as limited for individuals with intellectual disability is facilitated by the social exclusion they face rather than disability. This leads to structural discrimination, with things such as negative attitudes towards people with disabilities

(PWD). Inaccessible health facilities serve as a hindrance in preventing PWDs from getting the treatments they require (Nelson, Pettersson, & Emmelin, 2020).

The prevalence of ID in the African context remains unclear. For instance, in South Africa, there is limited specific epidemiological data on people with ID as diverse approaches and definitions are utilized in establishing ID. Formal ID evaluations aren't done very regularly. McKenzie et al. (2013) study in South Africa on people with intellectual disability showed they had restricted access to treatment in healthcare facilities. The needs of individuals with intellectual disability in South Africa are rarely recognized regardless of the services and policies meant to work in their favour as this is an area that is less prioritized. It is critical to recognise the epidemiological knowledge gap, and consequences of disability so as to prepare and cater to the requirements of individuals with an intellectual disability throughout their lives (Adnams, 2010).

The 2019 census in Kenya established that 2.2% of Kenyans have a disability (KNBS, 2019). However, the census did not capture the number of individuals with ID despite incorporating the Washington Group questionnaire that identifies PWDs. The Kenya Institute of Special Education (KISE) conducted a survey in 2016-2017 which highlighted that 11.4% of children aged 2 to 21 years have special needs (Rohwerder, 2020). 3.1% of the Kenyan population aged 3 to 21 years has a visual impairment, 3.0% have a physical disability and 2.5% have intellectual disabilities (Juma, 2018).

About 50% of all Kenyan mothers with more than one teenage birth their Intelligence Quotient (IQ) are usually lower (Migunde et al., 2011). Teenagers with intellectual disability are more susceptible of becoming teenage parents. There is the assumption that they have more pressing health needs and sexual reproductive health (SRH) should not be a priority for them. These youths are already at a higher initiation of sexual engagements at a younger or suffering from sexual abuse

before turning 18 years because of low self-esteem levels and poverty (Jones and Domenico, 2006).

Young people with disabilities (YPWD) at times do not have access to sexual and reproductive health information since it is not extensively communicated. For instance, in numerous developing countries YPWD rarely get any guidance on Human immunodeficiency virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS), because the health facilities are physically inaccessible, materials for the visually impaired are not available, and therapists do not speak sign language. Furthermore, most health care personnel are unaware of handicap issues, thus unable to treat them (Yousafzai et al., 2005).

According to a comprehensive analysis of the incidence of individuals with intellectual disability experiencing sexual abuse, it highlights that between 7% and 34% of them have suffered sexual abuse as an adult with the most common abuser being a peer who has an intellectual disability too (Smit, Scheffers, Emck, Van Busschbach, & Beek, 2019). According to a qualitative synthesis, there is a wide spectrum of sexual abuse and the repercussions might be social, behavioural, or psychological. Unsuitable sexual conversation, self-injury, and poor self-conduct are more prevalent in individuals with ID (Smit et al., 2019).

Individuals with intellectual disabilities in any society face stigmatization and myriad challenges in accessing SRH services. The study aimed to explore the access of sexual and reproductive health by people with intellectual disabilities in Kenya. It investigated the barriers faced by individuals with intellectual disability as they sought to meet their sexual and reproductive health needs as the country works toward implementing universal health coverage. This corresponds with Goal number three of the United Nations Sustainable Development Goals which aims to ensure good health and wellbeing for everyone through improved sexual and reproductive healthcare

information and services as this is incorporated into national forums and strategies by 2030 (Ritchie, Roser, Mispy, Ortiz-Ospina, 2018). It is through the advocacy of SRH for PWIDS that the issues such as the provision of vital health services, HIV, sexually transmitted infections (STIs), maternal mortality, and sexual and gender-based violence (SGBV) will be prioritized.

1.2 Problem statement

People with disabilities require a right to sexual and reproductive health and rights (SRHR) information and services, this was stipulated in the United Nations Convention on the Rights of Persons with Disabilities (WHO, 2009). However, the ability to actualize these rights is limited for those with intellectual disabilities (Chappell et al., 2018). The Ministry of Health (MOH) of Kenya approved the National Reproductive Health Policy of 2009 - 2015 which had the theme: 'Enhancing the Reproductive Health Status for all Kenyans'. It sought to create a framework that would facilitate the delivery of high-quality SRH services that would be effective, efficient, and fair with the emphasis on reaching the most vulnerable people in society like people with ID. Unfortunately, individuals with intellectual disabilities often are left out of accessing the SRH services as these efforts have not been actualized.

The expression of sexuality and sexual behaviour is shaped by and influenced by the standards set by society particularly gender roles and relations (WHO, 2012). Moreover, people with ID continue to face marginalisation, stigma, and disparities in health since their plight is undervalued thus inequities in accessing health services (Hatton & Emerson, 2015). This has served as a major deterrent for a majority while attempting to obtain sexual and reproductive health care as people fear being stigmatized by their communities and social groups as they are considered sexually inactive. In Kenya, the majority of health facilities rarely offer any preferential treatment or specialized care to people with intellectual disabilities who are barely given any special

considerations. As such an evaluation of people who have ID was conducted to detail the specific SRH needs they face. Thus, this study sought to explore the social, economic, and institution-based challenges people with ID (men and women) experienced as they accessed SRH.

The following research questions guided the study:

- I. What are the specific SRH needs of people with ID in Nairobi County?
- II. What socio economic, and institutional based challenges do people with ID face when accessing SRH?

1.3 Objectives of the study

1.3.1 General objective

The study's overall objective was to understand the access to sexual and reproductive health of people with intellectual disabilities in Nairobi City County.

1.3.2 Specific objectives

- I. To identify the specific SRH needs of people with ID in Nairobi City County.
- II. To document the challenges people with ID experience at different levels in Nairobi City County.

1.4 Assumptions of the study

- I. Individuals with intellectual disabilities have sexual and reproductive health needs.
- II. Individuals with intellectual disability encounter challenges in obtaining sexual and reproductive health care as they are assumed to be asexual.

1.5 Justification of the study

Although the topic of PWDs has gained prominence in the recent past, current literature demonstrates gaps in the knowledge about the implications of disabilities for people with ID SRH.

Access to SRH services is a basic human right since it allows people to experience fertility, enjoy partnerships, family, and being parents, and receive information on reproduction and family planning.

The challenge to access SRH services faced by people with ID in Kenya has been almost invisible. This could have been caused by the way society views disability and sexuality. This includes the delusion that individuals with intellectual disability are sexually inactive and are considered as asexual. Additionally, according to popular belief, people with disability do not need sexual relations or intimate personal relations since they do not experience any sexual arousal and they are unattractive as their bodies are ugly (Maxwell et al., 2007). Therefore, the research topic contributes to raising awareness and bringing to light the predicament of individuals with intellectual disability in accessing SRH services. This study has generated useful information that will be critical in informing policymakers and Ministry of Health (MoH) officials and enable them to develop policies that explicitly address the SRH needs of people with ID.

1.6 Scope and Limitations of the study

The study was carried out in Nairobi City County. The research was limited to adults with ID in their reproductive age therefore, the participant's ages ranged between 18 and 45 years.

Relevant data on individuals with ID in Kenya is scarce thus, the study was unable to establish the exact number of individuals with ID in the specific study area. Moreover, the study focused on individuals with mild and moderate ID. Time taken to conduct interviews was longer than anticipated as some participants were restless and it took longer for others to comprehend the interview questions. This was resolved by allowing the study participants to adequate time to express themselves. Furthermore, the qualitative nature of the study meant that only a few participants took part and this has limited the generalization of the study results.

1.7 Definition of key terms

Disability - are long-term consequences of physical, developmental, cognitive, mental, or sensory impairments which inhibit the ability of a person to integrate into society.

Sexual and Reproductive Health – in connection to sexuality, it is a state of total physical, psychological, and social wellbeing in all aspects relating to the reproductive system and its activities and processes. The study expanded the definition to include access to pre-natal and post-natal care, access to maternity services, HIV/AIDS, and reproductive health check-ups for people with ID.

Intellectual disability – Intellectual Disability (ID) is described as a condition typified by significant deficits in both cognitive and adaptive capacities.

Access – it is a term that refers to the freedom, right, or opportunity to benefit from quality care or use SRH services irrespective of someone's status.

2.0 CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter gives a general overview of literature on intellectual disability (ID). It highlights the specific needs of people with ID, and challenges people with ID encounter while seeking sexual and reproductive health (SRH) services in Nairobi City County, Kenya for clearer understanding of the topic. This chapter also contains the theoretical and conceptual framework that the study adopted.

2.2 Understanding Intellectual Disability

The concept of intellectual disability is based on highlighting severe impairments that significantly limit cognitive functioning and adaptive behaviour. It must also be evident before the age of 18 (Schalock, 2014). Intellectual disability shouldn't be considered a disease since one person cannot infect another. It can't be categorized under mental illness, such as depression (Tsiouris et al., 2011). Intellectual disability cannot be cured. Intellectual disability does not prohibit children from learning and exploring new activities, they just require more effort and time as compared to other children (Schalock, 2014).

ID is also called cognitive disability or mental retardation. According to the U.S. Department of Education (2010), the latter was dropped in October 2010 when the Rosa Law was signed by President Obama, used in the Individuals with Disabilities Education Act (IDEA) as the name to refer to people with ID. It had a negative connotation to it as the people associated with it used to be victims of discrimination thus misconceptions arose around the nature of the disorder. Rosa's Law ensured that "intellectual disability" was the new terminology to use. The meaning remained the same. Thus, "intellectual disability" can be defined as slightly below average in cognitive capabilities accompanied by adaptive behaviour that is manifested during the developing phase

and has a negative impression on a child's academic performance (U.S. Department of Education, 2010).

2.2.1 Forms of intellectual disability

Down syndrome, autism, fragile X syndrome, and developmental delay are the most common ID forms. Genetics has a significant role in ID (APA, 2013). According to Parker et al. (2010) down syndrome in the United States is the most prevalent form of intellectual disability caused by genetics, and occurs nearly once every 700 live births. According to Coffee et al. (2009) Fragile X syndrome which affects one out of every 5,000 males is the most renowned genetic cause of ID. Exposure to hazardous materials, dietary inadequacies, paediatric brain infections, injury to the brain, and maternal illnesses are all examples of environmental variables that might cause ID. Additionally, pre and postnatal complications may lead to brain injury resulting in ID (Gustafsson, 2003).

2.2.2 Classification of ID

The American Association on Intellectual and Developmental Disabilities (AAIDD) has come up with a scale for assessing the extent of ID, the Supports Intensity Scale (SIS). Instead of characterizing severity by deficiencies, the SIS focuses on the different kinds and degrees of support required to enable an individual to live independently. The SIS assesses an individual's assistance needs across a scale of 49 life activities. These activities include home and community, learning, formal work/ job, social engagements, and, health and safety (APA, 2013).

Intellectual disabilities range from mild, moderate, and severe to profound and they limit cognitive functioning, which manifests in form of impairments in adaptive functioning. People who have mild ID progress slower in cognitive development as well as and day to day life activities (Shree & Shukla, 2016). These people can gain everyday life skills that allow them to

live like the rest of the population requiring minimal assistance (Shree & Shukla, 2016; Sattler, 2002). Individuals with moderate ID can learn practical skills which enable them to tend to themselves. Severe ID manifests itself as significant developmental challenges but they can comprehend speech although their communication skills are limited. Supervision is usually required when dealing with people suffering from severe ID despite their ability to learn daily routines and practice self-care (Harris & Greenspan, 2016; Sattler, 2002).

2.3 Specific SRH needs for people with ID

Sexual and reproductive health is a critical component of overall public health since it forms the basis of life cycles. SRH does not only refer to the absence of disease but it also covers the process of conception to birth and the other hygiene precautions required to maintain a healthy lifestyle among people (Tanabe, Pearce & Krause, 2018).

SRH among individuals with ID has not received enough attention since the approaches used do not account for the specific needs of ID patients. The SRH needs of these individuals are most of the time ignored in different social settings with caregivers uncertain of the approach to use (Powell et al., 2020). Although sexuality is an integral part the components of being human health professionals, people closely related to People with ID believe that romantic or intimate sexual relationships are not necessary between two people with ID hence making them label such people either as asexual or hypersexual (Kramers-Olen, 2016). A multitude of misconceptions, biases, and stereotypes collide in ways that negatively impact people with ID (Kramers-Olen, 2016). However, access to SRH should be all-inclusive and not discriminate. Since without access to SRH education, the magnitude of risks such as succumbing to sexual abuse or contracting sexually transmitted illnesses escalates (Ngilangwa et al., 2016).

Individuals with ID too can have sexual experiences although in some cases, some may have a negative perception of sex, which underscores the need to adjust the existing sexual education strategies for maximum inclusion. People with ID decision-making ability and experience are limited since they lack the appropriate skills necessary to establish healthy relationships and sexual limits (Diah & Samsudin, 2020). Therefore, providing sexual education for individuals with ID can be one of the most effective ways of achieving inclusion in SRH. More so, it is impossible to overestimate the significance of sexual health information for individuals with intellectual disability since a lack of information might raise the possibility of STIs and sexual exploitation (McDaniels & Fleming, 2016).

2.4 Access to SRH among individuals with ID

Access denotes to the ability to receive quality care and SRH services irrespective of someone's status. Kenya has made significant progress in addressing matters about disability on local and international conventions to facilitate the creation of national laws that emphasize the need for equal opportunities for all. For instance, the Persons with Disabilities Act (PDA) 2003 highlights that people with ID have rights and can be rehabilitated for harmonization of opportunities and established the Council for individuals with Disabilities at the national level. The Act also protects the rights of PWDs at every stage of life and therefore, they must be accorded specialized care to ensure that their sexual rights are fulfilled among other needs. The goal is not only to focus on equitable treatment and allocation of opportunities for PWDs but also to eradicate conscious discrimination and reform policies that discriminate against them (KNBS and NCAPD, 2008).

Jadoha and Pownall (2014), conducted a comparative study seeking to understand the social relations among 30 youths with mild levels of ID and 30 people from the wider population. The results showed that the intellectually challenged students were less informed on sexual matters. It

further revealed that the young women suffering from ID were not well informed as to their male counterparts which highlighted gender disparity. Addressing SRH successfully requires in-depth understanding thus increasing the necessity of special education as a means to end the stigma and marginalization of individuals with ID. Individuals with ID often speak about the longing of receiving support when they get into relationships with caregivers (Bane et al., 2012). Sex education is essential for young people to develop sexual agency (Egan and Hawkes, 2009). It helps the youth gain information and skills vital to better perceive themselves as sexual beings and opt for choices that support SRH (Robinson, 2013). Around the world, school-based sexuality education can reach a lot of young people (Kivela et al., 2011).

2.5 Challenges faced by ID patients in accessing SRH services

Although there is a growing understanding and acknowledgment of persons with ID's rights to live normal lives and make personal decisions, enjoying sexual freedoms are typically restricted in comparison to other handicapped people or the general community (McCabe, 1999). It might partly be because of concerns from families which fear exploitation, STIs, and instances of pregnancy (Pownall et al., 2012). However, this might reflect residual infantilizing perceptions and stigma from society toward Individuals with ID (Evans et al., 2009).

Most times, the challenges that face individuals with ID is lack of legal help, social inclusion, support and understanding. Sexual education lacking emanates from the policies that limit the flow of information to the people that need it the most (Tanabe, Nagujjah, Rimal, Bukania & Krause, 2015). People with ID remain ignorant about their bodies and their rights to express what they want and may also experience difficulties in interacting with potential partners.

There is a scarcity of information on sexual health curricula for individuals with ID that is both effective and empirically valid (McDaniels & Fleming, 2016). When it comes to sexual health

education, it is often taught in response to a specific incident rather than before problems arise (Schaafsma et al., 2015). More investigation is required to determine the prevalence of harmless and dangerous sexual practices as well as the various factors influencing this population's sexual health knowledge (Borawska-Charko et al., 2017). Thus, additional information will be necessary, especially on the consequences of shame and social isolation of people with ID and sexual experiences (Borawska-Charko et al., 2017).

Individuals with ID are more probable to have fewer friends than the general population since they rarely socialize (Gilmore & Cuskelly, 2014). They require assistance with daily duties and living with caregivers or parents may hinder people with ID from forming autonomous friendships or building sexual relationships (Gilmore & Cuskelly, 2014). One of the most common perpetrators of abuse is when an individual with ID depends on the people that abuse them (Powell et al., 2020). According to various studies, people with intellectual disabilities believe that developing personal connections is more profound with other people who also have intellectual disabilities (Gilmore & Cuskelly, 2014).

Most parents whose children have ID are reluctant to discuss sexual matters with them. When parents of children with ID notice their children engaging in abhorrent behaviour such as public indecency that is when they openly talk about sexuality. Their major concerns as parents are socially inappropriate behaviour, menstrual management and abuse (Menon & Sivakami, 2019).

Pownall et al. (2020) highlights mothers of adolescent youths with ID discussed fewer sexual matters than mothers of adolescents without ID. They began these talks later in life and voiced more concerns about sexual susceptibility compared to the mothers of the other adolescents without ID. Families believed that withholding facts from their adolescent youths was in their best interest as they were shielding them from possible exploitation. They also said that the children

lacked the same sexual impulses as the other adolescents who were their age-mates, and were uninterested in dating. This was especially true for the mothers of daughters who felt more vulnerable to getting pregnant.

Persons with ID continue to have a negative attitude regarding parenting. Those attitudes might have an effect on the accessibility of competence-based support for parents and their offspring with ID (Aunos & Feldman, 2002). Moreover, most programs focus on pregnancy prevention as opposed to preparing people with disabilities for having children of their own (Aunos & Feldman, 2002).

Lack of or limited SRH awareness among individuals with ID and their caregivers propagates the underlying risks regarding sexuality to prevail, which emphasizes the importance of this research in advocating for efficient SRH education for intellectually challenged people. Caregivers of children with ID consider sexuality issues a taboo subject (Tanabe et al., 2018). Although support personnel have a higher possibility of discussing the issue of sexuality and partnerships with persons with ID, some staff are hesitant because they lack the appropriate training on the subject, conflicting parental preferences, a deficiency of structural policies, as well as lack of trust (Evans et al., 2009).

Due to lack of resources, education and a shortage of health care professionals and health centres access to SRH services is limited in low- and middle-income countries. There are socio-economic, physical and cultural barriers that prevent people with ID and their caregivers from receiving the necessary SRH services. Some of these factors include; negative attitudes from caregivers, poor coordination among healthcare providers, limited funding and lack of physical access to clinics and social amenities (Adugna, Nabbouh, Shehata & Ghahari, 2020).

In a participatory study conducted in a humanitarian setting including individuals aged between 15-19 in refugee situations in Nepal and East African countries: Kenya and Uganda with physical intellectual, sensory, and mental impairment the barriers identified in accessing SRH services were the distressing factor where the health providers were being disrespectful (Tanabe et al., 2015). Discrimination against expectant women with disability was perpetrated by the health workers and chastised on the pregnancy and giving birth. Nuptial status played a significant role in determining whether or not a pregnancy was approved (Tanabe et al., 2015). Across the board, there was high risk of sexual violence, particularly for people with ID (Tanabe et al., 2015).

Engaging people with intellectual disabilities requires privacy for them to discuss their SRH needs openly and confidently. Reporting sexual abuse may be difficult for people with communication difficulties thus limiting response measures. Although people with ID have similar sexual interpersonal demands as other normal people, they do so in different ways, as there are limiting factors to their ability to form healthy relationships. People with ID require reliable social support and sexual education for them to have safe, healthy relationships and constructive sexual expression (Gilmore & Cuskelly, 2014).

2.6 Theoretical Models to Disability

There are three basic models to understanding disability. The three are the Charity, the Medical and the Human Rights Models

2.6.1 The Charity, Medical, Social and Human Rights Models of Disability Interventions

Charity Model of Disability

This model refers to Disability as victimhood. This model clusters individuals with disabilities under the category of victims. Their state is depressing as they are suffering. People who are able-

bodied should help them since they require specialized care which makes them different (Duyan, 2007). The charity model of disability proponents is typically charitable organizations and institutions or individuals who believe disability is a personal tragedy and that individuals with disability need help (Duyan, 2007).

Medical Model of Disability

According to Thomas & Woods (2003), the medical model is also termed the personal tragedy model (Retief & Letšosa, 2018). Disability is viewed as inherently bad, as a pitiful condition thus the name personal tragedy because it is a loss to both the individual and their family. The model considered disability as that which could be avoided and in other instances remedied (Carlson, 2010).

According to the medical model of disability, PWD differs from what is considered normal in society, thus the model conveniently came up with terms like an invalid, handicapped and retarded (Creamer, 2009). This viewpoint on disability affirms the notion that individuals with disabilities are not at the same level with their peers in society. Johnstone (2012) states that this approach promotes dualism that categorizes able-bodied individuals to be superior to those with disabilities.

Health experts that follow the medical approach perceive people as issues to be resolved, sometimes not considering the aspects that affect the person's life in general (Thomas & Woods, 2003). Kasser & Lytle (2005) emphasize that the medical approaches pays emphasis on a individual's limitations that inherently assumes settings that increase or negatively impact an individual's ability to function.

The medical approach places considerable authority on medical specialists who use the above-mentioned criteria in diagnosis because the criteria was developed from the standpoint of what is thought to be normal in society (Thomas & Woods, 2003). Nonetheless, since many PWDs will never be cured of their condition, medical practitioners who follow the medical approach sometimes see PWD as an embarrassment to society (Pfeiffer, 2003).

Social Model of Disability

The social model of disability views disability as a result of social and environmental factors rather than inherent personal defects (Degener, 2017). According to the social model disability cannot to exclusively associated with an individual's disability but it is attributed to the inaccessible physical environments, lack of inclusive policies and laws, and discriminatory attitudes (Degener, 2017). It emphasizes that society should strive to remove these barriers and actively promote inclusion and equality for all disabled individuals.

Human Rights Model of Disability

Basic human rights principles govern the human rights model. It was developed in 2006 by the United Nations (DARU, 2019). The framework acknowledges that disability is a natural component of human diversity. It should be accepted and embraced in all its forms as PWD have the same rights as everyone else. It further asserts that disability must not be considered as criteria for infringing on other people's rights.

This model gains its affinity from the social model although there are some glaring differences. Primarily, the social model ensures individuals comprehend the social structural influences that determine our perception of impairments, the human rights model goes further to explain,

establishing a theoretical outline for an impairment policy that emphasizes human dignity of PWDs (Degener, 2017). Generally, the social concept sceptical programs for public health that push for prevention of impairments, the human rights approach acknowledges the fact that well-structured preventative policy could be viewed as a kind of human rights protection for people with disabilities (Degener, 2017). Finally, the human rights model gives practical suggestions on improving PWDs ' living conditions (Degener, 2017) whereas the social approach highlights the fact that individual persons with disability are poor. The research therefore, adopted the human rights model to guide the study.

2.6.2 Relevance of the Human Rights Model to the study

The study adopted the human rights framework of disability. The theory applied to the study since the study examined the specific needs and challenges faced by people with ID which served as an impediment to their access to SRH services. It operates from the premise that people with ID also have rights that must be respected.

The medical framework on disability views PWD as people who need to be fixed. It addresses the concept of ableism which negatively depicts intellectual disability. This negative attitude towards disability has resulted in dubious medical operations for disabled persons, such as involuntary sterilization and death (Retief & Letšosa, 2018). The social approach on disability acknowledges systemic barriers, social exclusion and humiliating attitudes that are characteristic to make it difficult for people with disability to accomplish their goals (Okiyo, 2010). The human rights approach was therefore, used to examine the specific challenges faced by people with ID in accessing SRH. The charity model of disability addresses the concept of how able-bodied people view individuals with ID as victims of their circumstances and feel obliged to offer help. They end

up creating stereotypes about people with ID which always have a negative connotation and impedes their access to SRH services. The human rights disability model, unlike the other two, acknowledges that disability is an important aspect of human diversity and that PWD is entitled to the same right as everyone else. The measures that governments must abide by to defend and protect the rights of PWD are explained in this model (Korolkova & Anthony, 2016). This addresses the aspect of advocacy in creating access that is equitable for SRH services for individuals with ID.

Conceptual Framework

The study was guided by the conceptual framework in figure 2.1 below

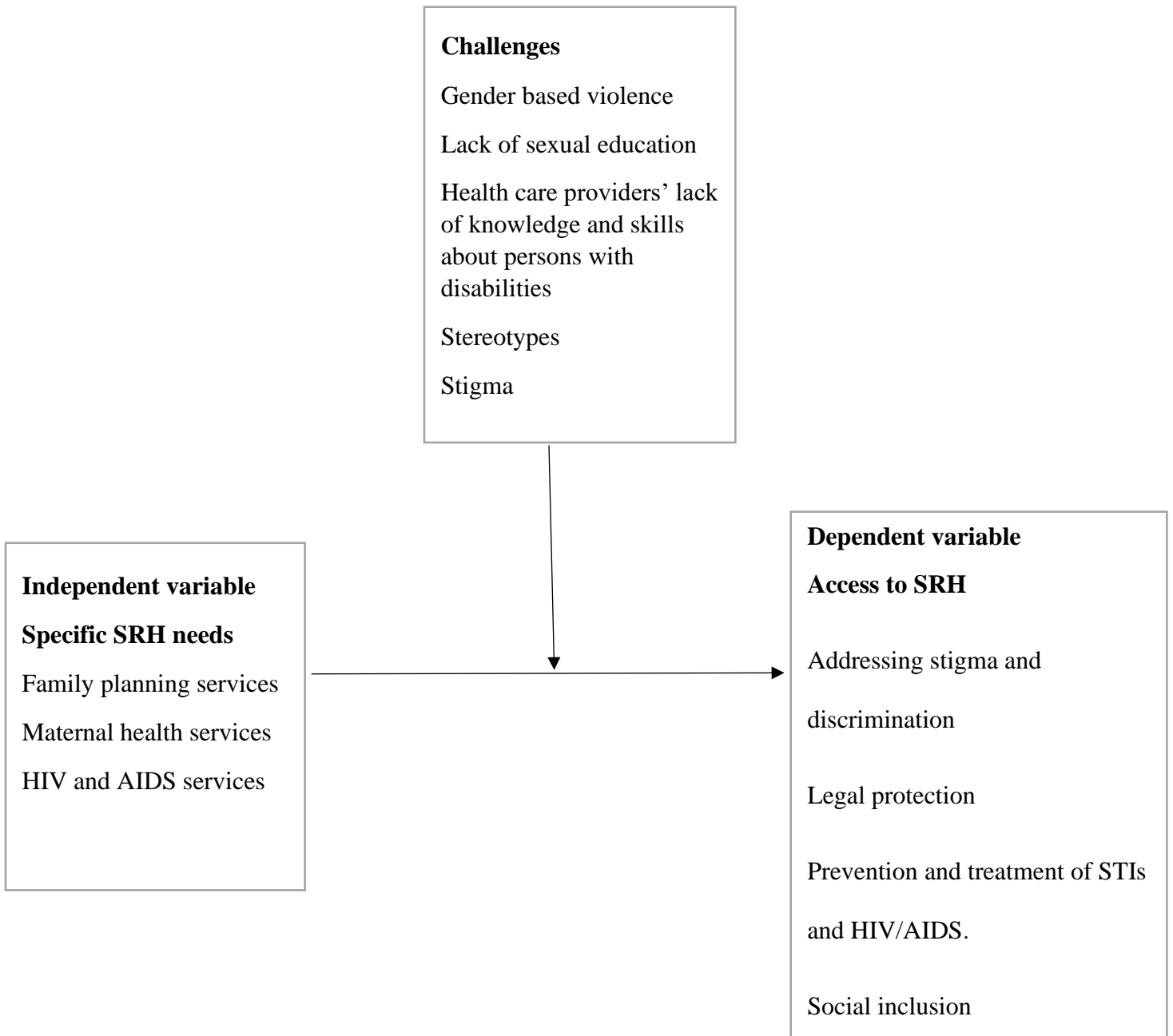


Figure 2.1: Conceptual framework

3.0 CHAPTER THREE: METHODOLOGY

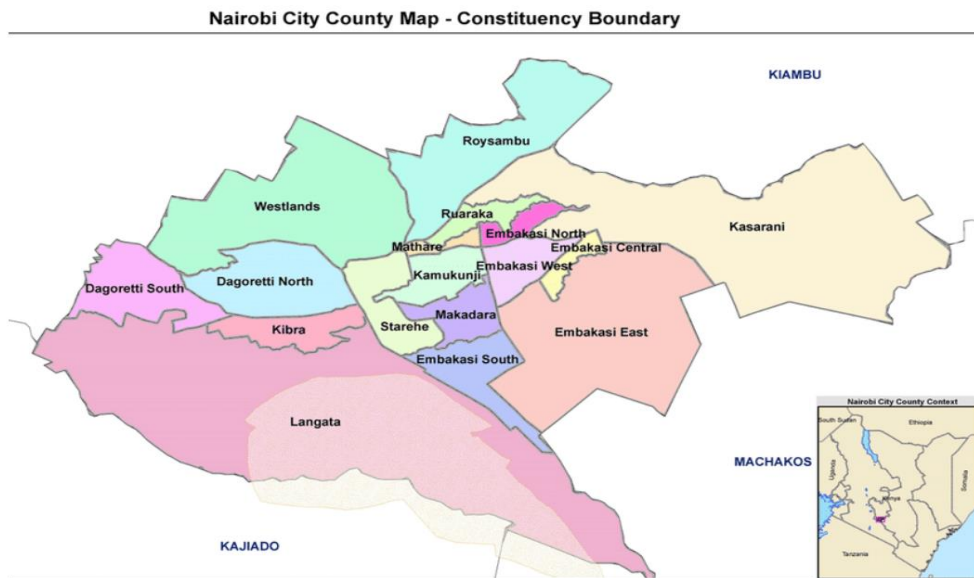
3.1 Introduction

This chapter includes the methodological approach that guided the study.

3.2 Research site

The research was anchored in Nairobi City County.

The prevalence rates of disability in Kenya as determined by the 2019 census showed that people who live in rural areas and those who live in cities have disability rates of 2.6% and 1.4% respectively (Owino, 2020). In Nairobi County, 0.2% of the population presented cognitive difficulties while 0.1% presented self-care difficulties (Owino, 2020). Generally, there is limited data in Kenya on individuals with ID accessing SRH services. The research site in Nairobi City County was within Special Olympics Kenya, Mama Lucy Hospital and Mbagathi Hospital



Nairobi City-County map showing constituencies and associated boundaries.

Figure 3.1: Map of Nairobi County

Special Olympics is an international organization that attends to athletes with ID. Special Olympics Kenya was founded in 1978 and was the first program to be established in Africa. In 2016, Special Olympics had 57,476 registered Athletes and Unified Partners (Masila, 2018). Special Olympics liaises with Mama Lucy Hospital and Mbagathi Hospital since they are both located in Nairobi city. These are the two facilities they refer individuals with ID who require health care services.

Mbagathi Hospital was established in the 1950s to treat infectious diseases that required isolation such as Tuberculosis and Meningitis. It is now the equivalent of a level five hospital.

Mama Lucy Kibaki is a level 5 hospital located in Embakasi Constituency. It was established in 2011 and officially opened in 2013. The hospital offers both outpatient and in-patient services.

3.3 Research design

The study adopted an exploratory-descriptive study design that utilized a qualitative research method approach in the exploration of the specific requirements and needs of individuals with ID and the challenges they face in search for SRH services within Nairobi City County. The study sought to get in-depth information on the experiences of people with ID accessing SRH services considering there is little information on this topic. The study utilized in-depth interviews and key informant interviews as methods of data gathering. The participants were recruited from Special Olympics Kenya through purposive sampling.

The key informants included health workers and individuals who directly work with people with ID in their pursuit of SRH services.

3.4 Study population and unit of analysis

The population of the study consisted of women and men with ID who were within the Special Olympics selected facilities as already noted. The unit of analysis was the individual person with intellectual disability.

3.5 Sampling

Purposive sampling was used in identifying the informants. The study reached out to 20 participants both men and women. Eligibility criteria for the study was that the individual had to have mild or moderate ID. The study included both men and women aged between 18 to 45 years of age since they are in their reproductive ages. The participants in the study had to be holders of the disability card issued by the National Council of People with Disabilities.

Besides the individuals with ID, the study also purposively selected key informants based on their official duties and those who are constantly interacting with individuals with ID including the healthcare providers as well as the people in the education sector.

3.6 Data collection and procedures

In-Depth Interviews and Key Informant Interviews were utilized in the study to provide a deeper understanding of the specific needs of the individuals with ID as well as the challenges they face in accessing SRH services in Nairobi City County.

3.6.1 In-Depth Interviews

The study used in-depth interviews to collect information from the people with ID. IDIs entail thorough individual interviews with a few participants to explore a situation. 20 participants were interviewed and their experiences noted. The interviews sought to interrogate the specific challenges individuals with ID encounter while accessing SRH services in Nairobi City County.

3.6.2 Key Informant Interviews

The study used Key informant interviews alongside the IDIs. The KII focused on six informants who were selected based on their knowledge and expertise on the study topic. The KIIs targeted some personnel who worked with individuals with ID including a Special Needs Education Teacher, a nurse, a community health volunteer, staff working in an organization providing GBV prevention and interventions, also a Health Officer in charge of reproductive health services and Disability and Rehabilitation Officer from Nairobi Metropolitan Services. These people who are responsible for guiding people with ID and providing SRH services provided insights into access to SRH services for people with ID.

3.7 Data processing and analysis

The qualitative data gathered from IDI and KII was transcribed and translated where necessary and transcripts reviewed to ensure quality. Along the transcripts, the field notes were also converted into text. Codes were assigned to words and phrases in each response and a code tree developed from the review of the different transcripts to identify emerging themes. Coding was done using the Nvivo software and themes were directly drawn from the data as guided by the specific objectives. The study results were presented via direct quotations and narratives.

3.8 Ethical considerations

Ethical principles governing social research, as well as breaches of the principles, are centred around a few themes that repeat in different ways. The different research breaches include failure to seek consent, injuring the participant, breach of privacy, and use of deceit (Crandall et al., 1978).

This study aligned with the human rights principles outlined in the UN Convention on Rights of Persons with Disability (CRPD). These are values that should be upheld as they prioritize essential

individual autonomy, respect and freedom for an individual to make their own decisions, fairness, and inclusion, by honouring the difference (CRPD, 2006).

This study also adhered to the Ethical guidelines used in research when working with People with Disabilities underscoring the importance of reminding participants with cognitive limitations of the purpose and the implications of the research and providing them with simple easy-to-follow information. For those with difficulties in remembering and concentrating, the interview did allow short breaks every ten minutes to facilitate their participation (National Disability Authority, 2009).

The study's aims and procedures were disclosed to the study participants. Participants were informed of their rights. They were also informed about the fact that participation in the study was optional with an assurance of their ability to leave at any given point without facing any repercussions. All other relevant information including any foreseen or anticipated risks and how to tackle them in case they occur, and any benefits or compensations to be accrued from the exercise was provided beforehand. The participants were assured of anonymity and confidentiality of their data if they choose to participate in the study. It was made clear that anything they say will remain confidential within the research circles and would be used only for the intended purposes.

4.0 CHAPTER FOUR: PRESENTATION, ANALYSIS, AND INTERPRETATION OF RESULTS AND DISCUSSION.

4.1 Introduction

This chapter presents the findings of the study on the access to the sexual and reproductive health of people with intellectual disabilities in Nairobi City County. The chapter presents the socio-demographic characteristics of the study participants coupled with in-depth insights into the specific SRH needs of people with ID. It also focuses on the different challenges people with intellectual disability in Nairobi City County face as they seek to receive sexual and reproductive health services.

4.2 Demographic characteristics of the respondents

This section describes the traits of the respondent's form of disability, marital status, level of education, and number of children.

4.2.1 Age of participants

The study participants ages are significant as individuals who are under the age of 18 years are considered minors and might not use the SRH services that were subject in this study.

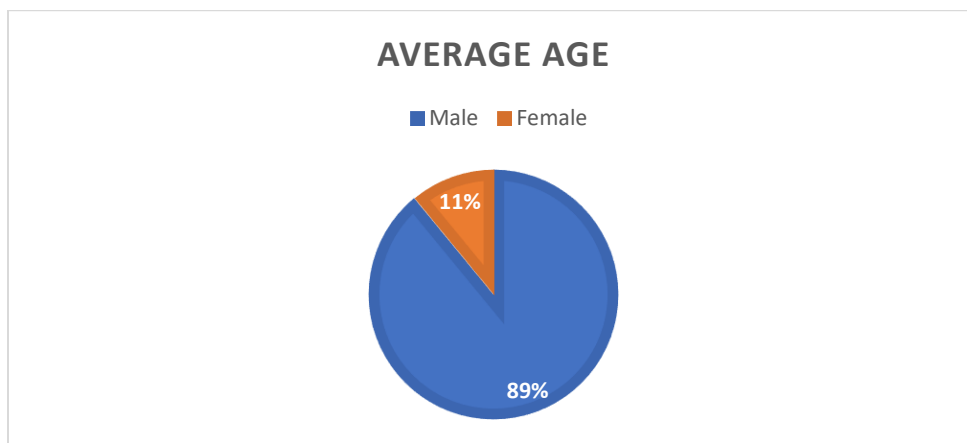


Figure 4.1 Age of participants

4.2.2 Marital status

Marital status is an important aspect to consider when studying people with ID seeking SRH services as it highlights other issues affecting them. Table 4.1 shows that none of the female participants were married while 4 of the 10 men were married. While 13 of the 20 participants were single with 3 men as separated from their spouses.

Table 1: Marital status

Marital status	Male	Female	Frequency
Single	6	7	13
Married	4	0	4
Separated	3	0	3

4.2.3 Level of education

When working with people with intellectual disability education is a crucial aspect as it is considered that people with low levels of education have a hard time SRH. People with disability at times have a hard time making decisions, and their social skills too might affect their ability to seek SRH services.

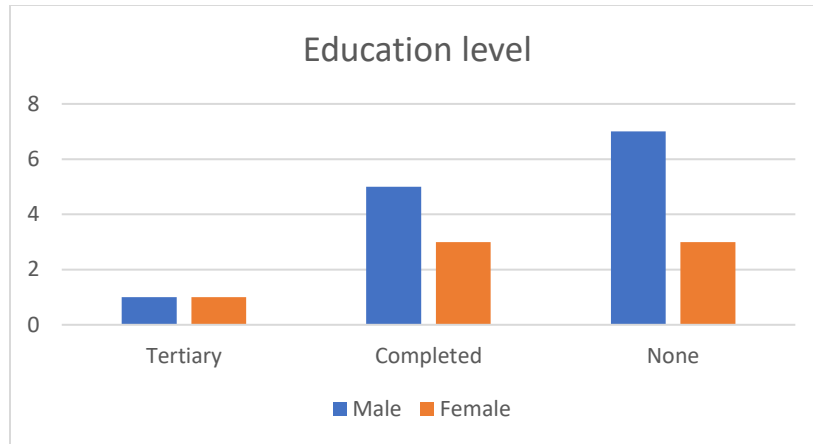


Figure 4.2 Level of education

Figure 4.2 shows that only 2 of the 20 study participants had attained tertiary level of education while 8 of the 20 participants had completed the special education system for people with ID. 10 of the 20 the study participants had not completed their special education which could be attributed to their intellectual disability. The evidence from the study highlighted that the challenges faced by people with ID in seeking SRH services were not related to their academic level.

4.2.4 Number of children

None of the female participants in the study had children while 7 of the 13 male participants had a child. The female participants highlighted during the informal discussions that they were encouraged to use family planning to avoid any unwanted pregnancies.

Table 2: Number of children

Gender	Number of study participants	Number of children
Male	13	7
Female	7	0

The lady who indicated that she has been on family planning pills opined thus:

“I received this information from my sister on family planning, and also I went to seek this information from Makadara Health Centre after I got pregnant when I turned 26 years old to avoid getting pregnant again”. (IDIF 2322)

“I am 31 years old, and I am married with two sons. I suffer from intellectual disability, but my biological parents play an active role in supporting my wife and me in caring for our children”. (IDIM 1422)

4.2 Specific SRH needs of people with ID in Nairobi

Accessing SRH is mandatory for everyone, and people with intellectual disability are not an exception despite the misconception defining them as asexual. People with ID are vulnerable and face various forms of discrimination thus, they require specialized SRH care as discussed in the subsequent section.

4.2.1 Accessing Health Facilities

According to the study findings, all the study participants accessed health facilities. 12 of the 20 the study participants had to be accompanied by someone to the hospital, mainly by guardians. The guardians consisted of nuclear family members, extended family members and teachers from special education institutions. Furthermore, 50% of these study participants were accompanied by their guardians into the consultation room to assist them in better communicating their health needs to the health worker.

“I am a 22-year-old man, and I have an intellectual disability. Usually, my parent accompanies me to the hospital, and my parent talks with the doctor. I am happy when my parent talks to the doctor as they are better at communicating and explaining to the doctor my symptoms”. (IDIM 1022)

“Sometimes I visit unaccompanied and other times I visit the hospital accompanied by my friend or mentor to help me express myself.” IDIM 2222

However, 75% of the study participants wanted to have the autonomy to make the decision on when to visit the doctor’s office and what kind of information to seek considering SRH is a sensitive topic to address in the guardian’s presence. Some of them noted thus:

“I am usually accompanied by my mum and she talks to the doctor on my behalf. I would like to visit the hospital alone so I can feel like an adult who is independent considering that I am 30 years old. (IDIM 1122).

“When I was in school I was accompanied by the dorm mistress during my health check-ups but I went into the doctor’s room alone”. (IDIF 1021).

“People with intellectual disability normally are accompanied to health facilities by their caregivers. This may make them not want to go visit the health facilities as they are uncomfortable with having someone in the consultation room with them while they discuss these sensitive topics on SRH”. (KII 1622).

4.2.2 Access to information on sexual and reproductive health

The study findings highlighted that HIV and SGBV were the two main topics of interest for people with intellectual disability. All the study participants had enquired about HIV and its prevention. The three credible sources of information on this topic were; teachers, family members, and health workers with the latter being considered the most credible source. None of the study participants mentioned leveraging the internet of media or as a resource for knowledge on sexual and reproductive health as depicted in the pie chart below.

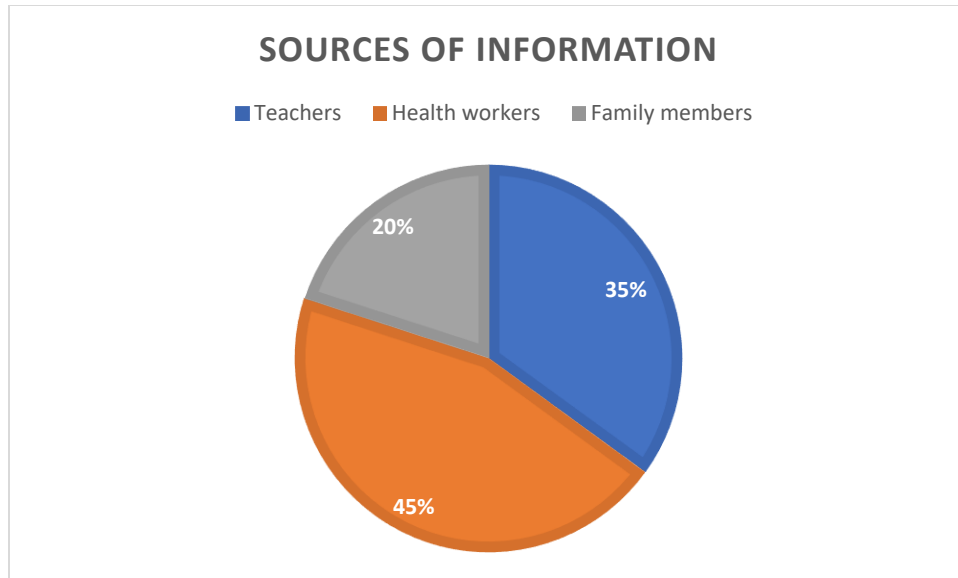


Figure 4.3: Sources of information

Additionally, there was a consensus on the need for more avenues for sharing information on SRH to people with ID to ensure the end of the stigmatization and misconceptions associated with people with ID who are considered asexual as illustrated in the excerpts below:

“Since most people with ID cannot read, posters with images should be put up in health facilities to give them information on the services that are available e.g. family planning (KII 1422).

“Posters with easy-to-understand SRH information can be put up in public offices such as in chiefs’ offices where the people with ID can access”. (KII 1222).

Study findings showed a huge disparity between women and men with an intellectual disability seeking information on SGBV. 4 of the 7 female participants had sought out information on SGBV compared to 4 of the 13 of their male counterparts which may be attributed to the dogmatic perception that men are less likely to be victims of SGBV.

The following excerpts describe what different informants expressed in regard to their sexuality:

“My mum has taught me how to protect myself from sexual violence. She has taught me to avoid certain people and where to seek help if I ever feel threatened”. (IDIM 1122).

“I was told by a doctor not to allow anybody to lie to me, whenever anyone calls me, I should ignore them as there are men who will trick you and get you pregnant”. (IDIF1022).

“I learnt about SGBV from a friend of mine who was raped and she told me what to do in case it happens to me”. (IDIF 2422).

“I work with adolescents and youth with ID and I know they are vulnerable to SGBV including sexual abuse due to heightened vulnerability, and their predators assume it is highly unlikely for them to be reported” (KII 1222).

People with disabilities face physical limitations that make them fit within the structure of high vulnerability to SGBV, negligence and marginalization (Crooks et al., 2019). A lot of stigma and marginalization come with disability and this causes difficulties in accessing medical facilities, which makes it even harder to create sustainability for the economy under such circumstances. Individuals with ID have a greater probability of sexual exploitation (Fisher et al., 2016). One out of every three every three persons with intellectual disability had experienced sexual exploitation as an adult (Tomsa et al. 2021). According to Smit et al. (2019) 7–34% of people with disability will be sexually abused. Individuals with ID experience different levels of sexual awareness, although they seem to have a restricted concept of relationships and sexuality in general (Jahoda & Pownall, 2014).

4.2.3 Accessing sexual and reproductive health services

According to the study findings, none of the study participants stated their past experiences in seeking SRH services to informing their health-seeking behaviours. Information about HIV was the most sought out service as all the participants had enquired about HIV from health centres, while 14 of the 20 participants had gotten tested. They all agreed that they had heard about HIV and its severity, and that is why they sought more information about the symptoms, prevention, and got tested to learn about their HIV status as illustrated in the excerpts below:

“I had accompanied someone to the hospital and while I was there, I was asked to go and test for HIV. The doctor educated me more on HIV and taught me on how to avoid being infected” (IDIM 1422).

“My girlfriend and I went to get a HIV test in hospital so as to know our status. We were of the opinion that knowing our status was important and could enable us avoid contracting the disease which still has no cure” (IDIM 2222).

“I was taught about this in school. I have also been taught about HIV when I went to get tested in the clinic” (IDIF 2422).

According to Di Giulio (2003), the lack of adequate information for the youth with disabilities on sexuality and disability at home and school is because of communication barriers and worries about the appropriateness of the content and sexuality education as there is the fear of encouraging sexual activities. People with intellectual disability have it, even worse considering that their sexual construct of sex is abnormal (Hingsburger et al., 2002), as individuals with ID have little access to information on SRH or HIV and engage in behaviour that is riskier than other individuals living with disability (Hingsburger et al., 2002). There is inadequate information on the transmission and prevention of HIV among people with different disabilities as well as dangerous

sexual behaviours with males tending to be more aware about HIV than women (Maart et al., 2010). Studies in South Africa had shown teenagers with intellectual disability had little knowledge and unsafe sexual encounter (Gilbert, 2008). The National South African study found that 14.1% of people with disabilities have HIV which was close to the country's overall rate of 16.9% among people between the age of 15 to 49 (Shisana et al., 2009). In the Kenyan deaf population, a 7% HIV surge was recorded (Taegtmeier et al., 2009). Furthermore, a study in Australia found that youthful individuals with ID were less knowledgeable about HIV compared to their non-disabled peers (McGillivray, 1999). According to these studies people with ID are in fact at danger of contracting HIV.

The study identified family planning as the second most sought service although its uptake did not match that of HIV/AIDS which was at 100% while family planning was at 12 of the 20 for the study participants. Seeking family planning services was more prominent among women which was at 4 of 7 as compared to 4 of the 13 male participants.

“People with ID need information on contraceptive use as their caregivers assume they are asexual so they do not teach them” (KII 1522).

“People with ID require information on contraceptives to protect themselves from unintended pregnancies and STIs/HIV since they are vulnerable” (KII 1422).

“I received information about using condoms to prevent myself from getting HIV when I went to get tested for HIV. I also got information about family panning from a doctor” (IDIM 2222).

4.2.4 Psychosocial support in seeking SRH services

According to this study, psychosocial support is referred to as the assistance offered to help patients and their families with their mental, social and emotional needs. All the study participants

appreciated understanding and receiving quality and non-discriminatory care whenever they sought health care services. They highlighted that they dreaded being misunderstood as they would at times associate it with ID. The following excerpts amplify the voices of the informants:

“When I went to get treatment for my legs, I also had to get tested for HIV and was told I was negative. I also asked the doctor about how I can avoid getting infected with HIV/AIDS and the doctor gave me this information in Kiswahili so I was able to understand” (ID1M 1022).

“I always inform the doctors that I have intellectual disability so I have a challenge expressing myself. They usually assist me and are patient with me. However, whenever I visit the hospital unaccompanied, I always get a challenge getting the medicine I have been prescribed for as I cannot read. Some health workers also do not understand Kiswahili yet I am unable to speak English. I usually see a specific doctor so if she is not there I ask the nurse on duty to call her so I can talk to her as she understands me, or I ask when she will be on duty so I can come back when she is available” (IDIF 2422).

4.3 Challenges faced by people with ID when seeking SRH services

People with intellectual disability face various barriers in accessing SRH services which stem from social and cultural perceptions that facilitate discrimination against people with ID as discussed in the subsequent section.

4.3.1 Family involvement

The study findings highlighted the first level of discrimination against people with ID is at the family level. The family's failure in prioritizing the SRH needs of people with ID leads to further marginalization of an already vulnerable person. Furthermore, the excessive indulgence of family members of individuals with IDs' SRH matters takes away their autonomy, negatively impacting their health-seeking behaviours.

“My wife went to get the family planning without informing me or getting my consent so when I wanted a baby, my wife did not want a baby. This became an issue in my marriage and we started falling out. I am the only boy in our family so I want many children” (IDIM 1922).

“One of the reasons limiting people with ID from accessing SRH services is that some parents haven't fully accepted their children are disabled leave alone that they have sexual and reproductive rights too” (KII 1322).

“People have a hard time understanding me including my family. I have experienced challenges getting a spouse as whenever I get a wife, my parents interfere and break up my marriage. My last marriage ended when they learnt that I went to get a HIV test with my wife, so they started rumours which angered her and she had to leave” (IDIM 2422).

The study therefore, concluded that there was need to work with the family members and the people individuals with ID trust the most in ending the stigma associated with intellectual disability which will ensure easier access to SRH services:

“Parents should also compliment the SRH topics we teach learners with ID in school instead of dissuading them from talking about this” (KII 1322).

“We need to sensitize staff and community members on acceptance of PWID. The sensitization of caregivers will ensure they will give consent for their children to participate in SRHR trainings” (KII 1522).

4.3.2 Healthcare workers lack of knowledge and skills in serving people with ID

The key informants who worked with people with ID highlighted that one of the main challenges people with ID face in seeking SRH services is getting specialized care. 3 of the 6 key informants stated they lacked the proper training required to serve people with ID. They highlighted the lack of training as the main impediment to properly disseminating sexual and reproductive health information and care to people with ID. The study further stated that whenever people with ID encountered instances whereby they did not receive the SRH services they anticipated, they believed the treatment was due to their disability which resulted in them feeling frustrated. The voices below exemplify this frustration:

“I received the information on HIV prevention but I did not understand some things such as if I go for a HIV test with my partner and I am negative and she is positive and we both want to continue with our relationship, how do we go about it?. The doctor did not answer this. I do not know why he didn't explain more” (IDIF 2222).

“There is need to have a specific person in health facilities whose sole role is to specifically address the needs of people with disabilities. This will encourage people with ID to frequently visit health facilities as the staff will have the capacity to be inclusive in meeting the SRH needs of people with ID” (KII 1322).

“There are communication barriers whereby people with disabilities are unable to communicate neither do SRH providers have the skills to communicate with them” (KII 1522).

Many health professionals experience discomfort when discussing SRH with their clients who have intellectual disabilities due to inadequate training while people with these conditions are even less likely to have these talks with healthcare workers (Thompson et al., 2014). Additionally, health providers report that educating people with ID on SRH is not part of their service delivery (Thompson et al., 2014). Health providers encounter many difficulties evaluating SRH knowledge among people with ID because they lack instructions on how to get people ready to view explicit material (Thompson et al., 2014). People with ID are more likely to be considered a gender minority or asexual. However, studies show that there is a need for an inclusive approach to SRH information for all youth particularly who are categorized as asexual (Wilson et al., 2018). Finally, there is need to have comprehensive sexual health education rather than having one that focuses on safety only which in most cases is incompatible with best practices and do not addresses the subject matter for people with ID. This will entail educating caregivers or parents on eradicating stereotypes about people with ID seeking SRH (Wilson et al., 2018).

4.3.3 Lack of sex education

The cases of discrimination against people with ID are well-documented as they are believed to be asexual (Gilmour et al., 2012). The study results corroborate these findings as society considers SRH not a priority for people with ID as they are believed to lack sexual or reproductive needs. This ignorance has facilitated the lack of awareness and thus deprived people with ID of their

sexual needs and rights as well as villainizing people with ID who discuss their SRH needs as it is considered taboo. This has had dire consequences as it has contributed to people with ID's vulnerability and lack of boundaries:

“They need to be taught boundaries, consent, what is appropriate sexual behaviour and how to control their sexual urges. For instance, I have observed boys who get aroused in school and go about groping female students and teachers too” (KII 1522).

“Basic knowledge and components of sexual and reproductive health such as circumcision and menstrual health for people with ID are not prioritized yet these are integral parts of ensuring that they are healthy and live fulfilling lives. There is need to emphasize on menstrual hygiene services including teaching them how to use different sanitary products to maintain their menstrual hygiene” (KII 1122).

“It is important to have parents and caregivers present when discussing SRH topics so that parents/caregivers trust that what you are teaching them is correct and they can also contribute to the discussion on people with ID accessing SRH” (KII 1422).

Many teenagers experience changes throughout menstruation and puberty (Quint, 2008). Parents teach their teenagers how to manage their menstrual hygiene, and there is a general expectation that the girls will be capable of handling the entire procedure individually in several months (Wallace, 2008). Adolescents with intellectual disability experience a challenge in managing their menstrual hygiene as they might struggle with some physical and behavioural skills associated with this entire process (Wallace, 2008). Failure to properly manage menstrual hygiene may lead to the development of infections (Sezgin & Akin, 1999). Health workers have a significant obligation to train and consult in maintaining and improving reproductive health. Their duties should particularly centre around the prevention of genital infections for adolescents and youth with special needs. Adolescents must take on the duty of self-care and be capable of managing their reproductive health independently and continuously to maximize their chances of success.

4.3.4 Poverty

According to the study, people with ID were overly reliant on their guardians. The repercussions of people with ID dependency on other people to access their SRH leads to their lack of decision-making independence about when to visit health centres and the kind of services to seek. The findings further highlighted that financial constraints make it hard at times for participants to access health facilities because of the cost of transportation incurred by the guardian and the individual with ID. Finally, there was an emphasis on making people with intellectual disability more independent by empowering them to seek income opportunities that will ensure that they can seek SRH services easier as illustrated in the excerpts:

“A lot of these families with people with ID are poor e.g. some girls do not have inner wears and are unable to afford pads” (KII 1122).

“It is difficult for them to get gainful employment so they are unable to afford SRH services and transport to health centres” (KII 1522).

“Vocational training is needed that caters for this special group so they can have access to livelihoods and afford to address their SRH needs” (KII 1322).

One of the biggest obstacles to gaining physical access to health centres was cited as being transportation, particularly in underdeveloped nations. Women with disability (WWD) decision to return for breast screening facilities was influenced by their access to transportation (Peter & Cotton, 2017). WWDs are unable to access health facilities located in cities due to lengthy travel times. According to Lee et al. (2015), research in the Philippines revealed that compared to people without disabilities, people with disabilities reported being more dependent on family members for transportation when seeking SRH services. Financial dependence serves as an impediment to being able to access health care services as relations change from time to time. In India, government facilities which provide lower-quality care than private facilities, are required to cater

to people of lower social economic status by offering SRH services (Dean et al., 2017). This is due to the financial and social costs of caring for children or adults with intellectual disability as well as the lack of employment opportunities for those with intellectual disabilities (Emerson, 2007). Families supporting individuals with ID are susceptible to experience poverty. The association between poverty and intellectual disability is more likely to contribute to the health and social inequities that affect people with ID and their families (Emerson, 2007).

5.0 CHAPTER FIVE

SUMMARY OF THE FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter comprises a summary of the key findings, conclusions, and recommendations as guided by the study objectives. This chapter is structured from the specific objectives of the study which are identifying the specific SRH needs of people with ID in Nairobi City County, and documenting the challenges people with ID face when accessing SRH services.

5.2 Summary

People with intellectual disability face a wide array of challenges in their daily lives ranging from communication, social skills, and even decision-making leading to their exclusion in the social, economic, and political way of life in society. Traditionally, in the African setup, sex and reproductive health are considered taboo topics mostly explored in cases of procreation. There is also laxity among caregivers in introducing SRH topics to children as there is a general fear that the caregivers will encourage them to start engaging in sex. The general perception of people with ID is that they are asexual rendering them sexually inactive in the eyes of society further reducing their probability of being taught about SRH. The case of sexual interest and sexual maturity in people with intellectual disability might cause alarm among caregivers. Society believes that people with ID have more urgent health needs hence the non-prioritization of SRH. This is evident throughout the study as 14 of the 20 study participants highlight that they learned about SRH in school and during health check-ups.

The lack of information on SRH was the main concern for society and people with intellectual disability. The key informants unanimously highlighted the need to teach and sensitize people with

ID on boundaries and how to conduct themselves in society reducing their chances of being manipulated and taken advantage of. The major conundrum facing people with ID is the society refraining from acknowledging their SRH needs yet people with ID suffer and bear the burden of this ignorance and when they are sexually exploited, they end up being ridiculed and judged harshly by the same society that ignored them. None of the study participants attributed the use of media or technology in accessing information on SRH which means that people with ID have limited sources of credible information considering that they are viewed as asexual and topics on sex and reproduction are rarely discussed around them.

Psychosocial support for people with ID is vital in creating positive health-seeking behaviour relating to SRH. Family members, teaching staff, and health workers are highlighted as the most trusted sources of information and people who can help individuals with ID. People with ID sometimes require assistance accessing health centres and communicating their SRH needs. There is still stigmatization on topics relating to HIV and family planning as the latter is linked to infidelity while the former is associated with being sexually active yet sex before marriage is discouraged. 15 of the 20 the study participants wanted to go into the doctor's consultation room alone due to the sensitive nature of the discussion on SRH. 3 of the 20 study participants were discontented with health workers' hesitation to disclose information on matters relating to sexual and reproductive health as health workers lack the capacity.

According to the study findings, people with ID lack access to the four pillars of reproductive well-being which include: support system, control, autonomy and respect. The action of society is reactive, as 4 of the 7 female participants were introduced to family planning to prevent them from getting pregnant again. The study participants argued that the decision was made for them, and they had to oblige since society assumes they cannot objectively make decisions. Furthermore,

none of the female study participants was married while 3 of the 13 male participants had been separated from their spouses which they attributed to interference from their families.

5.3 Conclusion

The study concluded that there is need to end the general stigmatization associated with people with intellectual disability. People with intellectual disability are not asexual contrary to the widespread myth, and they too are entitled to sexual and reproductive rights as this is their basic right. These study findings highlighted the reactive nature of society when dealing with people with ID seeking SRH which further heightened their probability of vulnerability as they are ill-equipped and informed when faced with SRH issues. Ending the discrimination against people with ID needs to start at the family level as the old adage goes, charity begins at home.

To end the stigmatization and improve access to SRH for people with intellectual disability there is a need to engage all the stakeholders such as; healthcare workers, caregivers, people with ID, disability change movements, and the government in clearly outlining challenges facing people with ID. This process will supplement in changing the perception towards people with ID as asexual and better SRH service delivery.

5.4 Recommendations

The study makes the following recommendations based on the findings:

1. The government should work with health providers in creating sexual and reproductive health programs to be specifically tailor-made for people with ID, and they should also include training on SGBV.
2. Disability change movements should form outreach programs targeting both the community and healthcare workers with the aim of ending stigmatization associated with

people with intellectual disability seeking sexual and reproductive health services should be initiated.

Recommendation for future research

A mixed methods research focusing on the sexual and reproductive health and socio demographics of people with intellectual disability in Nairobi City County is recommended. Such a study would highlight how gender, disability and socio-economic status intersect impacting access to SRH services by people with ID.

Reference

Adnams, C. M. (2010). Perspectives of intellectual disability in South Africa: Epidemiology, policy, services for children and adults. *Current opinion in psychiatry*, 23(5), 436-440

Adugna, M. B., Nabbouh, F., Shehata, S., & Ghahari, S. (2020). Barriers and facilitators to healthcare access for children with disabilities in low and middle income sub-Saharan African countries: a scoping review. *BMC health services research*, 20(1), 1-11.

Altundağ, S., & Çalbayram, N. Ç. (2016). Teaching menstrual care skills to intellectually disabled female students. *Journal of clinical nursing*, 25(13-14), 1962-1968.

APA (American Psychiatric Association). (2013) *Diagnostic and statistical manual of mental disorders*. Fifth ed. Washington, DC: APA

Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of applied research in intellectual disabilities*, 15(4), 285-296.

Bane, G., Deely, M., Donohoe, B., Dooher, M., Flaherty, J., Iriarte, E. G., Hopkins, R., Mahon, A., Minogue, G., Donagh, P. M., Doherty, S. O., Curry, M., Shannon, S., Tierney, E., & Wolfe, M. (2012). Relationships of people with learning disabilities in Ireland. *British Journal of Learning Disabilities*, 40(2), 109–122. <http://doi:10.1111/j.1468-3156.2012.00741>.

Borawska-Charko, M., Rohleder, P., & Finlay, W. M. L. (2017). The sexual health knowledge of people with intellectual disabilities: A review. *Sexuality Research and Social Policy*, 14(4), 393–409. <http://doi:10.1007/s13178-016-0267-4>.

Carlson, L., (2010), *The faces of intellectual disability*, Indiana University Press, Bloomington, IN.

Chappell, P., R. Johns, S. Nene, and J. Hanass-Hancock. (2018). “Educators’ Perceptions of Learners with Intellectual Disabilities’ Sexual Knowledge and Behaviour in KwaZulu- Natal, South Africa.” *Sex Education* 18 (2): 125–139.

Cieza, A., Causey, K., Kamenov, K., Hanson, S. W., Chatterji, S., & Vos, T. (2020). Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet*, 396(10267), 2006-2017.

Coffee B, Keith K, Albizua I, Malone T, Jowrey J, Sherman SL, Warren ST (2009). Incidence of fragile X syndrome by new-born screening for methylated FMR1 DNA. *American Journal of Human Genetics*. 2009;85(4):503–514.

Crandall, R. and Diener, E. (1978). *Ethics in social research*. Chicago: University of Chicago Press.

Creamer, D., (2009), *Disability and Christian theology: Embodied limits and constructive possibilities*, Oxford University Press, Oxford.

Crooks, C. V., Jaffe, P., Dunlop, C., Kerry, A., & Exner-Cortens, D. (2019). Preventing gender-based violence among adolescents and young adults: lessons from 25 years of program development and evaluation. *Violence against women*, 25(1), 29-55.

DARU (2019). *Introduction*. Disability Advocacy Resource Unit (DARU). <http://www.daru.org.au/how-we-talk-about-disability-matters/introduction>

Degener, T. (2017), 'A new human rights model of disability', in V. Della Fina, R. Cera & G. Palmisano (eds.), *The United Nations convention on the rights of persons with disabilities: A commentary*, pp. 41–60, Springer, Cham, Switzerland.

Diah, N. M., & Samsudin, S. (2020), August). What, When and How to Learn About Sex: The Narratives of Students with ID. In *Proceedings of the 1st Progress in Social Science, Humanities and Education Research Symposium (PSSHERS 2019)* (pp. 533-537). Dordrecht, The Netherlands: Atlantis Press.

Di Giulio, G. (2003). SEXUALITY AND PEOPLE LIVING WITH PHYSICAL OR DEVELOPMENTAL DISABILITIES: A REVIEW OF KEY ISSUES. *Canadian Journal of Human Sexuality*, 12(1).

Duyan, V. (2007), 'The community effects of disabled sports', in Centre of Excellence Defence Against Terrorism (ed.), *Amputee sports for victims of terrorism*, pp. 70–77, IOS Press, Amsterdam.

Egan, D.R., and G. Hawkes. (2009). "The Problem with Protection: Or, Why We Need to Move Towards Recognition and the Sexual Agency of Children." *Continuum-Journal of Media & Cultural Studies* 23 (3): 389–400. doi:10.1080/10304310902842975.

Emerson, E. (2007). Poverty and people with intellectual disabilities. *Mental retardation and developmental disabilities research reviews*, 13(2), 107-113.

Fisher, M. H., Baird, J. V., Currey, A. D., & Hodapp, R. M. (2016). Victimization and social vulnerability of adults with intellectual disability: A review of research extending beyond Wilson and Brewer. *Australian Psychologist*, 51(2), 114–127. <https://doi.org/10.1111/ap.12180>.

Gilmore L. & Cuskelly M. (2014) Vulnerability to loneliness in people with intellectual disability: an explanatory model. *Journal of Policy and Practice in Intellectual Disabilities* 11, 192 – 199.

Gilbert, I. (2008). *The knowledge of HIV/AIDS and the sexual attitudes and behaviour of adolescents with learning difficulties/disabilities* (Doctoral dissertation).

Goal 3: Good health and well-being - SDG tracker. (n.d.). Our World in Data. <https://sdg-tracker.org/good-health>

Government of Kenya, (2004). Persons with disability Act 2003. Nairobi: Government printer.

Gustafsson C. (2003). Intellectual disability and mental health problems: Evaluation of two clinical assessment instruments, occurrence of mental health problems and psychiatric care utilisation. *Acta Universitatis Upsaliensis*. Uppsala: 2003. [July 5, 2015]. (Comprehensive summaries of Uppsala dissertations from the Faculty of Medicine). <https://uu.diva-portal.org/smash/get/diva2:163146/FULLTEXT01>.

Harris, J. C. (2006). *Intellectual Disability: Understanding Its Development, Causes, Classification, Evaluation, and Treatment*. New York: Oxford University Press; 2006.

Harris, J. C., & Greenspan, S. (2016). Definition and nature of intellectual disability. *Handbook of evidence-based practices in intellectual and developmental disabilities*, 11-39.

Hatton, C., & Emerson, E. (2015). *Health disparities and intellectual disabilities*. Academic Press.
Healy, E., B. McGuire, D. Evans, and S. Carley. 2009. "Sexuality and Personal Relationships for People with an Intellectual Disability. Part I: Service-user Perspectives." *Journal of Intellectual Disability Research* 53 (11): 905–912.

Hingsburger, D., & Tough, S. (2002). Healthy sexuality: Attitudes, systems, and policies. *Research and practice for persons with severe disabilities*, 27(1), 8-17.

Jahoda, A., & Pownall, J. (2014). Sexual understanding, sources of information and social networks; the reports of young people with intellectual disabilities and their non-disabled peers. *Journal of Intellectual Disability Research*, 58(5), 430-441.

Johnstone, D. (2012). *An introduction to disability studies*, Taylor and Francis, Hoboken.

Jones, K. H., Domenico, D. M., & Valente, J. S. (2006). Incidence of pregnant and parenting teens with disabilities within FACS programs. *Journal of Family and Consumer Sciences*.

Juma, S. (2018). National survey on children with disabilities and special needs in education 2018.

Kasser, S. & Lytle, R. (2005). *Inclusive physical activity*, Human Kinetics, Champaign, IL.

Kenya National Bureau of Statistics and National Coordinating Agency for Population and Development Kenya. (2008). Kenya National Survey for Persons with Disabilities - Preliminary Report. Nairobi: National Coordinating Agency for Population and Development.

Kivela, J., E. Ketting, and R. Baltussen. (2011). *Cost and Cost-Effectiveness Analysis of United Nations Educational, Scientific and Cultural Organization School-Based Sexuality Education Programmes in Six Countries*. Paris: UNES.

Korolkova, J. and Anthony, A. (2016). Prepared for the Disability Human Rights Clinic (2016) [The United Nations Convention on the Rights of Persons with Disabilities and the right to support](#) accessed 10 February 2019

Kramers-Olen, A. (2016). Sexuality, intellectual disability, and human rights legislation. *South African Journal of Psychology*, 46(4), 504-516.

Kulick, D., and J. Rydström. (2015). *Loneliness and Its Opposite: Sex, Disability, and the Ethics of Engagement*. Durham: Duke University Press.

Lee, K., Devine, A., Marco, M. J., Zayas, J., Gill-Atkinson, L., & Vaughan, C. (2015). Sexual and reproductive health services for women with disability: a qualitative study with service providers in the Philippines. *BMC women's health*, 15(1), 1-11.

Lukkerz, J. (2014). "An Empty Space: Secondary School and Habilitation Staffs' Perspectives on Sex and Relationship Education." [En tom arena: Gymnasiesärskole- och

habiliteringspersonals perspektiv på sex- och samlevnadsundervisning.]” Licentiate thesis, Malmö: Malmö University.

Maart, S., & Jelsma, J. (2010). The sexual behaviour of physically disabled adolescents. *Disability and Rehabilitation*, 32(6), 438-443.

Masila, S. (2018). SPECIAL OLYMPICS KENYA KENYA FACT SHEET. In *Africa Unity Cup*. <https://dotorg.brightspotcdn.com/f0/69/cc8b029d43708fa33ad5fcc3623/kenya-factsheet2018.pdf>

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in developmental disabilities*, 32(2), 419-436.

Maxwell, J., J. W. Belser and D. Darlena. (2007). A Health Handbook for Women with Disabilities.

McCabe, M. P. (1999). Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability*, 17(2), 157-170.

McDaniels, B., & Fleming, A. (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability*, 34(2), 215–225. <https://doi:10.1007/s11195-016-9427-y>

McGillivray, J. A. (1999). Level of knowledge and risk of contracting HIV/AIDS amongst young adults with mild/moderate intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 12(2), 113-126.

Mckenzie, J. A., McConkey, R., & Adnams, C. (2013). Intellectual disability in Africa: Implications for research and service development. *Disability and Rehabilitation*, 35(20), 1750-1755.

Menon, P., & Sivakami, M. (2019). Exploring parental perceptions and concerns about sexuality and reproductive health of their child with intellectual and developmental disability (IDD) in Mumbai. *Frontiers in Sociology*, 4, 58.

Migunde, Q., Agak, J., & Odiwuor, W. (2011). Career aspirations and career development barriers of adolescents in Kisumu Municipality, Kenya. *Journal of Emerging Trends in Educational Research and Policy Studies*, 2(5), 320-324.

Ministry of Health (2009). *National Reproductive Health Strategy 2009-2015*. Nairobi: Government printer.

(n.d.). Disability Statistics | The National Disability Authority. <https://nda.ie/nda-files/ethical-guidance-for-research-with-people-with-disabilities.pdf>

Nelson, B., Odberg Pettersson, K., & Emmelin, M. (2020). Experiences of teaching sexual and reproductive health to students with intellectual disabilities. *Sex Education*, 20(4), 398-412.

Ngilangwa, D. P., Rajesh, S., Kawala, M., Mbeba, R., Sambili, B., Mkuwa, S., ... & Nyagero, J. (2016). Accessibility to sexual and reproductive health and rights education among marginalized youth in selected districts of Tanzania. *The Pan African Medical Journal*, 10(2), 120-135.

- Okiyo, M. (2010). Inclusion guidelines on disability and mainstreaming for development programs in Kenya. Nairobi: Handicap International.
- Owino, E. (2020). Status of disability in Kenya-Statistics from the 2019 census. *Development Initiatives. Population C*
- Parker, S. E, Mai, C. T, Canfield, M. A, Rickard, R, Wang Y, Meyer R. E. (2010). Updated national birth prevalence estimates for selected birth defects in the United States, 2004-2006. Birth Defects Research, Part A, *Clinical and Molecular Teratology*. 2010; 88:1008–1016.
- Peters, K., & Cotton, A. (2016). Environmental, structural and process barriers in breast cancer screening for women with physical disability: a qualitative study. *Radiography*, 22(3), e184-e189.
- Pfeiffer, D., (2003), ‘The disability studies paradigm’, in P. Devlieger, F. Rusch & D. Pfeiffer (eds.), *Rethinking disability: The emergence of new definitions, concepts and communities*, pp. 95–110, Garant Uitgevers, Antwerpen.
- Powell, R. M., Parish, S. L., Mitra, M., & Rosenthal, E. (2020). Role of family caregivers regarding sexual and reproductive health for women and girls with intellectual disability: A scoping review. *Journal of Intellectual Disability Research*, 64(2), 131-157.
- Pownall, J. D., Jahoda, A., & Hastings, R. P. (2012). Sexuality and sex education of adolescents with intellectual disability: Mothers' attitudes, experiences, and support needs. *Intellectual and developmental disabilities*, 50(2), 140-154.
- Quint, E. H. (2008). Menstrual issues in adolescents with physical and developmental disabilities. *Annals of the New York Academy of Sciences*, 1135(1), 230-236.
- Retief, M. & Letšosa, R. (2018) [Models of disability: A brief overview](#), HTS Teologiese Studies/Theological Studies 74(1), a4738.
- Robinson, K. H. (2013). *Innocence, Knowledge, and the Construction of Childhood: The Contradictory Nature of Sexuality and Censorship in Children’s Contemporary Lives*. New York: Routledge.
- Rohwerder, B. (2020). Disability Inclusive Development-Kenya Situational Analysis.
- Sattler, J. M. (2002). Assessment of children: Behavioral and clinical applications. San Diego: J.M. Sattler.
- Schaafsma, D., Kok, G., Stoffelen, J. M., & Curfs, L. M. (2015). Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review. *Journal of sex research*, 52(4), 412-432.
- Schalock RL, Borthwick-Duffy SA, Bradley VJ, Buntinx WH, Coulter DL, Craig EM, et al. (2010). Intellectual Disability: Definition, Classification, and Systems of Supports. Washington: ERIC.
- Schalock, R. L. (2014). Intellectual disability. *The Encyclopedia of Clinical Psychology*, 1-7.

- Seale, J., (2006). *E-learning and disability in higher education*, Routledge, London.
- Shisana, O., Rehle, T., Simbayi, L., Zuma, K., Jooste, S., Wyk, P. V., ... & Pezi, S. (2009). South African national HIV prevalence, incidence, behaviour and communication survey, 2008: a turning tide among teenagers?
- Shree, A., & Shukla, P. C. (2016). Intellectual Disability: Definition, classification, causes and characteristics. *Learning Community-An International Journal of Educational and Social Development*, 7(1), 9-20.
- Smit, M. J., Scheffers, M., Emck, C., van Busschbach, J. T., & Beek, P. J. (2019). Clinical characteristics of individuals with intellectual disability who have experienced sexual abuse. An overview of the literature. *Research in developmental disabilities*, 95, 103513.
- Statistics, N. B. (2019). Kenya Population and Housing Census Volume IV: Distribution of Population by Socio-Economic Characteristics. *Kenya National Bureau of Statistics*.
- Sezgin, B., & Akin, A. (1998). Adolescent Reproductive Health. *Health and Society*, 8, 27-32.
- Taegtmeyer, M., Hightower, A., Opiyo, W., Mwachiro, L., Henderson, K., Angala, P., ... & Marum, E. (2009). A peer-led HIV counselling and testing programme for the deaf in Kenya. *Disability and Rehabilitation*, 31(6), 508-514.
- Tanabe, M., Nagujjah, Y., Rimal, N., Bukania, F., & Krause, S. (2015). Intersecting sexual and reproductive health and disability in humanitarian settings: risks, needs, and capacities of refugees with disabilities in Kenya, Nepal, and Uganda. *Sexuality and disability*, 33(4), 411-427.
- Tanabe, M., Pearce, E., & Krause, S. K. (2018). "Nothing about us, without us": Conducting participatory action research among and with persons with disabilities in humanitarian settings. *Action Research*, 16(3), 280-298.
- Thomas, D. & Woods, H., (2003). *Working with people with learning disabilities*, Jessica Kingsley Publishers, London.
- Thompson, V. R., Stancliffe, R. J., Broom, A., & Wilson, N. J. (2014). Barriers to sexual health provision for people with intellectual disability: A disability service provider and clinician perspective. *Journal of Intellectual and Developmental Disability*, 39(2), 137-146.
- Tomsa, R., Gutu, S., Cojocar, D., Gutierrez-Bermejo, B., Flores, N., & Jenaro, C. (2021). Prevalence of sexual abuse in adults with intellectual disability: Systematic review and meta-Analysis. *International Journal of Environmental Research and Public Health*, 18(4), 1980. <https://doi.org/10.3390/ijerph18041980>.
- Tsiouris, J. A., Kim, S. Y., Brown, W. T., & Cohen, I. L. (2011). Association of aggressive behaviours with psychiatric disorders, age, sex and degree of intellectual disability: a large-scale survey. *Journal of Intellectual Disability Research*, 55(7), 636-649.
- U.S. Department of Education. (2010). 29th annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2007

UNFPA, W. (2021). Promoting sexual and reproductive health for persons with disabilities. Retrieved 4 September 2021, from http://apps.who.int/iris/bitstream/handle/10665/44207/9789241598682_eng.pdf;jsessionid=095F42E503A09C5F50C034D682EA0D1C?sequence=1

Wallace, R. (2008). Menstrual Management in Women with Intellectual Disabilities. Specialist Healthcare for Adults with Intellectual Disability, Guidelines for Clinicians.

What is intellectual disability? (2021, January 21). *Inclusive Health - 2019 Update*. <https://inclusivehealth.specialolympics.org/approach/what-is-intellectual-disability>

WHO (World Health Organization). (2009). *Promoting Sexual and Reproductive Health for Persons with Disabilities: WHO/UNFPA Guidance Note*. Geneva: WHO.

WHO (2011). *World Disability Report 2011*. WHO | World Health Organization.

Wilson, N. J., Macdonald, J., Hayman, B., Bright, A. M., Frawley, P., & Gallego, G. (2018). A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transgender, intersex or questioning. *Journal of Intellectual Disabilities*, 22(2), 171-196.

Yousafzai, A. K., Edwards, K., D'Allesandro, C., & Lindström, L. (2005). HIV/AIDS information and services: the situation experienced by adolescents with disabilities in Rwanda and Uganda. *Disability and rehabilitation*, 27(22), 1357-1363.

APPENDICES

APPENDIX I: CONSENT FORMS FOR PARTICIPANTS

ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH IN KENYA: THE CASE OF PEOPLE WITH INTELLECTUAL DISABILITIES

My name is Sarah Maranga, and I am a Master's student at the University of Nairobi studying Gender and Development Studies. I am carrying out a research to investigate the various challenges that people with intellectual disability face while seeking SRH services in Nairobi County. I am aware in Kenya people with intellectual disability face various challenges when seeking to fulfil their SRH needs. This research topic aims at ensuring these issues are amplified. For this to be actualized, I will need your assistance in gathering all relevant information. This will make a significant contribution to improving the delivery of services to people with ID. All the information that you will provide will be treated in confidence. Information that may identify you or your name as a participant shall not be disclosed to anyone. Please note that you will receive no immediate direct benefits by participating in this research.

You are not under obligation to respond to all the questions, and you may withdraw at any time during the interview, should you desire to do so. Considering that matters pertaining to SRH are personal in nature, please don't shy away from responding. Feel free to respond to all the questions to the best of your ability. Every question posed is significant, however, if you feel uncomfortable answering a question, you can opt to skip it.

Thank you.

Sincerely,

Sarah Maranga

Sign (Participant)

Date:

APPENDIX II: IN-DEPTH INTERVIEW GUIDE

General information on the participant:

1. Tell me a little about yourself?
 - a) What is your gender?
 - b) How old are you?
 - c) What is your marital status?
 - d) Do you have children?
 - e) What is your religion?
 - f) Are you in school?
 - g) Do you work?
 - h) Background details
 - i) Form of disability
 - j) Challenges faced while growing up

Access to health facilities

2. Have you ever sought for medical assistance from a hospital?
 - a) What is the name of the health centre you frequently visit? And why? (Accessibility of the health centre? General evaluation of the services offered as well as health providers attitudes.)
 - b) How are you treated at the hospital? (Are you treated with respect, given all the information? allowed to make a choice?)

- c) Did you go to the health centre on your own or someone accompanied you? If you were accompanied, who did you go with? What was the reason for this? How does it make you feel having someone accompany you?

Accessing information

3. Have you ever received any SRH information? If yes from who?
4. Have you received any SRH information in the recent past from any health centre? (Probe further, about how it happened and how it was delivered (phone call, WhatsApp, in person)? Whether it was appropriate or inappropriate? Was the language and information provided by the health care provider clear and comprehensible?)
- a) What were the reasons for seeking this information?
 - b) Did you get the knowledge or information you were looking for? What were your experiences?
 - c) Inquire on HIV/AIDS and STIs:
 - d) Inquire on Family Planning:
 - e) Inquire on SGBV:
 - f) How would you assess the quality of SRH information provided in health centre?
 - g) Who would you like to receive this information from?

Access to SRH services

5. Have you ever needed SRH services from health centres?
- a) Where did you get the service from? (Pharmacy, Clinic,)
 - b) Did you get the service you were looking for? What were your experiences?
 - c) Inquire on HIV/AIDS and STIs:
 - d) Inquire on SGBV:

- e) Inquire about any service sought about family planning? How would you describe your experiences?
- 6. Have your past experiences affected your decision regarding seeking SRH?

APPENDIX III: KEY INFORMANT INTERVIEW GUIDE

1. Please tell me about your work and how it relates with working with people with disability especially people with ID?
2. In your role what are some of the achievements or challenges you have observed for people with ID in accessing SRH services.
3. What do you think are the factors limiting people with intellectual disability from accessing SRH services?
4. What do you think are some of the benefits of ensuring that people with ID access specialized care in their search for SRH?
5. What areas do you think need strengthening when it comes to access of SRH services for people with ID? Why these areas? What can be done?