

**ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH SERVICES
FOR PERSONS WITH DISABILITIES: A CASE STUDY OF
CLARENDON HOME FOR PERSONS WITH DISABILITIES,
DURBAN, KWAZULU-NATAL.**

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2013

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ABSTRACT

Sexual and reproductive health are integral parts of the health and well-being of every human being, however they remain sensitive and controversial issues, particularly when they concern persons with disabilities. Within the legal framework, sexual and reproductive health is recognized as basic human rights. They are also essential components of good health and personal development. Making sure that persons with disabilities have access to sexual and reproductive health services contributes to the fulfillment of their sexual and reproductive rights by providing them with more choices that potentially best suit their reproductive health needs. South Africa has one of the most progressive and liberal sexual and reproductive health laws and policies in the world, yet persons with disabilities still face major barriers in accessing these services. In fact, their sexuality has been largely overlooked or actively suppressed and in turn, their reproductive rights denied.

With this background information, the study aims to shed more insights into the experiences and perspectives of persons with disabilities in accessing sexual and reproductive health in Durban, KwaZulu-Natal. Following the rights-based approach it assesses their awareness of sexual and reproductive health services and determines the factors that hinder their access to sexual and reproductive health services.

The findings from the sample of 16 persons with different types of disabilities suggest that access to sexual and reproductive health services is complex and involve a variety of factors. The majority of respondents revealed that sexual and reproductive health services are a big part of their lives. However, there seemed to be a huge gap between their needs for services and their right to access these services. The general consensus was that persons with disabilities face challenges and multiple barriers to access services. Significantly these barriers are not raised by the disability itself but are related to specific contexts or instances of persons with disabilities trying to access services. From the discussions it was apparent that respondents' rights to be treated with dignity and to access sexual and reproductive health services is often overshadowed by social isolation, discrimination and other stereotypical assumptions that the society holds about the sexuality of persons with disabilities. Often, persons with disabilities are perceived as not sexually active hence information on sexual and reproductive health matters is not widely available in formats accessible to them. Health providers appeared surprised that person with disabilities will

require assistance with family planning services and they are not given choices about suitable birth control methods rather often the nurses suggested that they terminate their pregnancies or to be sterilized. This reveals a need to address access to sexual and reproductive health services for persons with disabilities especially, through public health facilities in South Africa.

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
DOH	Department of Health
DFID	Department for International Development
HIV	Human Immunodeficiency Virus
ICPD	International Conference on Population and Development
IPPF	International Planned Parenthood Federation
PWD	Persons with Disabilities
SRH	Sexual and Reproductive Health
SRHS	Sexual and Reproductive Health Services
Stats SA	Statistics South Africa
STI	Sexually Transmitted Infections
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Fund for Population Activities
WHO	World Health Organization

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CHAPTER 1

INTRODUCTION

1.1 Background and problem statement

Sexual and reproductive health are integral parts of the health and well-being of every human being, however they remain sensitive and controversial issues, particularly when they concern persons with disabilities (Hunt and De Mesquit 2006). Within the legal framework, sexual health and reproductive health are recognized as basic human rights (Griffin 2006; Department of International Development 2004). They are also essential components of good health and personal development (World Health Organisation (WHO) 2003; United Nations 1995). Many studies report that persons with disabilities lack access to sexual and reproductive health (SRH) services, especially in low-income countries (for example, Swartz et al. 2009; Groce et al. 2009; Mulindwa 2003; Anderson and Kitchin 2000; Brecker et al. 1997; Nosek et al. 1995) although they are well recognised as human right issues. In fact, their sexuality has been largely overlooked or actively suppressed and reproductive rights denied (United Nations Fund for Population Activities (UNFPA) 2007).

Stereotypical notions have been “institutionalized throughout the society” about sexual and reproductive health of persons with disabilities (Oliver 1996, 33). In most societies, and South Africa is no exception, persons with disabilities have been erroneously perceived as unable to perform physical act of sexual intercourse and hence they are therefore remotely not thought of as sexually active (Hunt and De Mesquit 2006). On the other hand, they are assumed to be hypersexual, and that therefore discussions about sex will trigger uncontrolled sexual behaviours (Anderson and Kitchin 2000). Persons with disabilities are often viewed as sick or childlike therefore they are perceived as asexual; incapable of meaningful sexual relationships; unable to carry a pregnancy and not interested in establishing families (Mgwili and Watermeyer 2006; Smith et al. 2004; Milligan and Neufeldt 2001). Moreover, cultural myths and misconceptions surround their sexual and reproductive health. In some cultural settings it is assumed that a parent with a disability will give birth to a disabled child therefore persons with disabilities should be discouraged from falling pregnant and reproducing (Waxman-Fiducia 1997). However, scientific evidence shows that genetic

disabilities occur in a small number of births and this is not unique to child-bearers with disabilities (UNFPA 2007).

The cultural myths and misperceptions surrounding the sexuality of persons with disabilities have many implications. Foremost it means that they are often left without support and information which in turn contributes to the barriers that hinder their access to sexual and reproductive health services. Based on their study in the Northern Ireland, Anderson and Kitchin (2000), assert that the planning and design of most sexual and reproductive health services, family planning clinics in particular, reflect that persons with disabilities were not expected to be using the services, either for consultation, treatment or receiving information. Persons with disabilities experience multiple barriers in accessing SRH services. Ample evidence has been generated that establishes that these barriers are not necessarily part of having a disability, instead, arise from society's stereotypical attitudes and ignorance (including the attitudes of the services providers), harsh social isolation, stigmatization, and discrimination experienced within communities owing to having disabilities (Swartz et al. 2009; Groce et al. 2009; Brecker et al. 1997; Nosek et al. 1995). Service providers often do not provide persons with disabilities with services, health workers at clinics refuse to give them free condoms, and policy makers ignore them in their action plans (Yousafzi and Edwards 2004). As a result, their needs for sexual and reproductive health services are not easily accomplished and their needs are neglected.

In 2006, United Nations Convention on the Rights of Persons with Disabilities identified persons with disabilities as “those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others” (United Nations Convention on the Rights of Persons with Disabilities 2008, article1).

In South Africa, there are considerable debates about the appropriate term to refer to those who have disabilities. Some argue that the term “disabled people” focuses on the person being “disabled by society” and places the disabling factor within society, particularly the ways in which society fails to include disabled people (Priestly 2006). Whereas the term

“people with disabilities” gives the impression that an individual is the owner of the disability (Bleazard 2010). Others contend that the term “people with disability” is more appropriate and implies that you see the person first then their impairment. Both these terms are, however, within the social model of disability which puts emphases on the disabling social, environmental and attitudinal factors, rather than the lack of ability by an individual (Finkelstein 2005; Barton and Oliver 2000; Dowling and Dolan 2001). Disabled People South Africa (DPSA) endorses both terms and uses them interchangeably. For the purpose of this study, the term “persons with disabilities” will be used. This has been indicated as a term that is not derogatory and is effectively used internationally.

According to the World Health Organization (2011) report, persons with disabilities make up more than a billion of the global population-constituting about 15% of the world’s population. This figure is on the steep increase due to violence, including conflict and sexual and gender based violence and accidents, the rise in chronic diseases such as HIV and AIDS, poor access to health care services, poverty and ageing population (Groce et al. 2009). Persons with disabilities are disproportionately represented in low-income countries. Data indicates that about 80% of persons with disabilities live in low- income countries. They experience deprivation of opportunities in all aspects of life, including education (UNFPA 2007). In South Africa, persons with disabilities are disproportionately represented among the poor and they face stigma and discrimination (Emmett 2006).

1.2 Research context: KwaZulu-Natal Province

KwaZulu-Natal is one of the nine provinces in South Africa. It is located in the southeast of the country. KwaZulu-Natal is the province with the second largest population after Gauteng province. According to 2011 mid- year population estimates, there were 50.59 million people in South Africa and approximately 10.82 million (21.39%) live in the province of KwaZulu-Natal (Statistics South Africa (Stats SA) 2011). KwaZulu-Natal is made up of four population groups: 68% African, 20% Indian, 9% White, and 3% Coloured.

The province is faced with various socio-economic problems, including high levels of poverty, unemployment, and HIV and AIDS. South Africa is one of the countries most

affected by HIV and AIDS and has the largest estimated number of persons living with HIV and AIDS in the world (Joint United Nations Programme on HIV/AIDS (UNAIDS) 2012). The 2011 estimates on the national HIV prevalence indicate that approximately 10.6%- 5.38 million of people in South Africa are HIV positive. This number has increased from 4.21 million in 2001 (Stats SA 2011). HIV and AIDS is one of the major socio-economic challenges facing South Africa. Recent reports show that the AIDS pandemic has orphaned 1.99 million children (Stats SA 2010). Furthermore, HIV and AIDS have left a tremendous strain on the country's health services. The province of KwaZulu-Natal remains the epicentre of the HIV and AIDS pandemic and in 2009 the HIV prevalence was 25% (Department of Health 2011; Shisana et al. 2009). Observations demonstrate that heterosexual intercourse remains the predominant mode of HIV and AIDS transmission followed by mother-to-child transmission in South Africa (Shisana et al. 2009).

There are no official statistics on the prevalence of HIV and AIDS among persons with disabilities. Only a handful of HIV prevalence data for African countries has been published recently (for example Taegtmeier et al. 2009; Touko 2008). Findings from these studies reveal that the HIV and AIDS prevalence rate among persons with disabilities is high. For instance, Taegtmeier et al. (2009) reported a 7% HIV prevalence rate among persons with deafness in Kenya. Touko (2008) reported a 4% HIV prevalence rate among persons with deafness in Cameroon. Nonetheless, it is increasingly recognized that the HIV and AIDS pandemic has left no segment of the population untouched or unaffected (Groce 2005). In South Africa, persons with disabilities are identified among the key populations that are most likely to be exposed to or transmit HIV (UNAIDS 2012). Other groups recognised as vulnerable to HIV and AIDS include, young women between the ages of 15 and 25 years; young people living close to national roads and informal settlements; young people not attending school and girls who drop out of school before matriculating; people from low socio-economic groups; uncircumcised men; sex workers and their clients; people who abuse alcohol and illegal substances; men who have sex with men and transgender individuals (UNAIDS 2012, 12). Subsequently, many efforts have been channelled around prevention, care support and mitigation for HIV and AIDS; however studies reveal that little has been done to target persons with disabilities in South Africa (Rohleder et al. 2009). In part, because it is commonly assumed that persons with disabilities are not sexually active or they

are even asexual therefore not at risk of sexual and reproductive ill-health, including HIV and AIDS infections. Ironically, persons with disabilities have a greater risk of sexual exploitation and rape and the perpetrators are reported to be persons without disabilities (Groce 2003; Sobsey 1994). This places them at the risk of contracting STIs including HIV and AIDS infections.

1.3 Sexual behaviours among persons with disabilities

The Planned Parenthood Federation of Canada (2008) argues that everyone is sexual from birth to death regardless of culture, sexual orientation or disability status. However, being sexual does not necessarily mean being sexually active, rather sexuality encompasses how individuals feel about themselves, their body image, and their ability to be emotionally intimate with others, in addition to their reproductive choices (DPSA 2004).

Notwithstanding the popular misconceptions that persons with disabilities are asexual or not sexually active, in South Africa and elsewhere a few studies have persistently shown that persons with disabilities are as likely to be sexually active as those without disabilities and that persons with disabilities do engage in risky sexual behaviours. Moreover, persons with disabilities marry and have children although in differing degree with their non-disabled peers (Swartz et al. 2009; Wazakali, Mpofu and Devlieger 2006; Mulindwa 2003). In their study, Swartz and colleagues found that in South Africa, persons with disabilities begin sexual activity at a young age (Swartz et al. 2009). In this study, persons with physical and intellectual disabilities reported about early-age first time sexual experiences, younger than 13 years old, in comparison to persons with visual disabilities. There were concerns that this might reflect the incidences of forced sex or sexual abuse, however, the survey findings suggested relatively low incidences, as only few women reported to have experienced it (Swartz et al. 2009). In another study conducted among 90 adolescents with moderate learning disabilities; learners from one of the special schools in Durban (Dawood et al. 2006), reported that 17 percent were engaged in sexual intercourse between the ages of 14 and 16. Similarly, a qualitative study among young people with physical disabilities in Nyanga township in the Western Cape province, affirmed that young persons with disabilities are likely to be sexually experienced as their non-disabled peers (Wazakali, Mpofu and Devlieger

2006), yet they have limited working knowledge about HIV compared to their non-disabled peers.

Studies in other countries, for instance in Uganda, revealed that women with disabilities began sexual activity at the age of 16 and males at the age of 17. Additionally, 77 percent of women who participated in this study had been pregnant this also indicates the degree of sexual activity (Mulindwa 2003). In Cameroon, a quantitative study by Touko (2008) including 126 persons with deafness suggested that their average age for first sexual encounters was about a year earlier than the national average (16.5 years). All these and other studies demonstrate that persons with disabilities are sexually active and experience the same sexual and reproductive health problems; therefore, they should not be excluded from sexual and reproductive health services. Men and women with disabilities and adolescents need to know how to protect themselves against unwanted pregnancies, unsafe abortion, STIs and HIV and AIDS and gender based violence and other sexual and reproductive health problems. Hence, there is a need to include them in sex education. Persons with disabilities have to learn about sexual issues and responsibilities that come with exploring and experiencing one's sexuality (Swartz et al. 2009; UNFPA 2007).

1.4 What is sexual and reproductive health?

At the 1994 International Conference on Population and Development (ICPD) held in Cairo, Egypt, sexual and reproductive health (SRH) was defined as not just the absence of disease but a complete “state of physical, emotional, mental and social well-being related to sexuality and reproduction” (United Nations 1995). It implies that both men and women are able to have satisfying and safe sex life and they are empowered to prevent, treat, and minimise the impact of sexually transmitted infections (STIs) including HIV and AIDS, unplanned pregnancy, and to choose when to have children and how many children to have. Significantly, the definition states that men and women should be able to exercise these choices without fear of stigma, coercion or violence (United Nations 1995). The plan of action drafted at the 1994 ICDP, that many countries adopted including South Africa, stipulates that sexual and reproductive health includes “the rights of men and women to be informed and have access to safe, effective, affordable and acceptable methods of family

planning of their choice, and the right to appropriate health care services that enable women to safely go through pregnancy and childbirth” (United Nations 1995).

1.5 Policy environment on SRH services

The 1994 ICPD and Fourth World Conference on Women held in Beijing in 1995 were hailed for focusing on sexual and reproductive health. Particularly they are regarded as landmarks for the reproductive health agenda in that they embraced the concepts of sexual and reproductive health and rights, and reinforced gender equity (United Nations 1995). There was a paradigm shift from regarding family planning for population and fertility control to a focus on meeting individual women’s needs for a wide array of reproductive health services (Roseman and Reichenbach 2010). The shift towards sexual and reproductive health goes beyond a merely medical and technical view of sexuality and reproduction. The rights of individuals to access sexual and reproductive health services and information, to use services with privacy and confidentiality, and to be treated with dignity and respect were explicitly recognized (Pachauri 2009). It was from this conference that the sexual and reproductive health rights and needs of people with disabilities were recognized (United Nations 1995). The Plan of Action committed governments to strive for universal access to sexual and reproductive health services.

Universal access means there is sufficient information and that services are accessible, available, acceptable, and meet the needs of all the population. Universal access entails that access to services and treatment should be based on the principles of equity and freedom. Therefore barriers to sexual and reproductive health services, such as high cost for poor and inaccessible buildings for persons with disabilities should be removed. In addition, the service providers should be considerate to the gender or the racial, cultural background and religious factors of the clients (Griffin 2006). Universal access calls for governments to “make use of research to understand and address the barriers disadvantaged groups face in accessing services, as well as non-health sector approaches that could help to improve their conditions” (United Nations 1995, n. p.).

Another important international policy document that focuses specifically on the sexual health of persons with disabilities is “Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (United Nations 1993). It states that:

Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family planning methods, as well as to information in accessible form on the sexual functioning of their bodies’ (United Nations 1993, n.p.).

Since the advent of democracy in 1994, South Africa has been identified as one of the most progressive countries in the world in terms of policy and recognition of sexual and reproductive health rights (Cooper et al. 2004). Policies and laws have been put into place to entrench the rights of persons with disabilities and their access to essential services, including sexual and reproductive health services. Some examples of such policies include the 1996 Constitution of the Republic of South Africa, Integrated National Disability Strategy (Office of the Deputy President 1997). Specifically, clause 27 (1) in the Bill of Rights stipulates: “Everyone has the right to have access to health care services, including reproductive health care” (Constitution of the Republic of South Africa 1996, n.p.). Similarly, White Paper on an Integrated National Disability Strategy (Office of the Deputy President 1997, 25) states that “appropriate, accessible and affordable health services and equal opportunities must be provided for persons with disabilities”.

According to the Department of Social Development (2000), South Africa has a strong policy framework to ensure both sexual and reproductive rights and access to sexual and reproductive health care services. For instance, the White Paper on the Transformation of the Health System stipulates that primary health care services should be delivered in an integrated manner so that the person’s diverse needs, including sexual and reproductive health needs, can be met in one place at one time” (Department of Social Development 2000,

54). The 1998 National Population Policy recognizes that in order to achieve the objectives of sexual and reproductive health, one of the strategies is through:

....improving the quality, accessibility, availability and affordability of primary health care services, including reproductive health and health promotion services (such as family planning), to the entire population in order to reduce mortality and unwanted pregnancies, with a special focus on disadvantaged groups, currently underserved areas, and adolescents; and eliminating disparities in the provision of such services (White paper on Population Policy 1998, n.p.).

The Department of Health (DoH) identifies sexual and reproductive health as a key priority area for health in South Africa and the State is the main provider of sexual and reproductive health services. According to the Department of Health (2007, 36), sexual and reproductive health services refer to a “constellation of services aimed at fostering sexual and reproductive health. They include preventive and promotive services (such as information, education, communication and counselling); management of STIs/HIV and AIDS, infertility, abortion, cancers of the reproduction system; contraceptive services; antenatal care, safe delivery and post natal care”. All these services are freely available through public health facilities (Mqhayi et al. 2004) and in comparison with other Sub-Saharan countries; South Africa has high contraceptive use (South Africa Demographic and Health Survey 1998). Additionally, the male condoms remain widely available at most public sector health facilities, but only a limited number of facilities supply the female condoms.

Admittedly, South Africa has good enabling sexual and reproductive health policies; however, this is not always translated into programmes and practices, to enhance access to sexual and reproductive health services for persons with disabilities. Persons with disabilities still face major barriers in accessing these services. For this study, the understanding of access is drawn from WHO (2003, n.p.) and it entails the “degree to which health care services are unrestricted by geographical, economic, social, organizational and linguistic barriers”. This means that sexual and reproductive health services are capable of being used, easily approached, and providing access to the people who wish to utilize those available services.

Despite the aforementioned advances, persons with disabilities in South Africa are quoted saying “policy makers and development agencies continue to talk about us without us” (HIV and AIDS and Disability Conference Report 2003, 10). Thus, Bleazard (2010, 2), believes that “significant efforts are still needed to put policies and laws into practice on a personal level, and to continue projects where disabled persons speak on their own behalf”. The aim of this case study is to explore experiences and perspectives of persons with disabilities regarding access to sexual and reproductive health services. In order to document this, the case study draws on in-depth interviews conducted with persons with disabilities residing in Clarendon Home for the Disabled in Durban, KwaZulu-Natal, South Africa.

1.6 Why the study focuses on persons with disabilities?

The issue of the sexual and reproductive health of persons with disabilities has recently evoked a considerable global concern especially due to their continuing vulnerability to sexually transmitted infections (STIs) including HIV and AIDS infections (Groce 2004), yet without the benefits of accessible sexual and reproductive health services. Additionally, growing evidence reveals that people living with HIV and AIDS are at risk of becoming disabled and this could be permanent (Chireshe et al. 2010). Persons with disabilities may actually “have greater needs for SRH education and services than non-disabled people due to their increased vulnerability to abuse” (Groce et al. 2009, 5). Increasing studies reveal that persons with disabilities are three times more likely to be victims of sexual, emotional and physical abuse (Groce et al. 2009). However, they are less likely to access police intervention, legal protection or prophylactic care (Groce and Trasi 2004). It is well recognized that physical abuse is the major cause of ill-sexual and reproductive health. In particular, research has revealed that women in abusive relationships are at risk of early and unwanted pregnancies and STIs including HIV infections (Griffin 2006; Groce 2003).

Addressing sexual and reproductive health is recognized as key in mitigating the spread of HIV and AIDS by preventing new infections (Bankole and Malarcher 2010). Realizing the serious nature of the problem, the need for sexual and reproductive health of persons with disabilities to be treated as a priority by governments has been raised at several international

conferences. Additionally, one of the United Nation's Millennium goals is to achieve "universal access to sexual and reproductive health services" by 2015 (Groce et al. 2009). In 2007, the executive director for UNFPA, Thoraya Obaid argued that this goal cannot be achieved unless "persons with disabilities are brought into the mainstream and included in programmes to improve sexual and reproductive health" (UNFPA 2007).

1.7 Rationale for the Study

Persons with disabilities constitute a significant proportion of the world's population and they are part of every social, economic, sexual orientation, race, religion, age and cultural groups. Anyone at any time can be born with or acquire a disability (UNFPA 2007). In South Africa, the prevalence rates of disability vary significantly across gender, race, income groups and provinces. The province of KwaZulu-Natal has the highest number of persons with disabilities in South Africa. According to Statistics South Africa, there was 470 588 proximately 5.0% of PWD in the KwaZulu-Natal province, the highest compared to other provinces (Stats SA 2006). This figure shows that PWD constitute a significant portion of the population of KwaZulu-Natal.

Reviewed literature suggests that sexual and reproductive health services are inaccessible for persons with disabilities. Kaplan et al. (2006), contend that lack of attention to sexual and reproductive health needs of persons with disabilities is not only reflected in limited research but also in clinical guidelines and practices. Sexual and reproductive health experts and advocates posit that existing services in fact can be easily adapted to accommodate persons with disabilities at little or no additional costs (Groce et al. 2009; Grant and Hannass-Hancock 2009; Swartz et al. 2009). However, the first and a principal step is increasing awareness. Moreover, much can be accomplished through involving persons with disabilities in research and ultimately in programmes designed to reach the general community (Groce et al. 2009). In South Africa, there are limited studies that focus on the sexual and reproductive health of persons with disabilities, as well as their experiences in accessing sexual and reproductive health services. As a result, this qualitative study seeks to address the gaps in knowledge and highlights research gaps that need to be addressed with regard to the sexual and reproductive health of persons with disabilities. The findings of the present study are

expected to inform policy makers on issues of sexual and reproductive health for persons with disabilities and help design programmes and policies that would improve their access to sexual and reproductive health services.

1.8 Objectives of the Study

The main aim of the study is to shed more insights into the experiences and perspectives of persons with disabilities in accessing sexual and reproductive health in Durban, KwaZulu-Natal. The objectives include:

- To assess their awareness of sexual and reproductive health services;
- To explore their experiences in accessing sexual and reproductive health services;
- To determine the factors that hinders their access to sexual and reproductive health services

Key research questions:

- How accessible are sexual and reproductive health care services for persons with disabilities?
- What are their experiences of accessing sexual and reproductive health services?
- How would they describe their relationship with health care providers?
- Are there difficulties they face in accessing sexual and reproductive health services?
- How do they cope with the barriers to accessing services?

1.9 Theoretical Framework

The study is based on Rights-Based Approach (RBA) which is based on international values and standards, set out in the Universal Declaration of Human Rights and other international human rights treaties (Griffin 2006). Linked to this and relevant to this study, the International Planned Parenthood Federation (IPPF) Charter on Sexual and Reproductive Rights' specifically mentions persons with disabilities. It states that "no person shall be discriminated against in their access to information, and sexual and reproductive health care services, on the grounds of mental or physical disability" (IPPF 1996, n.p.).

The rights-based approach as a framework advocates that services are accessible to all segments of the population and emphasizes the promotion of quality of life and free choice for all individuals, especially those who are vulnerable because of poverty, stigma, marginalization and violence (Pachauri 2009; Department of International Development 2004). The rights-based approach includes providing sexual and reproductive services and information, paying attention to sexuality and sexual rights of various groups (Griffin 2006). The framework stresses that sexual and reproductive health services should be affordable to every segment of the population and it strengthens the ability of those who are disadvantaged in the society to demand and use services and information and to be heard (Pachauri 2009). Griffin (2006), mentions that the rights-based approach shifts the focus away from meeting narrow demographic targets to the recognition of the needs and rights of individuals (Griffin 2006).

A central principle of a rights-based approach is equitable access and non-discrimination (Griffin 2006). The rights-based approach recognizes social, cultural, political and economic factors that marginalize people and deny them access to services and the opportunity to address their sexual and reproductive health needs (Griffin 2006). According to this framework, poverty and stigma and marginalization are major factors contributing to unequal access to services (Griffin 2006). For instance, while national access to sexual and reproductive services has improved in South Africa, access differs among socio-economic groups and rural and urban populations. In particular, studies have established that poor people have limited access to sexual and reproductive services and thus are prone to sexual and reproductive health problems (Groce 2003). Thus, the rights-based approach identifies government as a “duty bearer” stating that government has an obligation to uphold everyone’s right to sexual and reproductive health services. Moreover, the approach places emphasis on the government’s obligation to ensure “equity in access to services and address the wider discriminatory policies and laws that can constrain access” (Pacharui 2009, 4).

Moreover, a rights- based approach also implies responsibilities. That is, individuals have the option to behave responsibly-but this assumes they have relevant knowledge, skills and

resources to do so, which rests on the responsibilities of others, such as, researchers, health professionals, religious leaders, national governments, donor governments and others (Shaw 2006 cited in Pachauri 2009).

In summary, the rights-based–approach takes into account the interplay of factors that potentially hinder equal access to services. It acknowledges that barriers to sexual and reproductive health have major social, cultural, political determinants and consequences that need to be addressed in other ways.

1.10 Organization of the study dissertation

This dissertation consists of five chapters. Chapter one introduces the study. It gives background information, outlines the research problem, and states the objectives and purpose of the research, the significance and the theoretical framework informing the study, namely, the rights-based approach. Chapter two presents the literature reviewed on persons with disabilities and sexual and reproductive health services. It comprises sub-topics such as prevalence of disability in South Africa; experiences and perspectives of persons with disabilities regarding access to sexual and reproductive health services as discussed in the international and local literature. Chapter three presents the research methodology used in this study. It looks at the study sample; the sample selection process; the collection and analysis of data. Chapter four presents the findings of the in-depth interviews. Chapter five presents the discussions of the findings of the study, the recommendations and final conclusion.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The chapter reviews literature on persons with disabilities and their access to sexual and reproductive health. The chapter outlines the prevalence of disability in South Africa; the extent of sexual and reproductive health problems. It discusses factors that hinder and facilitate the use and access to sexual and reproductive health services for persons with disabilities as they have been discussed in the literature.

2. 2. Disability in South Africa

2.2.1 Disability prevalence

In South Africa, as in many other developing countries, information on the prevalence rates of disability is fragmented and unreliable (Stats SA 2005; Office of the Deputy President 1997). According to Statistics South Africa, persons with various forms of disability accounted for 2 255 982 in the 2001 Population Census. This figure constituted 5 % of the population of South Africa enumerated in the Census (Stats SA 2005). This is in comparison with the estimate of 5.2% , 12.8% and 6.6% from the 1995 October Household Survey (OHS), the National Health and Population Development and 1996 population Census, respectively (Emmett 2006, 209).

The lack of reliable and accurate statistics on prevalence of disability in South Africa is attributed to a number of factors namely, different definitions of disability and the methods used to collect data on disability (Office of the Deputy President 1997). For example, the question on disability in the 2001 Census differed significantly from the question posed in the 1996 Census, thus making it difficult to have comparable figures. In the 1996 Census, it was posed as: does a person have a serious sight, hearing, physical or mental disability? If yes, circle all applicable disabilities for the person: Sight, Hearing/Speech, Physical Disability, and Mental Disability. Whereas the question posed in 2001 was phrased as: does a person have any serious disability that prevents his/her full participation in activities? And the options for response to that were: None, Sight, Hearing, Communication, Physical, Intellectual and Emotional (Stats SA 2005). Moreover, the 1999 National Health and

Population survey included chronic illness as one type of disability (Emmett 2006). Other factors relate to different surveys; negative traditional attitudes towards people with disabilities; a poor service infrastructure for persons with disabilities especially in low income societies. All these have impeded on data collection thereby the overall picture on the extent of disability in South Africa (Office of the Deputy President 1997). The unreliability of information on disability prevalence in the country impacts adversely on the planning for the provision of services to persons with disabilities as well as the creation of an enabling environment for the equalisation of opportunities (Stats SA 2005).

In South Africa, disability prevalence varies widely across gender, racial groups, educational levels, provinces and socio-economic groups and between urban and rural populations. The province of KwaZulu-Natal has the greatest number (470 588) of persons with disabilities in comparison to the other eight provinces. In census 2001, the African population was reported as having the largest number of persons with disabilities, (1 854 376 or 5.2% out of a total of 35 416 1660, followed by Whites (191 693 or 4.5%), Coloureds (168 678 or 4.2%) and 41 235 or 3.7% Indians/Asians. Moreover, African women had disproportionately higher levels of reported disabilities and lower education levels in comparison to other population groups (Stats SA 2005). The table below shows the number of persons by population group.

Table 2.1: Number of disabled persons by gender and population group

Population group	Number of Persons with disabilities by Gender			Percentage		
	Male	Female	Total	Male	Female	Total
African	879 680	974696	1 854 376	5,2	5,3	5,2
Coloured	88583	80 095	168 678	4,6	3,9	4,2
Indian/Asian	21550	19 685	41 235	4,0	3,5	3,7
White	92230	99 463	191693	4,4	4,5	4,5
Total	1 082043	1 173 939	2 255 982	5,1	5,0	5,0

Source: Statistics South Africa (2006)

The type and severity of disability has a unique impact on an individual's ability to participate fully and effectively on an equal basis with others in the society. Disability has been classified into six categories in South Africa, namely, visual, physical, hearing, emotional,

intellectual or learning and communication disability. According to the 2001 population census visual disability has the highest prevalence (32%) followed by physical disability (30%), hearing (20%), emotional disability (16%), intellectual or learning disability (12.4%) and communication disability (7%) (Stats SA 2005).

2.3 Sexual and reproductive health problems: A global picture

Sexual and reproductive health is discussed in the literature as one important area of concern as it contributes enormously to the number of unnecessary deaths and disabilities among men, women and young people. According to UNFPA (2005), sexual and reproductive health problems are the second highest leading cause of ill health throughout the world, after communicable diseases. Millions of people are living with STIs and HIV which could have been prevented or treated (Department for International Development 2004). The global estimates indicate that each year 2 800 000 people die from HIV and AIDS and Africa accounts for 65% of these deaths. Moreover, about half a million babies are infected with HIV worldwide (WHO and Reproductive Health and Research Unit (RHR) 2009).

Annually, about 536 000 women die due to complications related to pregnancy or childbirth that can almost be treated effectively and 99% of these maternal deaths occur in developing countries (WHO and RHR 2009). Worldwide, lack of access to family planning services results in 80 million unintended and unwanted pregnancies each year. For women, lack of access to reproductive health services is a major cause of unsafe abortions that results in unacceptable high number of deaths. It is estimated that each year 68,000 deaths results from 19 million unsafe induced abortions carried out in developing countries (UNFPA 2005). Furthermore, 120 million couples have an unmet need for contraception. Moreover, insufficient provision of dual contraceptive methods such as the male and female condoms contributes to 340 million new curable STIs every year. Subsequently, 700 000 children are born with congenital syphilis (WHO and RHR 2009). All these sexual and reproductive health problems can be prevented through improved access to sexual and reproductive health services (Department for International Development 2004).

While several studies have documented how lack of access to sexual and reproductive health services has resulted in disability in previously able-bodied persons; scant attention has been given to the impact of lack of access to sexual and reproductive health services including HIV and AIDS services, among men and women and young people with disabilities (Groce 2003). Sexual and reproductive health for persons with disabilities is still surrounded by stigma and cultural myths, especially among parents, institutions and caregivers (Bleazard 2010; Anderson and Kitchin 2000). The predominant asexual misconception contributes to ignorance of sexual and reproduction health needs for this minority yet large group. Moreover, it enforces the culture of exclusion of persons with disabilities in sexual and reproductive health services.

2.4 Persons with disabilities and SRH services

A review of the literature suggests that persons with disabilities have the same needs for sexual and reproductive health services as non-disabled people. In fact most studies have revealed that persons with disabilities have the most to gain from improved access to sexual and reproductive health services, but they are least able to use and benefit from available services (Groce et al. 2009; Becker et al.1997). Traditionally, persons with disabilities have been denied their rights to establish sexual relationships and families (Groce et al. 2009). In most communities, persons with disabilities have too often lived lives of isolation and invisibility (Gill, Kirschner and Reis 1994), overly protected by their parents, and never expected to marry or have children (Becker et al. 1997). Furthermore, they are sometimes placed in institutions, special homes, hospitals, and other group living situations, where they may not only be prohibited from making informed and independent decisions concerning their sexual and reproductive health, but where they may also experience an increased risk of sexual abuse and violence (Groce et al. 2009). As part of this pattern, many have been subjected to involuntary sterilization, forced marriages and unsafe abortion (UNFPA 2007).

A growing body of literature suggests that persons with disabilities are three times more likely to be victims of sexual, emotional and physical abuse and this makes them vulnerable to HIV and AIDS infections (Yousafzai and Edwards 2004; Groce 2003). For instance, in South Africa and across other sub-Saharan countries, many studies report that persons with

disabilities are three times more likely to be infected with HIV than the general population, in part, due to poverty, discrimination and marginalization, low knowledge about HIV and AIDS, risky sexual behaviours, lower education achievements and illiteracy, sexual abuse and rape and lack of access to services (Swartz et al. 2009; Rohleder and Swartz 2009; Rohleder et al. 2009; Philander and Swartz 2006; Wazakali, Mpofu and Devlieger 2006; Groce 2005; Yousafzai and Edwards 2004; Yousafzai et al. 2004). Studies found that they are routinely left out of HIV and AIDS prevention efforts and service delivery despite the amount of work on HIV and AIDS, especially in South Africa (Swartz et al. 2009; Grant, Strode and Hannass-Hancock 2009; Swartz, Schneider and Rohleder 2006). As it is there is no official data on the prevalence of HIV infections among this population. While services could be adjusted to cater for the specific needs of persons with disabilities, it is uncertain if the attitudes of society could be changed accordingly.

2.5 Barriers to SRH services

Research evidence has shown that the need for sexual and reproductive health services have remained largely unmet or even denied and often persons with disabilities experience tremendous barriers in accessing sexual and reproductive health services (Swartz et al. 2009; Groce et al. 2009; Bremer, Cockburn and Ruth 2009; UNFPA 2007; Mulindwa 2003; Becker et al. 1997). The literature has shown that, often barriers to access services are not necessarily part of having a disability; instead they often reflect lack of social attention, a lack of legal protection, and lack of understanding and support (UNFPA 2007). A few studies in South Africa (for example Swartz et al. 2009; Mgwili and Watermeyer 2006) and elsewhere suggest that the common barriers to sexual and reproductive health services for persons with disabilities arise from social, emotional and physical factors. The mostly identified factors that hinder access to sexual and reproductive health services relate to environmental/physical, negative and stereotyped attitudes by service providers and society at large towards persons with disabilities, cultural norms, stigma and discrimination, lack of information, marginalization in the community and the misconception that disabled people are not sexually active (Bremer, Cockburn and Ruth 2009; Yousafzai et al. 2004; Nosek, Young, Rintala et al. 1995). All these factors are created by the social environment that often fails to consider the needs of this group.

2.5.1 Environmental/ physical barriers

Existing literature suggests that sexual and reproductive health services are physically inaccessible for persons with disabilities. Most studies if not all have cited environmental/physical barriers hindering access to sexual and reproductive health services for persons with disabilities. Often persons with disabilities encounter difficulties in accessing sexual and reproductive health services because health facilities are located far from their homes. In such cases, persons with disabilities have to bear the cost for arranging transport or paying for someone to accompany them to the facility. This is often a challenge or even impossible for many because of poverty among this group. For instance, in South Africa, persons with disabilities are amongst the poorest within communities (Emmett 2006; Dube 2004). Poverty among persons with disabilities is intimately linked to lack of education, high levels of illiteracy and unemployment (Stats SA 2005). Poverty affects their ability to pay for transport to reach health facilities, which often is impossible to reach by foot, especially for persons with physical disabilities. This is more likely to discourage persons with disabilities from using preventive, care and treatment services.

Another major issue related to physical barriers is lack of transportation. In various studies, including one in South Africa, found that transport was a barrier to accessing sexual and reproductive services. A study which was conducted throughout South Africa on sexuality and access to HIV and AIDS care services among persons with disabilities revealed that public transportation and poor road conditions serve as an inhibiting factor to persons with disabilities consulting health services, especially in rural settings (Swartz et al. 2009). Using both qualitative and quantitative techniques this study included 285 respondents from urban and rural areas. Findings revealed that for many persons with disabilities in remote rural areas, road conditions- with their bumps, dirt, and steep hills-represent an enormous challenge; due to bumps, dirt, and steep hills, therefore persons with physical disabilities find it almost impossible to move. This study further revealed that even where HIV and AIDS awareness programme campaigns are often held it is not accessible for person with disabilities. These findings suggest that the needs for such services for persons with disabilities are often neglected within communities. The continuous circle of exclusion of persons with disabilities in services is mostly facilitated by the misperception that they are not sexually active hence do not have a need for such services.

In another study conducted in Uganda on reproductive health and HIV and AIDS among 371 persons with disabilities a similar challenge was mentioned, revealing that sexual and reproductive health services are geographically inaccessible. Specifically, the public transportation is not disability friendly (Mulindwa 2003). In this study the focus group participants reported that sometimes taxi drivers refuse to take them to health facilities because they occupy more than one seat whilst they can only afford to pay for one. A study done in Lusaka, Zambia with women with physical disabilities also reported negative experiences with transportation which results in women with disabilities refraining from seeking services, especially maternal care services (Smith et al. 2004). Women with disabilities reported that they felt discouraged to make routine visits to the clinics or hospitals for antenatal screening because of transportation issues (Smith et al. 2004). Correspondingly a qualitative study done in Malawi, (Mji et al. 2008), showed that the transportation challenges that persons with disabilities face are not only limited to poverty and adaptability issues, rather it is negatively influenced by the societal stereotypes and myths about persons with disabilities. This study revealed that in some cultures persons with disabilities are viewed as a curse therefore they should not be allowed in public transportation (Mji et al. 2008). Lack of suitable and affordable transportation often creates frustrations among this population, in particular, frustrations in trying to access sexual and reproductive health service might result in avoidance or delays in seeking health interventions.

Mace (1998) argues that for persons with disabilities access means more than getting to the clinic or hospital; it includes structural and functional barriers that emerge when a person with disability attempts to use services and facilities available to people without disabilities (cited in Mele, Archer and Pusch 2005). Several studies have shown that health facilities often have architectural barriers, that a client who is in a wheel chair or blind cannot access or find it difficult to manoeuvre in the building (Swartz et al 2009; Anderson and Kitchin 2000; Becker et al. 1997). For example, in South Africa most government health clinics do not have ramps and elevators to accommodate wheelchairs. Also doorways are too narrow making it difficult for persons using wheel chairs to access (Swartz et al. 2009).

In a study conducted in the United States on breast and cervical cancer screening among women with physical disabilities, Nosek and Howland (1997) observed that the set-up of

examination rooms are inaccessible for clients with physical disabilities. In this study respondents reported difficulties in transferring to examination tables because they are too high to reach for people with physique-related disabilities and the service providers may not have training on how to assist clients with disabilities or are not even willing to assist them. Women reported that the physicians believed that a woman with a disability would not understand the rationale behind cervical screening (Nosek et al. 1995). Partly because, the causes of cervical cancer are mainly associated with sexual activities and women with disabilities are presumed to be asexual or should not engage in sexual intercourse hence they do not see the need for screening (Nosek et al. 1995). This is short-sighted, especially in the context of HIV and AIDS. Routine screening is essential because it might help with early detection of STIs. Moreover, such a negative attitude is detrimental not only because it denies women with disabilities their sexual health rights, but it fails to take into account that the probability of experiencing sexual violence for a longer period is high amongst women with disabilities (Groce and Trasi 2004).

2.5.2 Service provider's attitudinal barriers

It is widely recognized that health service providers play a significant role in the quality of sexual and reproductive health services and clients' access to them. Service-providers include government doctors and nurses, counsellors, community-based distributors, midwives and social workers, pharmacists, and the assistants to all these (Tavrow 2010). Service providers' attitudes and practices can be an important determinant of clients returning to use sexual and reproductive health services (Jewkes, Abrahams and Mvo 1998; Tavrow 2010). For example, in South Africa, studies discovered that when providers are friendly and welcoming, young people are more likely to utilize the services and even discuss sensitive issues with them (for example Jewkes, Abrahams and Mvo 1998). Moreover, service providers may be the only source of reliable information, essentially for illiterate and uneducated people, or those with limited access to the mass media, such as persons with disabilities.

Several studies suggest that persons with disabilities consider service provider's attitudes to be the most difficult barrier to overcome (Swartz et al. 2009; Mulindwa 2003). Milligan and Nuefeldt (2001,95), report that persons with disabilities "are routinely told by physicians and

other health staff they would very likely never marry, never have a family, and certainly would not have a sex life”. Service providers often appear surprised or shocked when persons with disabilities request contraceptives or when they come for family planning including HIV and AIDS services, due to the common misperceptions about them. Service providers often assume that persons with disabilities, especially women would not be good parents, so they frequently advise them not to have children (Marlacher 2010; Aunos and Feldman 2002). In some settings, such as India, studies found that persons with intellectual and physical disabilities are even subjected to forced sterilization (Mohapatra and Nohanty 2004).

A study conducted in Orissa, India among 725 women with physical disabilities found high prevalence of rape, forced sterilization and physical abuse (Mohapatra and Nohanty 2004). The study revealed that 6% of women with physical disabilities and 8% with intellectual disabilities have been coercively sterilized and 25% have been raped and incest among girls with disabilities was very common (Mohapatra and Nohanty 2004). Mohapatra and Nohanty (2004), state that the sterilization of women with disabilities is often done without informing them about sexual and reproductive health matters. In another study conducted in Belgium Servias et al. (2004) discovered that the sterilization rates among women with intellectual disabilities are three times more compared to the general population. Servias et al. (2004) state that although sterilization programmes have been banned, institutions and the families of women with intellectual disabilities are the agents often giving permission for the sterilization of women with disabilities.

In South Africa, though policies on non-consensual sterilization have been abolished, the Sterilization Act of 1998 still makes legal provision for the involuntary sterilization of women with disabilities (Office of the Deputy President 1997). De Villiers (2002) in a study on sterilization of persons with intellectual disabilities in South Africa argues that, the rights to make decisions about procreation and contraception is denied for persons with intellectual disabilities. De Villiers (2002) points out that, there exists a conflict between the interests of individuals with intellectual disabilities and the interests of the society. Sterilization without consent is not only a violation of basic human rights, while it may prevent persons with disabilities from having children, it does not protect them from other sexual and reproductive health problems such as sexual abuse or rape and STIs and HIV infections.

The South African National AIDS Council (SANAC 2008) reports that persons with disabilities are not treated with respect, dignity and fairness by the health service providers. A study conducted at one of the state hospitals in the Eastern Cape Province of South Africa, revealed strong stereotypes and prejudices towards the reproductive health care of women with disabilities (Mgwili and Watermeyer 2006). This study explored particularly experiences of women with disabilities in accessing family planning clinics, antenatal clinics and delivery rooms. The findings revealed that women with disabilities endured high levels of discrimination. Respondents reported being treated with the supposition that they are asexual by the clinic staff. Service providers are said to appear surprised and confused as to why women with disabilities will need reproductive health care service. Moreover, respondents felt that nurses disapproved of the fact that they had become pregnant, and were about to give birth. Nurses were said to pass comments such as “men have low morals”. Mgwili and Watermeyer (2006, 266) posit “the implication here was either that the woman had been raped or yet more disturbing, that a man would have low moral fibre to engage in sexual activity with her”. These negative and prejudicial experiences led some women to consider discontinuing attending anti-natal care services. This makes persons with disabilities prone to antenatal complications which may remain undiagnosed and untreated due to the lack of access to services.

In South Africa, poor interpersonal relations between health service providers and clients are widely reported. It is not only unique to clients with disabilities, but to the general population as well. Some studies in South Africa have found that health service providers are often verbally coercive even physically violent with most women in labour wards. In their study in one of the government health clinics, Jewkes, Abrahams and Mvo (1998), documented that all women delivering at the facility reported experiencing shouting, scolding, rudeness or sarcasm from service providers and they felt that this was a way to discourage future deliveries there. Some authors (for example, Mgwili and Watermeyer 2006) believe that this unwelcoming attitude can be attributed to staff shortage that may raise feelings of frustrations and extreme distress due to high patients’ loads and poor working conditions and payments. Nonetheless, this does not substitute clinical practice which foregrounds transparency, dignity and the right to freedom for persons with disabilities. However, of all disadvantaged groups

in society, persons with disabilities are the most socially excluded, life opportunities remain severely restricted for many persons living with different forms of disability (Howard 1999).

Women with disabilities feel their ability to be good mothers is often questioned by the health service providers. For example, nurses pose questions such: “how are you going to hold your baby?” (Smith et al. 2004, 124). “Negative attitudes are reinforced every time disability is portrayed as a problem where disabled persons are regarded as being helpless and dependent, as sick, or as tragic victims” (Office of the Deputy President 1997, 34). Moreover, in South Africa it was found that women with disabilities who do have children sometimes experience scorn and rejection when they visit sexual and reproductive health services particularly in the rural areas (Centre for Reproductive Health Rights, 2002). Thus, the attitudes of health services providers create subtle and sometimes overt barriers to access to sexual and reproductive health services for persons with disabilities. On the other hand, it must be noted that attending to the sexual and reproductive health needs of persons with disabilities in a country with limited resources such as South Africa is a challenge. Helander (1998) points out that, there is a gap between the needs of persons with disabilities and the services provided. In particular, most health professionals lack training on issues of disabilities and are therefore insensitive when dealing with persons with disabilities (Groce et al. 2009). Hence, they often focus on disability instead of the sexual and reproductive health problems a person with disability might present them with.

The findings from the study by Mgwili and Watermeyer (2006) confirm those conducted in other African countries (Bremer, Cockburn and Ruth 2009; Mji et al. 2008; Mulindwa 2003), that women with disabilities are confronted with negative attitudes when seeking sexual and reproductive health services from the health service providers. A study conducted in Cameroon found that women with physical disabilities experience sexual, physical and emotional abuse at medical settings. Hence they are deterred from visiting such services for their sexual and reproductive health. Similarly, qualitative studies in Zambia (Smith et al. 2004), Malawi and Namibia (Mji et al. 2008) participants reported problems when they go to the hospital for antenatal screening, delivery and post-natal services. Findings demonstrated that health service providers lack knowledge on how to address the SRH needs for a woman with disability. Nurses treat them as if they are not supposed to give birth. Family planning

providers tend to be unaware of the reproductive health needs of persons with disabilities and often see no need for routine STIs check-up and do not suggest contraceptives methods (Mji et al. 2008).

A qualitative study on HIV and AIDS and sexual and reproductive health needs of persons with disabilities in Malawi and Namibia (Mji et al. 2008) revealed that persons with disabilities are often subjected to various forms of questioning. In this study, in-depth interviews and focus groups participants reported that service providers often question their need to have access to contraceptives. That is, they felt that they are not entitled or there is no need for them to be provided with contraceptive methods as they are not supposed to engage in sexual activities let alone giving birth (Mji et al. 2008). Women with disabilities reported being mocked and humiliated even physically abused by nurses in the hospital, especially when they revealed that they are pregnant. Moreover, respondents expressed feelings of dissatisfaction that the health professionals decided on the method of delivery for them; without prior examination they were unnecessarily referred to the hospital for caesarean delivery. Respondents also reported being ignored and neglected when in labour which sometimes resulted in them losing their unborn child (Mji et al. 2008).

Furthermore, findings from a study exploring barriers to accessing safe motherhood and reproductive health services by women with disabilities in Lusaka, Zambia, revealed that when a woman with disability become pregnant she is less likely to have access to prenatal, labour and delivery and post-natal services than her able-bodied peers (Smith et al., 2004). The professional nurses' negative attitudes are reported to be the major barrier to access. For example, some nurses ask questions like "how did you get pregnant"? or pass comments such as "shame poor woman, who raped you?" (Smith et al. 2004, 124). Similarly, Welner (1997) reports that when a woman with a disability makes an appointment for prenatal care, the health providers sometimes erroneously assume that she will want to terminate the pregnancy. A similar notion has been observed in South Africa where professional nurses are more likely to recommend long-term birth control for persons with disabilities (Mgwili and Watermeyer 2006).

A qualitative study in the United State on “Barriers to Reproductive Health Maintenance among Women with Physical Disabilities” (Nosek et al 1995), found that women with disabilities find sexual and reproductive health services inaccessible due to the interplay of individual and social factors. A total of the 31 interviews were completed among women with disabilities. The findings from this study suggested that the interaction with medical facilities since childhood, often based on negative experiences, can have a lifelong traumatic impact. Respondents reported being emotionally, physically and sexually abused at the hospital. This weakened the trust the respondents had in health services, since their needs are not being addressed. Some women reported that they lacked knowledge about their reproductive health, in part because they had restricted access to such information as adolescents; their immediate families never discussed the subject of sexuality with them, they either learn about sexuality from the extended family members or friends.

Furthermore, the respondents indicated that they never believed that health information relating to reproductive health applied to them. Women who acquired disability later in life felt that at the rehabilitation centres they received inadequate information about the impact of disability on their sexuality. The majority of the respondents indicated that they experience difficulties obtaining reliable information on contraceptive methods. Women also reported encountering barriers to getting health insurance and health facilities were said to be inaccessible. Women with physical disabilities reported that they were deterred from using sexual and reproductive health services due service providers’ negative attitudes. The barriers to access put the lives of women with disabilities at health risk, because women reported respiratory infections and urinary tract infections higher than average (Nosek et al. 1995). These findings indicate lack of access to good-quality health care and appropriate information on sexual and reproductive health matters for women with disabilities. Unfortunately, negative attitudes among service providers reflect those of society in general, creating obstacles for people with disabilities.

In the absence of access to sexual and reproductive health services women with disabilities opt for traditional medicines, where sometimes due to lack of insight into maternal health their disability has adversely compromised their reproductive health organs or even costing the lives of their unborn babies (Mji et al. 2008). Moreover, due to their negative experiences

and the unwelcoming attitudes in the hospital or clinics, clients with disabilities might be reluctant to return to services. Adversely this can result in unintended pregnancies, delayed treatment for STIs, continued transmission of diseases, late detection of cancer and HIV or injury or death associated with an unsafe abortion (Tavrow 2010). Also women with disabilities might be repeatedly subjected to sexual abuse without being able to access help.

2.5.3 Stigma and discrimination

Many studies discovered that fear of stigma and discrimination prevented persons with disabilities from accessing sexual and reproductive health services (Swartz et al. 2009; Nosek et al. 1995). In most socio-cultural settings persons with disabilities are greatly stigmatized and this greatly affects their effective integration into the society (Waxman-Fudducia 1997). Stigma and discrimination are related and confusing terms. Discrimination entails subjection to the stereotypes, misconceptions and assumptions of others about disability (Yee and Breslin 2010). Hinshaw (2005) described the term stigma as an attribute that triggers social discrediting. The implications are a denial of privacy, only a superficial acceptance in a group and the perception as being a non-person.

Swartz et al. (2009), in their study conducted in South Africa observed that stigma associated with HIV and AIDS and disability adversely impacted on persons with disabilities and their experiences at sexual and reproductive health services. Respondents reported that they are uncomfortable visiting HIV Counselling and Testing (HCT) services, because often these services are in a separate part of the clinic or hospital. Stigma, however, is not confined to clinics and hospitals, but also among persons with disabilities themselves. Rule et al. (2010, 25) assert “stigma within the disability community toward members who are HIV positive may be more severe than the stigma of being disabled in an AIDS clinic”. Stigma and discrimination prevent persons with disabilities from seeking treatment and support related to STIs including HIV and AIDS. These findings confirm those in a study carried out in Lusaka, Zambia, in which women with disabilities felt that they attracted a lot of negative attention when using reproductive health care services, which discouraged them from the use of such services (Smith et al. 2004). This study reported that some pregnant women with disabilities were being ridiculed by clinic staff and questioned for seeking birth control. Rather than

assisting women with disabilities, service providers in Zambia sometimes labelled them as “complicated cases” and unnecessarily referred them to hospitals for primary care services (Smith et al. 2004). The discriminatory attitudes towards pregnant women with disabilities were also confirmed in a study conducted by Groce et al (2009). They report that even community based midwives often refuse to see women with disabilities, stating that, the process needs the help of a specialist which is not necessarily the case.

In many societies, stigma against persons with disabilities is intimately associated with ignorance. According to Groce et al. (2009), in some communities where stigma against persons with disabilities is severe, persons with disabilities may be kept indoors. Hence, reaching such persons with sexual and reproductive health information and services is important but difficult. Smith et al. (2004) assert that the negative attitudes of the society and stereotypical view and the lack of disability-related support often are not only exerting influence on the formulation (or non-formulation) of policy, but lead to low self esteem and how persons with disabilities feel about their sexuality and reproduction. Therefore, “sexual and reproductive health personnel’s must work to overcome stigma and uphold the rights of persons with disabilities” (Groce et al. 2009, 20).

2.5.4 Informational and communication barriers

In the literature, lack or limited knowledge is cited as another factor that makes sexual and reproductive health services inaccessible to persons with disabilities. Persons with disabilities, especially women have difficulty obtaining reliable information about contraception; they lack basic knowledge of their sexual and reproductive health (Swartz et al, 2009). This is partly, attributed to high levels of illiteracy among this group (Anderson and Kitchin 2000). On the global level, according to 1997 UNFPA’s estimates only 1% of women with disabilities are literate. In South Africa, lack of information has also been identified as one of the factors that prevent persons with disabilities from fully accessing sexual and reproductive health services. Swartz et al. (2009) pointed out that it is likely that persons with disabilities in general have limited working knowledge in English and information on sexual and reproductive health, including HIV and AIDS is generally not communicated in their own language.

It must be noted that persons with disabilities are not a homogenous group and access to information and services vary according to the type and nature of disability. For instance, persons who have visual impairments or persons with deafness are often marginalized in accessing information through mass media, including newspapers, radios or television and general information on sexual and reproductive health services is rarely available in alternative communication formats such as audio tapes, large prints or Braille or in a simple and understandable language for people with learning disabilities. Also there are no sign language interpreters for persons with deafness, while persons with physical disabilities find it almost impossible to access buildings if there are no ramps or elevators (Bremmer, Cockburn and Ruth 2009; Swartz et al. 2009; Dube 2004). The lack of sign language interpreters can raise barriers for persons with deafness because they might become concerned with issues of privacy and confidentiality because of the presence of additional persons. Studies carried out in Swaziland and Uganda confirm that persons with disabilities lack access to information on all aspects of sexual and reproductive health services needed and received (Yousafzai et al. 2005; Yousafzai et al. 2004; Mulindwa 2003).

Information communication is an essential part of access to public services (Office of the Deputy President 1997). However, society marginalizes and isolates persons with disabilities with respect to information related to sexual and reproductive health matters. Often, information about sexual and reproductive health is presented in formats that are inaccessible for persons with disabilities. Nganwa et al. (2002) point out that isolation of persons with disabilities and lack of access to sexual and reproductive health information and services can potentially lead to unprotected sexual intercourse due to limited awareness of preventative measures. Mulindwa (2003,20) states that “media access is essential in increasing individual’s awareness and knowledge of what is taking place around them, which may eventually affect their perceptions and behaviours”. The perception that persons with disabilities are not sexually active can present barriers to safe sex education as well as prevent them from obtaining sound information about prevention and protection against HIV and AIDS (SANAC 2008). Moreover, information barriers are likely to result in inadequate prenatal care for women with disabilities. It is clear that engaging in unsafe sexual behaviour increases one’s vulnerability to HIV and AIDS. There is an urgent need to change

discriminatory attitudes on the part of service providers and the need to begin to offer comprehensive sexual and reproductive health education where the rights and needs of persons with disabilities are emphasized.

2.5.5 Lack of knowledge about SRH services

The literature has shown that persons with disabilities receive little or no education about sexual and reproductive health. In their study on experiences and perceptions of sexuality and HIV and AIDS among young people with physical disabilities in a South African township, Wazakili, Mpofu and Devlieger (2006) found that persons with disabilities have limited factual knowledge about sexuality and HIV and AIDS. Wazakali, Mpofu and Devlieger (2006) highlighted that socio-economic factors impact negatively on access to sexuality and HIV and AIDS information and services for young persons with disabilities. Conditions of poverty are also cited as inducing unsafe sexual behaviours by limiting people's decision making capabilities regarding sexual relations.

In contrast, in another study conducted with persons with physical disabilities in an urban university (Ashani 2009), respondents showed high levels of awareness about HIV and AIDS. However, the participants in this study indicated that service providers appeared shocked when a person on a wheel chair or crutches came for an AIDS test. Even though in this study respondents showed higher knowledge of HIV and AIDS, they expressed concerns about other young people with disabilities who are not able to attend school and not able to access facilities, in particular those in remote rural areas. Respondents suggested that higher levels of education, especially among women with disabilities, can contribute to their awareness of HIV transmission and improve their life skills to protect themselves (Ashani 2009). Whereas there is evidence that HIV infections happens regardless of education status (Iliffe 2006), better education is reported to improve ones awareness, empower them to assert their rights to services and increase their employment opportunities (Rule et al. 2010). Persons with disabilities are observed to have little knowledge of sexual and reproductive health services, lack access to services and have reduced ability to negotiate contraceptive use, especially condoms.

A survey in Ibadana, Nigeria suggested low levels of knowledge on HIV and AIDS especially among the hearing impaired and persons with speech impairments as well as lack of knowledge about where to access reproductive health services. In particular, this study was focusing on sexual behaviours and reproductive health knowledge among a set of youth with disabilities attending school. In total 52 out of 103 interviewed never heard of HIV and AIDS. Among the sexually active respondents, 54% had no knowledge of available reproductive health service should they have a need (Olaleye et al. 2007). In this study, the low level of awareness of contraception and the HIV and AIDS pandemic, among young people with disabilities, was attributed to the lack of exposure to educational programmes even though the respondents exhibited similar sexual behaviours as their able-bodied counterparts. The findings of the study, suggested that young people with disabilities were often exposed to sexual abuse and exploitation by people known to them such as friends and family members. Also there was a high risk of unwanted pregnancy, unsafe abortion and a risk of HIV infection (Olaleye et al. 2007).

In their study conducted in Swaziland, Yousafzai et al. (2004) found that respondents with disabilities listed many incorrect examples of modes of HIV transmission compared to their non-disabled counterparts; for example, sharing bowls and kissing. Women with disabilities discussed experiences of abuse and sexual exploitation (Yousafzai et al. 2004). Findings from a study in Cameroon (Bremer et al. 2009), suggested that understanding of reproductive health care services among women with disabilities was limited and only consisted of their health during pregnancy and childbirth. That is, the majority of persons with disabilities get to know or even use sexual and reproductive health services during pregnancy. In part, because, many parents with children with disabilities do not consider that their children might be sexually active. However, some respondents in this study indicated that they experienced extra attention, encouragement, and support at the prenatal clinic during their pregnancy because of their disability (Bremer et al. 2009).

Bremer et al. (2009) asserted that early education on sexuality matters and access to contraceptive methods are vital. Providing sex information and access to contraceptive methods reduces fear, anxiety, and unwanted pregnancies. Bremer and co-authors suggested that reproductive health information session, bringing together persons with disabilities and

persons without disabilities, would work to breakdown barriers, reducing stigma against persons with disabilities and positively affecting community perceptions in respect to sexuality and reproduction issues of persons with disabilities. Sexuality education becomes urgent in the South African context, a society severely affected by HIV and AIDS and alarming rates of sexual and physical abuses.

2.5.6 Women with disabilities: double barriers

It must be noted, however, that while men and women with disabilities are part of the disadvantaged minority group, their experiences regarding sexual vulnerability, risk of violence and access to sexual and health services are of varying degrees. Women with disabilities experience double oppression, because of gender and vulnerability due to their disability. Consequently they bear a disproportionately high burden of ill-sexual and reproductive health due to various but interrelated factors. The vulnerability of women with disabilities has been increased by factors such as gender based violence, poverty, marginalization and discrimination, lack of education, coerced marriages, forced abortion and sterilization (Groce et al. 2009; UNFPA 2007; Center for Reproductive Rights 2002).

In most countries the involuntary sterilization of persons with disabilities has been abolished. However, in many instances the policies have not been translated to practices, there is still some exception when it comes to sterilization of persons with intellectual disabilities. In South Africa for instance, the Sterilisation act of 1998 provides that no person should be sterilized without their full consent. De Villiers (2002) in her study of sterilization of persons with intellectual disabilities in South Africa points out that the country still makes legal provision for involuntary sterilization of persons with intellectual disabilities in the Sterilization Act of 1998. De Villiers (2002) argues that persons with intellectual disabilities are denied their right to procreation and contraception. Studies have reported that persons with disabilities, especially women, are often subjected to forced sterilisation, forced marriages and physical and sexual abuse (Groce and Trasi 2004; Mohapatra and Mohanty 2004; Yousafzi and Edwards 2004).

A study in Kampala, Katakwi and Rakai districts, in Uganda on reproductive health and HIV among persons with disabilities, found that sexual exploitation, unwanted pregnancies and complications during pregnancy and childbirth are some reproductive health problems that women with disabilities face due to lack of access to SRH services (Mulindwa 2003). In South Africa, studies have reported that women with disabilities are more likely to be single mothers without any support; their partners are more likely to abandon them once they fall pregnant and they are left with the responsibility of raising the children alone (Office of the Deputy President 1997). Further, the probability of being poor, malnourished and illiterate is higher among women with disabilities than men with disabilities (Office of the Deputy President 1997). Women and girls with deafness and blindness are especially vulnerable to rape; they are often targeted because they cannot visually identify the offenders and the possibilities of prosecution are limited (Yousafzi and Edwards 2004). Moreover, disability can impact contraception options. For example, a blind woman might face a challenge in using a condom. Therefore service providers must assist women with disabilities in exploring other more effective and suitable contraceptive methods.

Thus, access to sexual and reproductive health services requires that health workers to talk openly about sexuality and reproductive choices with their clients with or without disabilities – men, women and young people. It encompasses addressing the rights as it calls for medical and technical components of service provision (Department of Social Development 2000). In addition, gender stereotypes and the unequal power and resources distribution between women and men result in women with disabilities having limited power in negotiating for safer sex practices. Hence they are more susceptible to unwanted pregnancies, STIs including HIV. Gender inequality combined with poverty, patriarchy, or illiteracy and myths around disability increase vulnerability to sexual and reproductive ill-health (Swartz et al. 2009 SANAC 2008; Groce, Trasi and Yousafzi 2006; Yousafzi and Edwards 2004; Mulindwa 2003).

2.6 Summary

The available literature regarding access for persons with disabilities to sexual and reproductive health services suggests that persons with disabilities have difficulty obtaining

sexual and reproductive health services. This chapter has discussed factors that hinder access to sexual and reproductive health services for persons with disabilities. These include environmental/physical barriers, knowledge and informational barriers, discrimination and attitudinal barriers. However, there are gaps in the information of available literature. Becker et al. (1997), pointed out that a qualitative study can provide important insights into sexual and reproductive health experiences of persons with disabilities. Such an approach can reveal the issues that should be pursued in larger quantitative investigations and most, importantly, enable persons with disabilities to say in their own words what is important to them about their sexual and reproductive health services (Becker et al. 1997).

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

This chapter will outline the design of the study and the research methods employed to carry out this research. The case study was designed to examine access to sexual and reproductive health for persons with disabilities. The study was conducted with persons with disabilities residing in a facility that provides housing for people with disabilities in Durban, South Africa. This chapter will look at the study site-the Clarendon, sampling procedures, data collection and data analysis procedures and finally discusses the limitations and ethical issues related to this study.

3.2. Study Area

The study was conducted at Clarendon Home for the Disabled. The Clarendon Home is located in the Durban Central Business District, commonly known as eThekweni in the province of KwaZulu-Natal South Africa. Clarendon was primarily chosen because it is a residence for persons with disabilities. Clarendon Home was established by the KwaZulu-Natal Society for the Blind, however, the home is now a place of refuge for approximately 100 persons with different disabilities, including persons with deafness, blind or partially sighted and persons with physical disabilities. The home is not run as an institution and the residents live independently with their companions and children.

Clarendon Home for Disabled is characterized by high unemployment rates and lack of social services. The residents depend largely on government social grants for their socio-economic well-being. The residents have difficulty in accessing basic social services such as: water, sanitation and electricity. Each resident shares one small room with their families. Clarendon Home is in a desolent state and because of poverty and other factors residents have not been able to pay municipal charges for water and electricity. For the past four years the residents have been appealing for donations to offset the home's current electricity and water bill that is in arrears. When this study was carried out, the flat burnt down and was in the process of being renovated with the help of different donors, including eThekweni municipality and

private businesses. Due to this process, the residents were being moved to temporary special homes and institutions in and around Durban.

Clarendon home is located in Maud Mfusi Street previously known as St George Street. Maud Mfusi Street is located in the Durban city centre where crime is rampant and illegal prostitution is high. Next to Clarendon Home there is a huge taxi rank and the eThekweni community church. The residents feel that the taxi owners are responsible for the high water bills in part, because the taxi operators have been using their water connections to wash their taxis without obtaining the consent of the residents of Clarendon Home. This study relied on qualitative research conducted at Clarendon House with persons with disabilities.

3.3 Research Methodology

3.3.1. Qualitative methods

Qualitative research is an umbrella term, including a wide range of epistemological point of views, research strategies, and specific techniques for understanding people in their natural contexts (Denzin and Lincoln 2000). Qualitative research is based on the premise that knowledge about humans is not possible without describing human experience as it is lived and as it is defined by the people themselves (Polit and Hungler 1994). Terreblanche, Kelly and Durrheim (1999) explain that qualitative researchers want to make sense of feelings, experiences, social situations, or phenomena as they occur in the real world and therefore want to study them in their natural setting. Qualitative research involves fieldwork, which means the researcher has to go to the study site and observe the behaviours and learn about the experiences of the respondents. According to Terreblanche and Durrheim (2002) this method allows the researcher to study selected issues in depth. Qualitative research methods were deemed most appropriate because the study seeks detailed accounts relating to subjective experiences and perspectives of persons with disabilities with regards to access to sexual and reproductive health services. This method gave the study respondents the opportunity to talk broadly about their experiences and the meanings they give to their experiences with regard to accessing sexual and reproductive health services in Durban. Qualitative methods enabled the researcher to obtain detailed answers to questions posed in

the study and to discover the multiple factors that influence, facilitate and hinder access to sexual and reproductive health services for persons with disabilities.

In qualitative research, the researcher is central part of data collection and data analysis. To a great extent, the quality of the data depends on the methodological skill, sensitivity, and integrity of the researcher (Patton 2002, 4). Qualitative methods, in the form of in-depth interviews were used for the data collection because it helped gain insights into individual's lived experiences, their perspectives and meanings. This method allowed the respondents to express their views using their own words based on their unique experiences rather than in the words of the researcher. Waxman-Fiduccia (1996) points out that understanding the realities of men and women with disabilities depends on the investigator's viewing persons with disabilities as experts, viewing persons with disabilities as a unique group, and not positioning people without disabilities as the standard measurement. Qualitative methods mainly rely on open ended questions which allowed the researcher's flexibility to probe further answers, specifically on issues that were raised during the interviews.

Nevertheless, qualitative methods have their own limitations. Some of these are that they are time consuming, more expensive, and liable to bias (Sarandakos 2005). It took a lot of time to get to the respondents places, conducting interviews with them and analysing this unstructured information. It also requires the researcher to build trust with the respondents, especially since it is a sensitive topic, like disability and sexual and reproductive health. The researcher had to build trust with each respondent by ensuring that all information provided will be treated with confidentiality. The findings from the qualitative studies cannot be generalized to the entire population because they are based on a small sample, that is, the opinions and experiences of individuals cannot be the representative of the entire population. Moreover, the findings might be influenced by the researcher's biases.

3.4 Data collection methods

3.4.1 Selection of respondents

This study employed non-probability sampling techniques. According to De Vos (1998), a non-probability sampling techniques is where the chance of selecting a particular individual

is not determined by the statistical principle of randomness (De Vos 1998). Within the non-probability sampling techniques, purposive sampling was used to select the respondents. The researcher ensures the “sample is composed of elements that contain the most characteristics, representative of typical attributes of the population” (Rubin and Babbie 2005, 247). The primary consideration in purposive sampling is the judgment of the researcher as to who can provide the best information to achieve the study objectives (Kumar 1999). In purposive sampling the primary concern is to acquire in-depth information from those who are in a position to give it (Cohen 2007, 115). Purposive sampling also depends on their willingness and availability to participate (Durrheim and Painter 2006). The reason for choosing purposive sampling is because the identified population contains the characteristics that are likely to produce the valuable information for the objectives of the study. Also, the study area was convenient because the researcher resides close to it. Another reason the said group was chosen was the ease of access to respondents because persons with disabilities are a hard to reach group.

According to Durrheim and Painter (2006), purposive sampling takes place when the group is homogeneous, sharing the same experience of a specific situation. In this study, though respondents formed a homogeneous group by falling into the niche category of persons with disabilities and the context of their setting being that they all reside in Clarendon Home; the researcher also selected the respondents with the aim of approximating a relatively even representation of disability types and gender. Essentially, the respondents were individuals with unique experiences and perspectives.

One of the advantages of using purposive sampling is that “it allows the researcher to home in on people or events which are good grounds for believing will be critical for the research” (Denscombe 1998, 15). However, the sample is prone to bias and its adequacy is limited by the researcher’s ability to perceive characteristics in the target population.

Before undertaking the study, the researcher had a preliminary meeting with one of the committee members of Clarendon Home in order to seek permission to conduct the study and to assess the possibility of getting respondents who might be willing to share in-depth

information on sexual and reproductive health matters. To recruit respondents for the study, the researcher sought the help of the Clarendon –House committee members in order to gain the right to engage with the respondents. The researcher also talked with another researcher (who is disabled) who has conducted research in this area and she was very helpful in terms of suggesting ways to recruit respondents for the study and to establish good rapport with them. After each respondent was approached and was given detailed information about the purpose of the study, they indicated their willingness to participate in the study. Some, after they have understood the objectives of the study, suggested other persons who will be willing to participate in the study and share their unique experiences as well.

3.4.2 In-depth interviews

The qualitative method of data collection used in the study was in the form of in-depth interviews. In the study, it was important to provide a framework within which respondents could express their own understandings, perspectives and experiences in their own words. Sexual and reproductive health and disability remain sensitive and taboo subjects thus in-depth interviews were deemed most suitable as this study required a detailed account of the subjective experiences of each respondents. In-depth interviews were useful for this study because they allowed the respondents to express their views, knowledge, perspectives and opinions regarding access to sexual and reproductive health services, drawing from their own unique experiences. According to Greef (2005, 282), in-depth interviews are useful for data collection as the process of interviewing “merely extends and formalizes conversation”. Furthermore, in-depth interviews are focused, discursive and allow the researcher and respondents to explore an issue in detail (De Vos 2001). This technique also reduced biases that sometimes come with predetermined or suggested answers as respondents were free to share their experiences and express their perspectives on access to sexual and reproductive health services in Durban.

A total of 16 in-depth interviews were completed. The data was collected over a three months period from June to August 2011. In addition to targeting person with diverse disabilities, including persons who are partially sighted, blind and have physical disabilities using crutches and who are dependent on wheel chairs, the study included sexually active men and

women. The study used only sexually active respondents, because sexual activities and relations are more likely expose people to pregnancies, planned or unplanned, sexually transmitted infections including HIV and AIDS; therefore are likely to be in need and potential users of sexual and reproductive health services. The study targeted people who are 21 years of age and older. Essentially, during the preparation phase of the fieldwork, it seemed it would be more difficult to get people in Clarendon Home who are below the age of 21 and who will be confident enough to talk about sex and their sexual and reproductive health experiences. Because of this and to ensure the maturity of responses, the study targeted people who are 21 years and older.

Guided by the literature, a semi- structured interview schedule with open ended questions was designed specifically for the study. Interviews began by collecting demographic information of each respondent. Open ended questions were designed to understand accessibility of sexual and reproductive health services for persons with disabilities and their perspectives and experiences in trying to utilize services from public health service providers. The interviews, as a tool also allowed the researcher to gain insights into some of the factors that impede and facilitate access to sexual and reproductive health services for persons with disabilities in Durban, South Africa. The in-depth interviews allowed for greater flexibility in exploring certain topics in more depth as they arose (interview guide is provided in Appendix 1). Questions covered six main sections: knowledge and awareness of sexual and reproductive health among persons with disabilities; use of sexual and reproductive health services by persons with disabilities; need for sexual and reproductive health services and experiences in accessing sexual and reproductive services; factors that may potentially hinder and facilitate access; and suggestions on improvement of access to quality sexual and reproductive services for persons with disabilities. For each question, a set of specific probes made it possible to elicit in-depth information on perceived barriers and how persons with disabilities cope with lack of access to sexual and reproductive health services.

The interview guide allowed for each respondent to be asked the same set of questions which yielded similar textual descriptive data. The semi-structured interview schedule was selected as the most appropriate method of data collection as it was likely to allow personal interaction that engendered a sense of trust and cooperation between the researcher and the

respondents (Rosenthal and Rosnow 1991). This was particularly important as it was anticipated that questions regarding sex, sexuality and reproduction might be considered sensitive and uncomfortable to talk about by some respondents. Interviews took place in the rooms of respondents to ensure easy access, privacy and to avoid potential confounding influences on the respondents.

All interviews were conducted in Zulu, with the exception of 2 by the researcher. All questions were translated from English to Zulu for interviews which were conducted in Zulu. All responses were digitally recorded and field notes were taken during the interviews. The consent of the respondents was secured before recording. Each interview session lasted on average 30 minutes to one-hour. All interviews were then transcribed and translated verbatim to English by the researcher.

Nevertheless, the researcher acknowledges the challenges of using in-depth interviews. First it is time consuming, especially the time it takes to conduct interviews. Essentially, to get in-depth information lengthens the interview and respondents might become annoyed with further probing. Also, it requires much time to transcribe the interviews, and to analyse the results (Boyce and Neale 2006). Furthermore, interviews entail the researcher to build trust with the respondents, especially with regards to sensitive topics such as disability and sexual and reproductive health for both the researcher and respondents. The following table summarizes the sample characteristics of each respondent in the study.

Table 3.1: Demographic characteristics of the respondents

No	Gender	Age	Type of disability	Marital status	Level of education
1	Male	28	Blind	Single	Never attended school
2	Female	37	Blind	Single(living with a partner for 10 years)	Grade 7
3	Female	30	Physically disabled (post-polio)	Single	Grade 12
4	Female	37	Physically disabled (polio)	Single (was living with a partner during the time of interview)	Grade 11
5	Male	34	Multi-disabilities	Single	University graduate
6	Female	30	A physically disabled (post-polio)	Single (was living with a partner during the time of interview)	Grade 10
7	Female	29	Partially sighted with albinism	Single	University student
8	Female	35	A physically disabled female (polio)	Single	University student
9	Male	27	A physically disabled (post-polio)	Single	Technikon student
10	Male	27	Partially sighted	Single	Grade 10
11	Female	42	A physically disabled (polio)	Married	Grade 11
12	Male	37	Blind	Single (paid bride wealth)	Grade 8
13	Male	46	A physically disabled (polio)	Single (living-in partner)	Grade 11
14	Female	40	Blind	Single (has been living with a in partner for 11 years)	Never attended school
15	Female	37	A physically disabled (polio)	Single (living-in partner for 2 years)	Grade 12
16	female	37	Blind	Single	University graduate

Note: This table excludes some of the demographic characteristics of the respondents likely to reveal their identity (e.g. number of children and exact type of employment)

3.5 Data analysis methods

The interpretive analysis was used to analyse the gathered data. The objectives of interpretive research is to “piece together people's words, observations, and documents into a coherent picture expressed through the voices of the participants” (Jessup and Trauth 2000, 12). According to Terreblanche and Durrheim (1999), the interpretive research method, assumes that people’s subjective experiences are real, we can understand others experiences by interacting with them and that qualitative methods are most appropriate for this goal. Interpretive analysis is an umbrella term for different analytic techniques that include phenomenology, grounded theory and thematic content analysis (Terreblanche and Kelly, 1999). In this study, the information collected through individual interviews was analysed using thematic content analysis.

Thematic analysis aims to identify themes within the data collected. Thematic analysis is more inductive because the categories into which themes were sorted were not decided prior to coding the data, rather were derived using the language of the interviews (Terreblanche and Kelly 1999). These categories are induced from prior analysis, the specific nature of categories and themes to be explored are not predetermined. This means that this form of research may take the researcher into issues and problems he or she had not anticipated.

Marshall and Rossman (1990,111) state that “data analysis is the process of bringing order, structure and meaning to the mass of data collected, for instance interview transcripts. It is a messy, ambiguous, time-consuming, creative and fascinating process”. Data analysis involved reading and re-reading of the interview transcripts and listening to digital records to gain an understanding of the issues being raised. In this study, the interview transcripts were checked repeatedly against the digital recording for accuracy.

After interview transcripts were completed, the researcher extracted passages from the transcripts and key themes and concepts were identified and coded to provide a rich framework to base analysis, to make comparisons and present the data. Individual’s experiences, comments and opinions were then categorized according to recurring selected themes from all the interview transcripts. The process of coding the data according to

common themes gave meaning to the experiences and perspectives of persons with disabilities with regard to access to sexual and reproductive health services in Durban, South Africa.

The themes range from one sentence to paragraphs in length. These major themes were then synthesized to carry out the analysis. The set of themes were reviewed and interpreted to understand the everyday experience of persons with disabilities regarding access to sexual and reproductive health services. After coding and translating and organizing the data, the findings were described. The key results are presented in the following chapter.

3.6 Reliability and Validity

Reliability refers to the extent to which measuring instruments are consistent. Bostwick and Kyte (1993, 121) state that “the more reliable our instruments and observations, the more consistent and dependable our results”. All interviews were conducted by the researcher to ensure consistency. Validity implies that the data collected should reflect the phenomena being measured (Reamer 1998). To ensure this the same interview guide was used for all interviews, though questions were not asked necessarily in the same sequence for each respondent. The findings of the study were compared with other studies investigating the same issue, to see if there are any similarities and difference and new insights on the issues explored.

3.7 Ethical consideration

Ethical approval for the study was obtained from the University of KwaZulu-Natal. Before conducting the study, the research proposal and consent form were submitted to the Ethics Committee of the Faculty of Humanities, Development, and Social Sciences at the University of KwaZulu-Natal. The ethical requirements as outlined in the University, were adhered to, in order to ensure the rights and privacy of the respondents are protected and respected. Prior to every interview, each respondent was briefed about the purpose of the study and was informed that his or her participation is entirely voluntary so s/he is free to participate or to withdraw any time s/he wish to do so. Verbal or written informed consent was acquired prior

to conducting interview with each participant. All respondents, except one, were able to sign the informed consent letter.

All respondents were assured of anonymity and confidentiality all times. Interviews were conducted in the respondent's rooms with only the researcher and the respondent present, with the exception of two interviews. One interview, at the request of the respondent was conducted with the respondent's friend present in the room during the interview. The other interview, the partner only went out for a few minutes and he came back in the middle of the interview indicating that he was not comfortable spending time outside since only their room is available to accommodate him even during the duration of the interview.

Respondents were assured that all personal information they have shared would be kept confidential and used solely for the stated purposes of the study; no response or comments would be linked to specific individuals upon the release of the study. For instance, in the data analysis some demographic characteristics of the respondents likely to reveal the identity of the respondents are omitted, such as the number of children and specific profession of each respondent. All respondents were left with a copy of informed consent letter, written in Zulu, which contained the contact details of the researcher.

3.8 Limitation of the study

Evidence suggests that disability and sexual and reproductive health remains a largely less attended-to issue in South Africa, as a result there was limited research to draw from. Rather, a growing body of research focuses on disability and HIV and AIDS and sexuality. Owing to this, the study relied mostly on studies conducted in other countries, for example, Zambia, Malawi, Uganda, and Cameroon, United States of America, Ireland and others. While, these studies proved useful in understanding access to sexual and productive health services for persons with disabilities, their applicability and relevance to the South African context remains somewhat limited.

Moreover, because interviews are time consuming and are not as economical as other methods such as questionnaires or telephonic interviews, it was necessary for the researcher to limit the number of interviews (16) conducted in order to make the project personally manageable. Furthermore, the findings from this study cannot claim to be a representative of the entire population of persons with disabilities in KwaZulu-Natal or South Africa. The research was undertaken in the city of Durban and all the information refers to experiences of persons with disabilities in Clarendon Home for the Disabled people. Thus, given the small sample size the findings of the study are not generalizable to all persons with disabilities in KwaZulu-Natal or South Africa.

Another limitation is the bias related to self-reporting especially on sensitive issues such as sexuality and reproductive health. As Alhberg (1994), points out, sexuality and sexual practices are such loaded subjects connected to identity and status- that reliability of people's report of their sexual behaviour can be questioned. Some respondents were uncomfortable to answer some questions; they will sometimes laugh or provide ambiguous responses. In order to overcome this, the researcher had to rephrase some questions this was done without changing the meaning of the question. Also the researcher was often referred as, "you, as a normal" person (without disability) by some respondents which might be an indication that respondents were not comfortable being interviewed by someone who is living with disabilities. In relation to this, the researcher attempted to establish trust with the respondents to ensure the issue of disabled or non-disabled does not influence the quality of data.

Other limitations lie in the method of data analysis. Qualitative analysis does not have direct procedures on how the data should be analysed, often they rely on the researcher's interpretation. Thematic analysis is a method that relies on the interpretation of the researcher and could lead to biases. However, the analysis was conducted systematically according to codes in order to draw out themes emerging from the data completed rather than preconceptions of the researcher. Also verbatim quotes were used to support and enrich the synopsis of the identified themes.

Nonetheless, the findings provide an important insight into access for persons with disabilities to sexual and reproductive health services. The study is not only intended to give persons with disabilities a voice but also find out what really matters to persons with disabilities in accessing sexual and reproductive health services, essentially in the era of HIV and AIDS.

CHAPTER 4 FINDINGS

4.1 Introduction

This chapter presents the findings of the study. In order to explore experiences of persons with disabilities with regards to their access to sexual and reproductive health services, the study first looks at the sexual and reproductive history of the respondents. It explores awareness and knowledge of services; factors facilitating use of services; barriers hindering access to sexual and reproductive health services for persons with disabilities; and finally, it considers their suggestions on how access to such services could be improved.

4. 2 Characteristics of the Respondents

In total, 16 in-depth interviews were completed. The study recruited a heterogeneous sample with respect to gender, age, educational attainment and types of disabilities. The purpose, however, was not to make statements about the study population but to come to an understanding of the lived experiences and perspectives of persons with disabilities regarding access to sexual and reproductive health services in Durban. The majority of the respondents were females (10) and 6 were males all residing in Clarendon Home for the Disabled in Durban, South Africa. The sample included persons with visual impairments: blind (5), partially sighted (1), partially sighted with albinism (1), one had multiple disabilities (blind and physically disabled) and 9 persons had physical disabilities. Persons with physical disabilities constituted more than half (9) of the sample. The respondents with physical disabilities were using assistive devices such as crutches, wheelchairs and calliper shoes.

The average age of the study respondents was 34 and their ages ranged from 27 to 46 years. Even though the respondents reported that they were single, a few were living with their partners at the time of interviews. Only one respondent was married. All the respondents were black South Africans with 14 Zulu speaking and 2 Xhosa speaking. Interviews were mostly conducted in Zulu. However, 2 of the respondents preferred to conduct the interview in English. All the study respondents were recipients of the state disability grants, with the exception of two who were formally employed. A few (4) respondents reported that they were self-employed. The types of income generating work that the respondents were doing

included, cane weaving and they sell their cane products to persons with disabilities in and around Durban. Others were doing bead crafts and some had small shops in their own rooms, in order to supplement their disability grants¹.

The level of education and literacy among the respondents was relatively high. Only, two respondents, one male and one female with visual impairments reported that they had never attended formal schooling and attributed this to the lack of education opportunities for people who are blind in South Africa. The public schools lack human resources and instructional material to adequately cater for the needs of children with different types of disabilities. As one of the respondents described his case:

“I lost my sight when I was 4 years. During those days Black disabled people were deprived of opportunities and their needs were neglected so I could not find a school. I only found a school when I was ten years old but they refused to accept me so as a result I never got an opportunity to attend school”. (IDI#1, male)

Of those who attended school, the majority had upper secondary school education, 2 of the respondents had completed secondary school education, 3 were in tertiary institutions and one female and male had graduate degrees and were employed as a lawyer and an electrical engineer respectively.

4.3 Understanding of sex

There were different levels of understanding of what is sex or sexuality in general amongst the respondents. The majority of the respondents, however, associated sex with emotional attaching, and safer sex, with the use of the male condom in particular. Some respondents understood having sex mainly as for procreation and pleasure. These are some of the responses that highlight these attitudes:

“To me it [sex] is the involvement of two people of opposite sex. Some people get involved, for instance if they are married or even if they are not married, for the purpose of making a baby. But others get involved sexually just to have fun”. (IDI#15, female)

¹ In South Africa If you are an adult (18 years or older) who is not able to work because of a mental or physical disability, you can get a monthly payment from the government called a disability grant. The amount of the grant changes every year. In 2012, the maximum grant was R1200.00 [\$141.55]per month.

“I understand sex as something you share with someone you are either dating or married to and I understand that if you are having sex it is important that you use protection”. (IDI=1, male)

“What I understand about it [having sex] is that you must know about protected sex. You must also know about sexually transmitted diseases and how to protect yourself.” (IDI#13, male)

It seemed that women with disabilities are interested in sex as a means of establishing emotional attachment. Often, they associated sex with love and raised the issue of being faithful to one’s partner as a means of protection against STIs whereas the male respondents appeared to be interested in sex for pleasure. For instance, one male respondent revealed that men with disabilities sometimes engage in risky sexual behaviours such as having sex with commercial sex workers. The following quotes demonstrate how men and women respondents differed in their understanding of sex:

“Sex is something that is meaningful and shared by two people who are in love with each other”. (IDI#3, female)

“Sex is something you do to get pleasure with a person who is your partner at that time.” (IDI=12, male)

“My understanding is that sex is something you only enjoy with someone you love and you must be faithful to that person. However, you cannot trust a man because you can never be sure what he gets up to if he is not with you”. (IDI#2, female)

“Sex involves especially falling in love but some of us love sex so much that we go and look for sex elsewhere, like a service with sex workers”.(IDI=5,male)

Women with disabilities expressed the concerns that they are often perceived as not sexually active and are therefore assumed to be virgins. From their experiences, a few female respondents mentioned that some (non-disabled) men approach them with the intentions of having sexual relationships with them not because they have real affection for them. Women reported that, this subjects women with disabilities to verbal abuse in particular when they are found not to be virgins. On the other hand, respondents mentioned that men take their virginity away and leave them for other (non-disabled) women. Women with disabilities felt that this put them at risk of sexual transmitted infections because men seem to have other

sexual partners while they are in a relationship with them. The following quotes highlight these experiences:

“People always assume that we do not have sex! Disabled people do have sex. Sometimes, men, especially men who are not disabled think that, because you are disabled you are a virgin. They assume that no one asks us out, because we cannot walk, we are confined in one place therefore no one sees us. Then they approach us with that mentality, but then when they find that we are actually not virgins they call us names, “saying these people are sluts”. (IDI#11, female)

“Some men, they look at your disability, and then he pretends as if he loves you whereas he does not love you. He only wants to use your body then after some time he abandons you just like that and get new girlfriends. In some cases, men look at your disability and date you just to pass time. You find that, you are a virgin, you have never slept with any man, and then they would undermine you because of your disability and infect you with sexually transmitted diseases. He will also have other girl friends on the side and because of his mischievous behaviour; he ends up getting sexually transmitted diseases and infects you as well”. (IDI=8, female)

One male respondent expressed the same concern and said,

“There is a belief that a person with disability does not get HIV you see, so even people without disabilities when they see a pretty girl with disability they will assume they are safe. This belief is based on the assumption that she live in one place and she only dates people who are like her, you see. There is still that mentality that persons with disabilities might not have HIV”. (IDI#1, male)

Women with disabilities felt that some of this arises out of men’s fear of identifying themselves as having girlfriends that have disabilities. One respondent explained,

“You see, sometimes, some men are scared to ask us out even if they love you, because they are scared what the society will say if I am dating her because she is disabled. They look at you, you are a problem, and you are a curse. You are not accepted in the community”. (IDI#16, female)

The above response suggests that women with disabilities sometimes find it difficult to form intimate relationship, mostly because of societal discriminatory attitudes towards persons with disabilities. Also the misconception that they are virgins may subject them to sexual exploitation thereby increasing their vulnerability to STIs including HIV and AIDS infections.

4.4 Knowledge and sources of information about SRH services

4.4.1 Knowledge and awareness

All respondents indicated that they have heard about family planning, sexual transmitted infections including HIV and AIDS education, prevention and treatment; HIV counselling and testing; antenatal and postnatal care clinics and termination of pregnancy or abortion; suggesting that awareness of sexual and reproductive health services were relatively high among the sampled persons with disabilities. Awareness of HIV and AIDS was similar among respondents, irrespective of gender, level of education or nature of disability. The findings also showed that persons with disabilities had working knowledge about STIs including HIV and AIDS. The following quotes highlights how respondents described their knowledge about sexual and reproductive health services,

“I know about all these things. I know about contraceptives. I also know about family planning. With regards to HIV and AIDS I even did counselling, isn’t VCT about counselling? I have been trained as a peer educator or lay counsellor if you would like to call it that”. (IDI#7, female)

“People need to understand that just because we are disabled it does not mean we cannot get involved in things like sex and so on and we do know that there are things like STIs and HIV and AIDS. On the radios they always talk about those things. Also there are places, meant to assist people with disabilities, like the KZN society for the Blind at Umbilo. They taught us how to do things on our own as people who are visually impaired. They educated us about HIV/AIDS, STIs and so on. So we do have knowledge, it is up to an individual whether they choose to behave responsibly or do what is inappropriate”. (IDI#10, male)

“I was part of Love Life ²programmes and I have also been part of Ground Breakers, so we used to visit schools and teach young people about responsible sexual behaviours, about how they should behave themselves. We were advising them on how they should behave themselves at home and if they have started engaging in sexual intercourse, how they should protect themselves against diseases”. (IDI#8, female)

These expressions illustrate that persons with disabilities are aware of sexual and reproductive health services. Some respondents have received formal training in HIV and AIDS as peer educators. They have also been involved in HIV and AIDS awareness training groups within communities.

² Love Life is South Africa’s largest national prevention initiative for young people launched in 1999.

4.4.2 Sources of information

The respondents indicated that they have obtained information on sexual and reproductive health matters from various sources. The majority mentioned that they have received information through health facilities, that is, hospitals/clinics followed by schools and peers with disabilities. This suggests that these are many available and accessible sources of communication for persons with disabilities in the study. As noted in the study, only two of the respondents reported to have obtained information, especially about HIV and AIDS from the mass media, radio in particular. Those who are visually impaired mentioned that they have never obtained information on sexual and reproductive health services through printed media. They indicated that there is no information available in alternative formats such as Braille or audio compact discs which would be accessible to them. Moreover, often they do not have anyone to read pamphlets that contain information on sexual and reproductive health for them. A few respondents (5) mentioned also to have received information about HIV and AIDS, STIs and their effects from organizations working with persons with disabilities in Durban, for example the Natal Society for the Blind. These are some of the responses describing how respondents heard about sexual and reproductive health services,

“In 2001, I attended a hand craft training offered by the Natal Society for the Blind; during the training we had workshops on HIV and AIDS, sexuality and things like that. There were social workers and nurses, they use to play audio compact discs (CDs) and we listened to how you get infected and what are the effects and stuff like that. They first played CDs that explained about diseases such cauliflower, for example, if you are someone who usually gets these diseases [STIs] you might give birth to a disabled child and sometimes you might even become barren if you usually contract sexual transmitted diseases”. (IDI#1, male)

“I received information at Chest clinic located at Market Street next to Durban Christian centre because they deal with all these things of STDs and testing. But I first received information at the hospital when I was pregnant with my first child”. (IDI#2, female)

It appeared from the study that health care services in South Africa have made it mandatory for all pregnant women attending antenatal clinics to undergo HIV testing. These women are offered counselling and informed about the importance of testing for HIV and how that could reduce mother-to-child HIV transmission, as expressed in the following quote:

“When you are pregnant, whether you like it or not at the clinic and hospital they tell you about everything. You also get tested for HIV. Before you are tested, you get counselling, they explain why you need to go for HIV”. (IDI#6, female)

Though the respondents stated they have some factual information and working knowledge on sexual and reproductive health services, the vast majority (14) of the respondents were of the opinion that they needed to be educated more about such services, in particular about matters relating to contraceptive methods and related side effects; types of sexually transmitted diseases so that they could make more informed choices regarding their sexual and reproductive health. Respondents stated the importance of having knowledge and information about sexual and reproductive health services and the risks associated with lack of factual knowledge. For instance, they mentioned that knowledge about contraceptives and STIs would not only improve their sexual and reproductive health but also reduce the risk of having many children that they will struggle to support.

“I would like more information on contraceptives; I have heard lots of scary stories about them”. (IDI#3, female)

“Recently I heard my friends talking about cauliflower; I do not know what that is so those are just some of the things we are not educated about. I do not visit the clinic frequently and when I do, I go for a specific illness and I get treated for that, you see, as someone with a disability [blind] I am unable to read most of the stuff for myself I only get such information and help when I visit the clinic”. (IDI#2, female)

“If you do not have information about the things we have been talking about [SRH services] that might put you at risk of not even completing 40 years because of these diseases. You can also be at risk of having many children that you cannot even afford to support”. (IDI#1, male)

Respondents suggested that awareness programs about services should include practical information such as demonstrating to persons with disabilities how to use condoms properly. They mentioned that persons with disabilities are often left out when it comes to sex education, including programs that educate people on how to use condoms properly, mostly with the aim of mitigating the spread of HIV and AIDS. As a result some cannot use condoms effectively. Some respondents stated that there have been poor efforts in educating women with disabilities about female condoms hence most of them have never even seen a female condom before. One respondent explained,

“A friend of mine told me that he does not know how to use a condom. He told me that he keeps on turning it incorrectly and by the time he turns it the right way his penis is no longer erect. I feel this is a problem; if people are not trained how to use a condom properly, they would tend to engage in unsafe sex when they are in a hurry. Also, most women with disabilities have never been told about female condoms. They conducted a workshop once in Pietermaritzburg where they were educating women who are blind on how to use a female condom. Some of them did not even know about it and they have never touched it. Those are some of the challenges that we face and you find that we get exposed to these diseases”. (IDI#1, male)

The lack of adequate knowledge on how to use condoms properly will contribute to low and inconsistent use of condoms among persons with disabilities. In the context of HIV and AIDS and sexual violence and where a female condom is considered the only tool enabling women to take the initiative in protecting their own reproductive health and that of their partners, it should be a matter of concern that women with disabilities cannot use the female condoms let alone having never seen one. Awareness and relevant information on sexual and reproductive health services should be made available and must be tailored to their individual needs.

Respondents revealed that they have never received information about contraceptives, STIs, including HIV and AIDS from their immediate family members, such as parents and siblings. Respondents said that often their sexuality is regarded as a very sensitive matter among their families and in general they are viewed as not sexually active or engaging in sexual activities by their families. Respondents mentioned that persons with disabilities are often viewed as children and as a result marginalized in terms of sexual education and reproduction matters. So they never get an opportunities to properly learn about sex at a younger ages compared to their non disabled peers. They stated that some families believe that children with disabilities should be kept in doors. Sexual education is an important part of giving people knowledge and creating awareness about safe and unsafe sexual behaviours. One respondent stated,

“When I was growing up, as a young woman, no one was willing to tell me about sexual issues, because these are very sensitive matters for us. Instead they whisper, no, no, no, we do not talk about those things when she is here. Also it is very difficulty for me because I am disabled or I am blind to reveal that I sometimes desire sex, I’ve got this desire, you see because it is a shame. When you start your menstrual period, you are not told, that you see now, you are entering puberty and you can fall pregnant at any time. To them [families] even those menstrual periods you started as a disabled or a blind person, it is a shame, why could it happen to her, you see. Then when you fall pregnant it is when they started to go mad. It is when they start to say, no she must go for an abortion, we are not ready for this shame, what would people at

church say, what would the community say? No, no, no, we can not stand the shame". During my first pregnant it was like I have killed 100 people. No one was willing to stand behind me and understand my position. You are not accepted in the community. Your family, rejects you, they reject you". (IDI# 16, female)

The above response points out that there is a diversity of needs among persons with disabilities with regards to sexual and reproduction education. Their families are often silent around reproduction matters which make it difficult especially for women with disabilities to understand even their first menstrual periods. This has many implications including unplanned and unwanted pregnancies. Their pregnancy is often regarded as bringing a shame to the family therefore pregnant persons with disabilities are often encouraged to undergo abortions instead. This reflects and reinforces discrimination against persons with disabilities with respect to their sexual and reproductive health. Respondents expressed that the failure of parents and families to understand that children with disabilities are sexually active might put persons with disabilities at risk of being sexually abused without even able to report the perpetrators, either because no one would believe them or the perpetrators scare them into not talking about the incident to anyone. Respondents mentioned that in some instances the perpetrators are family members. They take advantage of persons with disabilities because of their lack of knowledge on sexual matters. Respondents considered these as important issues especially in the era of HIV. Respondents knew some women with disabilities who have been victims of rape and the families never believed them. These are some of the comments made by the respondents.

"Other blind women will tell you, that at home I once told my mother that I was raped and my mother she did not believe that she was raped, who will rape me. I stayed with that wound, with that pain, you know with that bleeding wound that no one would like to believe me. Also at home or the societies, they do not make us ready for the outside world, to tell you what is happening, because you are also a girl". (IDI#11, female)

Another respondent said,

"The majority of disabled people have never been exposed to disability centres like the Natal Society for the Blind so they never got an opportunity to be educated about sexual matters. To know something you need someone to inform you. It is an unfortunate situation especially for our peers in rural areas. They do not know anything as most parents believe that if you are disabled, you just eat and they lock you in the room even though they hear every day on the radio about educating their children about HIV. Our families do not understand that having a disability does not mean you are not a human, you see. They assume you cannot engage in such things. So this means that even if you are raped you cannot talk or report it because they will

doubt you. So you can get infected with HIV, because obviously rapist would not use a condom. You cannot even report what happened because they would ask “where you heard that? Stop making up stories! You see. So there are those challenges if you are disabled, especially if you are blind”. (IDI#10, male)

Correspondingly another respondent commented,

“Most disabled people are sometimes abused by their family members. They do not understand sex, if a brother or an uncle puts her between his thighs because she is blind and she has never seen this thing even on television so she does not understand that now I am being abused and I thought this thing is nice or is right. The uncle will say keep quiet and do not inform other people. So sometimes you get abused on those things because there is a lack of knowledge”. (IDI#12, female)

The respondent added that the institutions and special schools for persons with disabilities also do not educate them about sexual and reproductive health matters. Respondents reported that in cases where persons with disabilities are sexually abused and raped they are not given the proper help they need by the police. Rather when they go to the police station, they are mocked and ridiculed by the police officers that are supposed to assist in convicting the perpetrators. One respondent explained,

“Even our institutions and the schools for persons with disabilities do not talk to us about sex and stuff. Most of the communities always think that sex is something not for us, you see. At some point in time I was told that somebody was raped and she was deaf and when she got to the police station to report the matter, the policeman said to her: so why are you reporting because you felt it was nice. You enjoyed it, you see, you see. So there is a lot that disabled people need to be educated about”. (IDI#16, female)

In the interviews it was clear that there were concerns raised about families failing to inform children with disabilities about sexual and reproductive matters, only one respondent mentioned parents and families as responsible for educating their children with disabilities about such matters.

“For such things, I am sure we all have parents, relatives and whatever. You see, I believe parents have to play a role in educating their children about such things. However, they should not assume that because the child is disabled therefore such things are not important to them. It is important for all children and disabled people all over the world to be educated about such things”. (IDI# 10, male)

4.4.1 Preferred sources about SRH services

Respondents believe that it is the responsibility of government and professional health workers to deliver information about sexual and reproductive health matters. They also mentioned other sources for disseminating information such as radios and groups involved in raising awareness within the communities. The majority of the respondents felt that educational information should be mainly distributed through public health facilities and efforts should be made to ensure that information is widely available and accessible to persons with disabilities in South Africa. This will enable them to expand their sexual and reproductive health knowledge and choices. Further, it will benefit persons with disabilities in relation to their sexual and reproductive health intentions and needs. Respondents believed that health service providers have factual information and knowledge and therefore should play an important role in generating awareness among people who seek contraceptive methods, HIV counselling and testing, antenatal care and education on STIs including HIV and AIDS. Respondents were of the opinion that health service providers are trained to provide sexual education and this would minimize the spread of STIs/HIV thereby cut down on treatment costs for the Department of Health (DoH) in South Africa. Respondents also mentioned that health service providers have the responsibility to maintain and respect client's privacy which would make them comfortable to talk about sexuality and reproduction matters. Some of these issues are clear in the following comments.

“I think the public health is where they should teach persons with disabilities about contraception. For instance, we are here at Clarendon Home, there are blind women, but you cannot see the nurses or public health professional or whatever health institutions coming to us and advise us about STIs and HIV and other things like family planning. As a blind person I cannot take a pamphlet and see what is written in the pamphlet, for instance”. (IDI#16, female)

“The department of health has to play a huge role because they are responsible for the treatment. So in order for them to cut down on treatment costs, they must invest more in educating and preventing new STDs and AIDS infections”. (IDI#1, male)

“I believe clinic workers are the only people who are trained to educate about such things. Also the clinics are open and accessible to everyone”. (IDI#2, female)

On the other hand respondents pointed out that some persons with disabilities have difficulty reading information at SRH services or reaching clinics due to the nature of their disabilities. In relation to this, respondents recommended that sexual health awareness raising groups should visit places like Clarendon Home where persons with disabilities live together. Respondents mentioned also that non-governmental organizations focusing on health matters

should do more to reach persons with disabilities. Respondents further mentioned the power of the mass media such as the radio to reach those who are blind and cannot access information through printed media.

“The NGOs that deal with health issues must come down to people with disabilities”. I think the radios should be playing important role, that is, they should continue making those awareness because as women who do not have access to pamphlets or documents because in most cases they are written in a way that exclude us as blind people. So that we can listen, you understand”. (IDI#16, female)

“I believe, as we are living in this flat and all of us are disabled, if. It’s just that the nurses are sometimes very disrespectful. But if there could be people that visit places where people with disabilities live together because it is hard for them to go to the clinics by themselves and stuff. So yah if there could be people who go to the centres where they live”. (IDI#7, female)

4.5 Sexual behaviours and contraceptive use

4.5.1 Sexual behaviours

As mentioned in the previous chapter, the study targeted men and women with disabilities who are sexually active on the premises that sexual activities and relations are most likely to increase one’s possibilities of needing and using sexual and reproductive health services. In relation to sexual behaviours, all the respondents had sexual intercourse, penetrative vaginal sex in particular. Fourteen respondents revealed they were sexually active during the time of the interviews, more so those with live-in partners. The estimated average age at first sexual intercourse is 20 years. The male respondents reported earlier sexual debut than the females. The age of first sexual encounter among the respondents ranged from 12 to 25 years for males and 16 to 30 years for females. All respondents reported their first sexual intercourse was voluntarily but not an informed decision. The findings suggest that peer pressure and curiosity to explore one’s sexuality seemed to be some of the reasons to engage in sexual intercourse, this reasoning was particularly common among males. Some male respondents described their first sexual encounter as follow:

My first sexual intercourse was maybe at the age of 12. Sometimes you start sex at the level where we do not even know anything, you are just curious because your friends are doing it. You know when you are a child you do not even ejaculate you just do it for fun and once you grow up it is more about the pleasure of knowing how it feels to sperminate. (IDI#5, male)

“I think I was 16 when I started to engage in such things[sexual activities]. You see I grew up in a township so by then I was aware about lots of things. You see, life in the

township is very fast. I was engaged in such things at a young age up until now".
(IDI#10, male)

The majority of the respondents revealed that they had previously contracted a sexually transmitted infection. The STIs that were mentioned by the respondents included: itching in their private parts, painful urination, rash in the private parts, and smelly discharge as well as HIV and AIDS. Of those contracted sexual transmitted infections they sought treatment and vast majority from public health facilities. It appeared that the majority of the respondents had used all public health facilities located within the city of Durban. Two female respondents said they went to chemists and bought pills to treat their STIs because they felt it was not necessary to seek help from the public health facilities. Two male respondents revealed that they are HIV positive and they were taking antiretroviral (ARV) medication. This reveals that persons with disabilities are also at the common risk of contracting HIV as the general population in South Africa. Therefore prevention, care, support and other HIV interventions must target this segment of the population that seemed to have been largely isolated, in particular when it comes to sexual and reproduction matters. This is, partly because of the misconceptions that they are asexual or unable to engage in sexual activities. The respondents talked openly about their HIV status and their visits to the health facilities for sexual and reproductive health services.

"My partner was tested HIV positive when she was pregnant. Then I thought maybe I might also be infected and I discovered that indeed it is like that". (IDI#13, male)

"I am on ARVs so I visit the hospital now and then. I started ARVs in 2008 March. So every month I go to Addington hospital to collect my treatment, like next month on the 15th of September I am going there again". (IDI#12, male)

The majority of the respondents had children of their own. Only two males said they never had children. One respondent reported that he has 7 children from different mothers. All women with disabilities in the sample indicated that they were taking care and raising their children. And while the vast majority of them appeared to manage well with childrearing, one female reported needing some sort of assistance when she has to take her child to the clinic for immunization. One of the female respondents mentioned that her husband, who also has a disability, is the person who usually assists her, with the childrearing responsibilities, like taking children to the clinic. She stated that,

“Sometimes my husband has to take our last born to the clinic for the medication or things like flu because in my condition it is not always easy to get to the clinic and wait in those long queues”. (IDI#11, female)

The responses and the number of pregnancies suggest that all respondents practiced vaginal penetrative sex thereby refuting the general view that persons with disabilities are asexual or are unable to perform sexual intercourse. To emphasise that persons with disabilities are as sexual active as non-disabled people, respondents described sex as something that comes naturally and expressed that human beings as they mature they feel the desire for sexual intercourse regardless of one’s disability status.

“They just see that you walk with crutches, you are on the wheel chair and they assume you are incapable of doing the job[sex] properly, therefore what are you going do with the condoms” (IDI#1,male)

“I think sex is something which is natural as a person grows to be an adult one of her needs is to enage in sexual relations. They develop sexual feelings therefore they find themselves having sexual intercourse. You see, sex is something which really proves that a person can be disabled or cannot be disabled but it is one of the things that a person may or might have a desire of having sexual contact with another person”. (IDI=16, female)

It is apparent that the respondents face various sexual and reproductive health problems as they revealed that they experienced STIs, sexual abuse and some were HIV positive. Moreover they are interested in establishing their own families and raising their own children, suggesting that persons with disabilities have a great need for services.

4.5.2 Contraceptive use

The vast majority (14) of the respondents reported that they are using some modern method of contraception. The contraceptive methods used included male condoms, injection and pills. The male condom was the most cited method of contraception. Amongst female respondents, a total of 4 were currently on birth control injections. Respondents mentioned that they used condoms particularly to protect themselves against sexually transmitted diseases including HIV and AIDS. This suggests that person with disabilities use condoms especially to protect against the risk of contracting HIV and AIDS, as described by the following respondents,

“If you are sexually active it is important that you use a protection. You must protect yourself. I usually use condoms so to make sure that I am well protected against sexual transmitted diseases”. (IDI#1, male)

“I do not use any contraceptive method but I use condoms every time I am having a sexual intercourse. I do not want any problems because there are many diseases nowadays”. (IDI#12, male)

On the other hand, a few respondents revealed that safer sex by using condoms was not always practiced, particularly when there is established trust between the couples. Trust was attributed to the duration of the relationship. Condoms were more likely to be used with partners whose sexual history was not known to the respondents. A few respondents mentioned that if they live together or have children the relationship evolves into a more stable one then they do not use condoms regularly during sexual intercourse or they discontinue using condoms altogether. This suggests that condom use decisions among the sample somewhat reflect the commitment, trust and meaningfulness of the relationship. Some of the reasons mentioned for the inconsistent use of dual protections are spontaneity in sexual relationship. Sex sometimes happens unexpected, that is, they get caught up in the spur of the moment. These are some of the quotes that illustrate this,

“I do not use any contraceptives. I do not want to lie. Even those condoms, I do not use them”. (IDI#3, female)

“For me I do real sex. I mean I engage in unprotected sex. I used to engage in protected sex but not now. I have been living with the father of my children for a long time now. This is our fourth child”. (IDI#14, female)

“Normally, if I do not know that person’s history sexual and I do not trust them, I tell him to use a condom because I want to keep my HIV status negative”. (IDI#8, female)

“To be honest even though we know about these condoms and stuff and we do use them, but sometimes it is not always the case. You do get caught in the moment especially when you are living together, things just happen and you forget about the condom”. (IDI#1, male)

The reported inconsistencies in the use of condoms, the occurrence of STIs including HIV and AIDS infections and the number of children borne suggests that persons with disabilities have a great need for sexual and reproductive health services. Therefore their needs and rights to

access services cannot be neglected. They should have access to sexual education and reproductive health services in order to enable them to make informed decisions. Essentially, educational programmes should emphasis on the risk for HIV transmission via unprotected sex. For instance, some respondents believed that persons with disabilities are at increased risk of HIV infections. They mentioned various contributing factors including, sharing of sexual partners and inconsistent use of condoms. Respondents mentioned that because persons with disabilities are grouped in one place this has an influence on their sexual behaviours: they tend to share sexual partners while on the other hand they do not use condoms consistently which increase their risk of STI and HIV and AIDS.

“They are at increased risk of HIV because these people love sex. They do not protect themselves. It seems as if they undermine condoms. They claim that condoms are not that safe. I believe if you cannot use a condom, you must abstain from having sex. People here [Clarendon Home], I do not think they use condoms; lots of people here are pregnant. People in this flat impregnate each other” (IDI#9, male)

“They are at greater risk, much greater risk. For most of them it is like they do not like prevention [using contraceptives], they are at greater risk. I have dated a couple of blind people and I noticed that they do not like using a condom. You see, I am usually the one suggesting a condom and I told them that I will not sleep with them without a condom. I even suggested that we break up with this other lady because she did not want us to use a condom. I told her, I will not sleep with you without a condom. I was not aware by then that I have this problem” [HIV positive]. (IDI#12, male)

“I really think that we, blind people we need to be informed more about HIV. I feel that we are at the increased risk of infection , I am not sure if we undermine ourselves too much or it is because we are grouped in one place, we have a tendency of sharing men; you find that I have an infection and everybody will contract the same disease because we share boyfriends. So I feel we really need more education on HIV”. (IDI#2, female)

“I will say they are at greater risk of HIV infections because, they are always having sex and you find that they do not use protection you see and sometimes being grouped in the same environment is a disadvantage. Let me just tell you the truth, as you can see our rooms are next to each other, take for instance these four rooms, let’s say you are aware that your neighbour is not around and his “fat girlfriend” is left alone and then you just cross next door and you hit and run [have sex] you see? You see, they need to be educated that they should don’t be mischievous when it comes to sex, but not everybody behaves like that”. (IDI#1, male)

It seems that many respondents share sexual partners and this increases the risk of STIs (including HIV and AIDS). Persons with disabilities are not at risk of contracting STIs including HIV because of engaging in sexual intercourse but rather because of the lack of use of protection.

4.6 Use of sexual and reproductive health services

The use of sexual and reproductive health services was probed by asking the respondents if they have ever visited the clinic or hospital to seek any of the sexual and reproductive health mentioned above. All respondents said that they have visited health facilities, that is, clinics or hospitals for sexual and reproductive health services for various reasons, including HIV counselling and testing, STIs treatment, contraceptives, HIV and AIDS services and prenatal care and post natal care clinics. More than half (9) of the respondents claimed that they go for routine HIV and AIDS check-ups. Knowledge of HIV and AIDS appeared to influence the use of male condoms as a main method of contraception though it was neither universal nor consistent as it has been discussed above.

A few female respondents mentioned that they have been to the healthcare clinics because they had problems with their periods and they attributed this to birth control injections. Women with disabilities in the sample stated that the problems experienced resulted in the discontinuation of contraceptive methods. One of the respondents mentioned that she visits health facilities regularly for sexual health screening such as routine pap smear and also for breast cancer check-ups. She mentioned that this is due to the nature of her disability. All female respondents reported that they have used antenatal and post-natal care clinics for routine check-ups during pregnancy, birth delivery and children's immunisation. It appeared that women with disabilities understand the importance of antenatal services for their health and that of their children.

“I have children so every month I take my younger one to the clinic for routine checks and vaccinations. I will do so until she is 12 months and from there I will take him again when he is 2 years and the last immunization will be when he is 5 years”.
(IDI#14, female)

“I have six children. During all my pregnancies I had to attend antenatal clinics. They [healthcare providers] do a routine checks to monitor how the baby is growing and the position of the baby in your stomach. They also check the heartbeat of the baby. During pregnancy you have to do different tests. You have to check your sugar levels, do blood tests and so on”. (IDI#11, female)

It appeared that the majority of the respondents were prompted by illness or a need for a service at that particular time and never a desire to seek more knowledge on sexual and reproductive health matters. And this was more so with the male respondents and some of the reasons cited is that they do not have time to visit healthcare facilities due to work commitments and that they hardly ever get ill. Some of the typical responses when the male respondents were asked about the reasons for visiting health facilities for sexual and reproductive health services were:

“I last went there in 2009 because I was sick, I had a drop [STI] and that was it. I do not like clinics and I do not think I will go to the clinic for condoms. I hardly get sick and if I do it is not something that would need a doctor.” (IDI# 10, male)

“You see, I was ill so I went to the clinic to get tested. The test results came back and indicated that I was not alright. Then I was put on counselling for 3 months, then after that they informed me that I have to start with HIV treatment that I will have to take for the rest of my life. That is why now I always go to Addington hospital”. (IDI#13, male)

Male respondents reported that they seldom visit health facilities for sexual and reproductive health services, with the exception of two who are on HIV and AIDS treatments. Some of the reasons mentioned for this are that male condoms are widely available. Males said they can access condoms either from schools, public places or buy them from the pharmacists. The male condom was the only family planning method mentioned and used by men with disabilities in the sample. Essentially, awareness of the risks associated with unprotected sex influenced the reported usage of condoms among males with disabilities.

“I hardly go to the clinic for those things [SRH services], because condoms are available at school and I get them for free”. (IDI#9, male)

Another male respondent expressed the same view and said,

“The thing is you can get condoms in every government offices or departments, such as police stations, most of the time when I pass by the police station I take some and

also at the councillors office if it happens that I go there, condoms are available everywhere.” (IDI#1, male)

The issues affecting the use of public health facilities for sexual and reproductive health services among males seemed to extend beyond health settings. For instance, male respondents stated that they do not obtain condoms from public health facilities because they are uncomfortable and too shy to ask for condoms as they may be seen by other users. From the interviews it transpired that some respondents both females and males would prefer condoms to be deposited somewhere within the health facilities so that they would not have to interact with health service providers and will also avoid being seen by other users. This suggests that sexual matters are viewed as taboo and private subjects among persons with disabilities in the sample. For instance some respondents said,

“It is very uncomfortable to ask someone details about sexual matters. For me it is just a taboo, it is a bit of a taboo to talk about sex unless I am used to you but to a stranger it is very scary”. (IDI#4, female)

“I am too shy to go to the clinic to ask for condoms, at least if they could be deposited somewhere where I can go and fetch for myself, without having to talk to anyone. The thing is it is known, there is only one thing you could use a condom for”. (IDI#9, male)

“Sometimes you will see condoms, I would like to take them but I’m afraid of what the people around me might think or say. You feel ashamed because you are disabled and what would people say. You fear that they would make assumptions about my disability and question if I am also sexually active. I have that fear and it prevents me from taking them. Then what happens is I end up not taking the condoms”. (IDI#4, female)

Also there was a perception among the male respondents that condoms distributed through public health facilities are not of good quality hence they would rather seek SRH services from the private health sector. One respondent stated,

“I buy condoms I do not think I would go to the clinic for condoms. I believe that I should always buy them because a friend of mine who is the doctor once told me that the government condoms are not guaranteed. I took that very serious because he is a doctor, and I believed what he told me. I only go there to check my status”. (IDI#10, male)

Among the male respondents, it also appeared that the gender of the health service provider can be a discouraging factor to seek sexual health services. Some males mentioned that they feel uncomfortable consulting with a female nurse because they felt that they might ridicule them when seeking treatment on sexual matters, for instance, for poor sexual performance. As a result, men with disabilities often avoided visiting health facilities for health problems relating to sexual and reproductive health matters,

“Sexual health services for any man, even those without disabilities, to stay away from you know, because you find that most nurses are females and they do not have a way of talking to us in the manner that encourages us to visit those health services. For people with disability it is much more of a problem because if a non disabled man gets scolded like that and is spoken to in an irresponsible fashion how much more if I am disabled. In 2006 I learnt that in the hospital in Newcastle a deaf guy was slapped on his face for coming to test for HIV. He was slapped by a health official”. (IDI#5, male)

“There are certain things you feel uncomfortable talking about especially if the service provider or the person I am with is a woman. If my sexual performance is a challenge most likely the woman will laugh if I am coming to address such issue so its not something which makes one feel uncomfortable to go to these things”. (IDI#13, male)

The frequency of visits to the health facilities for sexual and reproductive health services differed significantly amongst the respondents and between males and females. In general, males were less likely to visit these services than females. The interviews suggest that knowledge and awareness of sexual and reproductive health services does not necessarily translate into high usage of the mentioned services. The study then probed for factors that could potentially influence the use (or lack of thereof) of sexual and reproductive health services among this sample of persons with disabilities. Respondents were asked to reflect on the experiences with access to sexual and reproductive health services.

4.7 Experiences with accessing SRH services

Respondents reported both positive and negative experiences with regards to accessing sexual and reproductive health services. Respondents mentioned factors that facilitated and discouraged the use of SRH services.

4.7.1 Factors facilitating used services

Some of the factors influencing use of services included level of comfort at health facility, satisfaction with the services received; maximum privacy and confidentiality during the visit. A few respondents, especially females said they were comfortable visiting the healthcare facilities and felt that they could talk about sexual and reproductive health matters; including contraceptives, antenatal and postnatal care services, STIs treatment and HIV testing and counselling and this was so if on their first visit, the service providers gave them sufficient time during consultation; were respectful and attentive and also understood disability. This suggests that the quality of care- including respectful, politeness and friendly treatment is one of the most important aspects for persons with disabilities seeking SRH services. The following quotations illustrate this:

“I find it easier to talk to nurses about sex and other issues, especially if I will consult with a nurse who understands disability”. (IDI#3, female)

“When I had a drop I did not have a problem going to the clinic to seek treatment. I was comfortable and also I have been there for HIV testing. I am a talkative person so I do ask quite a lot of questions. I do not have any problem talking to the nurse or a social worker about those things, especially if they answer my questions with respect”. (IDI#5, male)

“I do not have a problem going to the clinic for these things [SRH services] but it depends on the personality of the nurse, some nurses are very disrespectful while others are nice”. (IDI#4, female)

In contrast, respondents argued that it is hurtful if the health service providers seem not to be paying attention to their needs or seemed not to be giving them sufficient time to discuss sexual and reproductive health problems and felt that any exhibit of slack treatment from the providers is because of their disabilities.

“Sometimes you consult with a nurse who talks to you just anyhow, who seems not to have time for you, it is very hurtful you even wonder if it is because you are disabled that is why he or she talks to me like that”. (IDI#6, female)

When you get there they say you are just sitting around and having sex that is the only thing you know”. (IDI#1, male)

Another factor often mentioned to facilitate the use of services by persons with disabilities was being satisfied with the service received on previous visit to the clinic or hospital. The level of satisfaction was largely attributed to health service providers' attitudes and behaviours during consultation, examination and treatment. Respondents said they were satisfied with the services because their privacy during the consultation was respected. Respondents felt that their privacy was maintained during consultation and treatment because the health service providers ensured that the door was always closed and they were alone in the consultation room. Also their personal needs and health information was kept confidential. Respondents stated:

“They respect my privacy because during consultation, I am alone in the consultation room with the nurse. I feel comfortable to tell her my problems because the door is always closed”. (IDI#2, female)

“I am very happy about the service I receive every time I go there. Also I am satisfied about the level of privacy between me and the person I am consulting with. I remember, in 2009 when I was sick [had an STI] they respected my privacy, the nurse I consulted with is a very close family relative but she never discussed it with them. She was very professional”. (IDI#1, male)

This, however, was not the case with all the respondents. Respondents with visual impairments in particular reported negative experiences and dissatisfaction with the quality of care received when seeking sexual and reproductive health service from the public health facilities due to lack of privacy. They felt that health service providers are not sensitive to the circumstances of persons with disabilities when addressing their sexual and reproductive health needs. Respondents reported instances where health providers discussed among each other when a person with disabilities presented them with a pregnancy or STIs. Also the providers are said to have failed to provide explicit information about their prescription. Respondents said that nurses assumed that persons with disabilities will not understand their prescriptions so they discussed with their colleagues hence breaching the rights of clients with disabilities to be treated with respect and dignity. Respondents indicated that they usually inform the health service providers that it is not necessary to invite a third person in the room because they can follow their advice if everything is explained to them and their prescription is marked properly. Respondents described the health service providers' tendency to discuss their personal issues with others as discriminating against persons with disabilities seeking sexual and reproductive health services. The following response

illustrates some challenges that persons with disabilities encounter when they visited the health care facilities for sexual and reproductive health matters,

“They do not respect it [privacy]. They call each other to discuss your problem. You see, at Addington hospital, it was really a process, even for a simple thing such as getting me to sign the papers. They assume it is complicated because I am blind. Even for my blood results, I told her [health worker] just tell me my results no matter what, I will accept them. No, instead she went out and brought another nurse, I am not sure for what. Hey life is really difficult outside there my child, the nurses treat us badly. If you have sexually transmitted diseases, they will say, see!!!”She is rotten, she likes men being blind! If you are on HIV treatment, I do not know why they find it difficult to and complicated on how they should mark your pills. These are some of the things I have experienced at the hospital”. (IDI#14, female)

The respondent said this deters persons with disabilities from seeking sexual and reproductive health services or causes them to delay seeking treatment early.

“You see, because of this, you end up reluctant to go to the hospital to seek help. You, rather stay at home while the disease continues eating you just because of the way the nurses treat us. I think those are some of the reasons even why many disabled people might have diseases such as HIV and AIDS”. (IDI#14, female)

Among females the treatment received during first pregnancy seemed to strongly influence whether they would return to public health facilities for sexual and reproductive health matters. A few women who were dissatisfied with the treatment received during pregnancy indicated that they have opted to seek services from the private health sector for their subsequent pregnancies. They felt that the public health facilities do not cater for the needs of persons with disabilities. For instance, they mentioned that the toilets are located far from the delivery rooms and nurses are usually not willing to assist.

“In public hospitals it is very difficult, normally in my last pregnancy I utilized the private one because there they have time to talk to you. They treat you with dignity because they know you paid. But in the public hospital after my last birth, I felt that I will never come back again because at that time it was even difficult for me to visit the toilet you know, because no one will take you there. No one will think that at least your bed should be closer to the toilet so that you will be able to go and pee or go do whatever. It was very difficult, it was not easy. You see, you will end up not even eating breakfast because when they arrive at your bed, they would just leave food there without even informing you”. (IDI#16, female)

4.7.2 Discouraging factors

Though many respondents were aware of the availability of SRH services, a few factors were commonly reiterated as discouraging the use of public health facilities for particular needs such as family planning services, STIs treatment, HIV counselling and testing and sometimes

antenatal care clinics. The factors inhibiting the use of services were unique. Noticeably, they varied by gender, type of disability and level of education. While females seemed more likely than males to seek sexual and reproductive health services, many women with disabilities reported that they were dissatisfied with services in general and felt discouraged to seek services, particularly from government owned health facilities. The discouraging factors mentioned are that the respondents felt subjected to redundant questioning, such as, how and why they engage in sexual activities; why they need contraceptives; and how they select their sexual partners, which is suggesting that healthcare service providers do not yet understand that persons with disabilities are sexually active. Hence they are not expected to utilize sexual and reproductive health services. Women mentioned that they were often viewed as mischievous for asking about sexual matters and seeking assistance with such services. Respondents reported that the health service providers appeared surprised when persons with disabilities turned out to have contracted STIs. Respondents further reported that nurses at the health care facilities asked them why they need to be tested for HIV and AIDS, suggesting that the general feeling among nurses is that persons with disabilities are not expected to be affected by HIV and AIDS. The following quotes embody those sentiments,

“In most cases if you are disabled and you ask about things like that [SRH], they look at you as if you are very mischievous”. (IDI#8, female)

“When you go there you are asked a thousand questions. They say, being like this, how do you sleep with a man? Why are you going around spreading and closing your legs? They do not understand that you are also a human being and you live in the community”. (IDI#15, female)

When a person with disability comes to the hospital with an STI and so on, the nurses ask lots of questions you see. You get all these sorts of talks from the nurses as if you live in isolation from others. As I have mentioned before, they ask why you are sleeping around and so on and so on”. (IDI#10, male)

“Some people with disabilities are discouraged to get tested because they are asked why they need to know about HIV because they are blind. Some people assume that blind people are not dating. These nurses, they ask how does HIV affects you because you are blind they forget that we are also living in this world. For instance, when I went there for testing, they asked what connects you with the virus, how the virus affects you because you are disabled. They do not expect you as a blind person to get infected with the virus. As a result most of disabled people do not go to the hospital they rather stay at home and not seek help even when they are sick. Some people only

test when they are ill which is not right to test when you are already ill. We need to be tested because HIV is transmitted in different ways". (IDI#12, male)

The female respondents reported that nurses appeared surprised that they had boyfriends. Females in the sample reported that nurses were shocked that they were in need of family planning services. They reported that they were sometimes scolded for asking the nurses about contraceptives. Instead of receiving more information about available and suitable birth control options, such as the loop and injectable contraceptives, the nurses suggested that they were sterilized. In fact, nurses seemed to be "angry" as to why a woman with disability would be sexually active and would fall pregnant. One female respondent explained,

"When you come to the clinic, and tell them I am here for family planning, they jump and say what! What! [Clapping hands] she wants family planning! Does she have a man? You see that is the problem. To them it is a shock. They would ask you why you do not sterilize. We are not being encouraged to use the loop; we are not encouraged to use the types of injections that are currently available. And the other thing which affects women with disabilities, when it comes to contraception, our public health workers, are not well enlightened about us, you see". (IDI#16, female)

Respondents mentioned that nurses at the hospitals found it difficult to accept that persons with disabilities want to have children and asked them who will look after their children. They reported that for instance, when they go to the clinic to deliver, the nurses asked them how many children they have and felt that they had too many children already. In relation to this, some female respondents mentioned that the health service providers sometimes advised them to have an abortion or sterilize as they believed that having more children would create burdens for their families. Hence, nurses suggested that women with disabilities should consider terminating their pregnancies and this was often done without any proper counselling. Pressure from health service providers and communities not to have children can compromise persons with disabilities decision –making autonomy around sexual and reproductive health choices.

"When I went there in 2005-2006 to deliver my second child I was mistreated. The nurse asked me lots of questions. She was very rude; I would never ever forget her. She first asked how many children do I have and I answered I am expecting my second child and her response was: what!? You like making babies whilst being blind! That really hurt, I was so upset and I responded rudely and I told her that being blind does not mean we do not have sexual desires". (IDI#2, female)

“When you get to the antenatal clinic, they tell you about abortion, especially when you are blind like me. When I went to Addington [hospital] and they discovered that I was two months pregnant with this child, my last born, they said I must terminate the pregnancy because I am blind, do you understand? A nurse tells you, just go to that side and make an appointment to do abortion”. I believe that before you do abortion you need counselling first, isn't? So I do not think the nurses even care to consider that I am talking from experience. The nurses said the pregnancy will create problems for you, and also you are causing problems for your family! They said who will care for your child; just all those sort of things, I am not sure how having a child becomes a burden to your family”. (IDI#14, female)

By contrast other respondents commented positively on their relationship with health care services providers. One respondent who felt that the spacing between her children was too close said that when she went for antenatal care she expected nurses to be rude and pass negative comments to and about her. Because of fear of being scolded, she requested for a permanent birth control option, instead the nurse was supportive and advised her not to opt for this method. The nurse helped her to understand and explore other contraceptive options in case she would decide to have more babies in future.

“The spacing between my children is close together and the nurses at the clinic are very rude!!! I had always seen them humiliating other people. I had my first child in 2005 and the second one in 2007. He was only 1 year and a month when I had to attend antenatal care again. Okay when I went there, they first ask you if you have another child .I was expecting her to lecture me [clicking her fingers] instead of that she just asked me nicely how old is your child and I told her. And I was so prepared for anything that she was going to say to me and she asked me what prevention [birth] method would I like to use, and I told her I want to do permanent birth control and she asked me why do you want permanent birth control? I said eish as you can see what happened and she said no, and she completely changed my attitude. She said you are not the first one to fall pregnant while your child is still very young so I would not advise you to do a permanent birth control, I would like you to first think about this carefully and about what do you want to do. I cried because I was not expecting her to treat me like that”. (IDI#4, female)

A few respondents reported that nurses often presumed that delivering a baby would be complicated for women with disabilities which was not the case for the women in the study. These women indicated that they delivered naturally and did not need caesarean section. Respondents emphasized their disability in general does not impact on their sexual and reproductive lives. But the negative attitudes they receive from the public and health care service providers induce fears that discourages them from seeking the services. One respondent described her delivery experience and said,

“For us, people who are physically disabled, the nurses ask questions such as, “how are you going to give birth since you are pregnant? How are you going to deliver?” Let me share this with you, most people who are physically disabled, they deliver naturally without caesarean section. They deliver naturally, no operation whatsoever. So if you ask me, how I am going to deliver, I feel so bad. I feel so bad. I’ve got four children, all of them I delivered naturally without any operation. But my sister, she is not disabled and has three children she had to be operated for all of them. So do you see the difference that disability has nothing to do with these sexual things and giving birth and all those things”. (IDI#15, female)

Respondents described their relationship with service providers as very unpleasant and very judgmental. According to the respondents, nurses felt that if persons with disabilities have many children it will put strain on the social services. For instance, respondents reported that nurses passed hostile comments and questions inquiring why they are having many children because this would pose more strain on them as tax payers since persons with disabilities depend largely on the state social grants for their socio-economic well being. Respondents felt that patients without disabilities receive better treatment and are not asked many questions when seeking such services.

“Nurses are very disrespectful they do not know how to talk to a disabled person, you see, especially if you ask them about such things. They are very disrespectful my God!! They shout at you, why you are producing so many children!!! You can see that they are just irritated. They even ask you what you need there”. (IDI#4, female)

Nurses abuse you emotionally. To me, they said, why you fell pregnant, you have many children already. Why aren’t you preventing [on contraceptives]? What I believe is that a non disabled person is treated right. To us, the nurses pass remarks such as; “this is our money you are wasting because you are receiving a disability grant”!! They complain and say it is their money. They are being taxed to support us and our children. They say it is their money; it is taken from their salaries to support us. So we are creating unnecessary expenses. These are some of the things I experience when I go to the hospital. You see, because of this, you end up reluctant to go to the hospital to seek help. You, rather stay at home while the disease continues eating you just because of the way the nurses treat us. You might even decide to deliver your baby at home, you see, just because of the mistreatment you experience at the hospital. The nurses treat us badly”. (IDI#14, female)

Respondents mentioned that they are viewed as people who should be spending time at church, worshipping rather than engaging in sexual activities.

“The public hospitals, seemingly, the public health workers have anger as to why you fell pregnant. Why do you want contraception? Why can’t you just praise God and

forget about sex? You must just go to church and forget about sex, you see, as if they are angry as to why should men be asking you out as if they are not being asked out by men. If you are there, it means you are naughty!!"(IDI#14, female)

Respondents reported that this questioning was accompanied by not being given sufficient time during consultation to discuss sexual matters or concerns that they may have regarding STIs including HIV and AIDS or contraceptive choices. They expressed that the unwelcoming behaviours and negative attitudes they are often subjected to when seeking sexual and reproductive health services leaves them feeling hurt, destroying their dignity and discriminated against them on the basis of their disabilities. Consequently, the fear of being discriminated against discouraged them from utilizing the public health facilities for sexual and reproductive health services as all these questions give them the impression that such services are not meant for persons with disabilities. There are some responses that echoed these sentiments:

"Nurses do not have your time. You are the burden. They interrogate you and they say "you like men"!! You see and that thing really hurts. It destroys your dignity and your reputation. You leave the room not feeling as yourself. You see, so it very discouraging it reduces your interest in wanting to go and visit the services because at the end you feel that it has nothing to do with you". (IDI#16, female)

"Often, some people have a fear, they are self-conscious. They fear that if I go to the hospital I will be treated badly because of my disability and due to that fear they end up not going to the hospital". (IDI#8, female)

Some respondents reported that the negative attitudes showed by the nurses expose them to various risks. Females shared stories about horrendous experiences they endured at the government hospitals when they went to deliver their babies. Respondents reported that nurses in some instances do not change bed linens that sometimes even had blood stains from the other patients who have been discharged. Respondents said that if they voice complaints about this, they are asked how they had seen that being blind. One respondent related her experience with one of the health hospitals in Durban and said.

You see King Edward, let me tell you about King Edward hospital, when I went there to deliver my last born. I was referred there because of my diabetic condition. When I got there, I was given a bed and on that bed there was someone who was just being discharged. I noticed that they did not change the linen on the bed and the other patient who was sleeping next to me also asked why they have not changed the bed. So I did not get under the cover and in the evening a sister [nurse] came and said,

why aren't you using the blanket you are going to feel cold? I answered; I would not be able to use this bed because the linen on this bed has not been changed. She asked where did you get that, how do you know that the bed has not been made and I said when I arrived the person who had been using it was still here and they did not change it after she left. I slept without a blanket that night I just used my jersey. Then in the morning when they came to make the bed, she said eish my child I thought you were just being stubborn, but you were right, how come the nurses who were working the day shift did not change the bed linen! The bed was red with blood. Do you see now, if I did not see the person who was on that bed when I arrived, I was going to sleep on somebody's dirt without seeing it because I am blind". (IDI#2, female)

4.8 Accessibility of SRH services

In addition to reasons given that discouraged both men and women from seeking SRH services, the vast majority (15) of respondents said there are many other barriers to accessing services ranging from physical barriers to apparatus functionality and negative-inter-personal factors. Every person in the study identified a number of barriers to accessing SRH services.

4.8.1 Physical Barriers

4.8.1.1 Distance to health facilities

Most respondents reported the distance to the healthcare facilities as being among the major factor that constraints the ability of persons with disabilities to access SRH services. Respondents indicated that the health facilities that offer SRH services are located in an area difficult to reach by foot especially for pregnant women. Pregnancy might add a whole new challenge to physical disabilities. So respondents rely on the public transport taxis for transportation to reach sexual and reproductive health services, which is very challenging for them. Respondents reported that the public transport is not only unfriendly for persons with disabilities, but also they have to walk a long distance to get to the taxi station because there is no transport that operates at a road closer to their place of residence, the Clarendon Home. A few respondents indicated that even if public transportation is available, travelling alone may be a challenge so they need someone to accompany them to access services and if there is no one available to assist, they are not able to access services alone. Some women indicated they had to discontinue using contraceptives because, when it is their date to collect

contraceptives, they could not find someone to go to the clinic with them. Respondents said, going to the clinic or hospital alone is a challenge and reported that the nurses scold them if they were not accompanied by anyone.

“ It is difficult because from here I have to walk to Park street to get a taxi to the clinic in market because there is no transport that comes to this side but coming back is even more difficult because there is no transport from there to here, I have to get off at West Street and I have to walk by foot up to here and sometimes I have to walk from the market to here [Clarendon Home]. It is very difficult, can you imagine you are pregnant and disabled”. (IDI#4, female)

On the other hand, a few respondents, particularly persons with physical disabilities such as those on wheel chairs and those who are visually impaired, indicated that their dependence on others assistance to access services, such as HIV testing and counselling and abortion services inhibits their usage of such services. They feel that having to disclose the reasons for visiting the clinics or hospitals to those accompanying them might lead to them being stigmatised. This and largely the societal entrenched stereotypes about sexuality and reproduction of persons with disabilities increase their risk and vulnerability to unwanted pregnancies, STIs including HIV and AIDS.

“Stigma, especially among people who are using wheel chairs and who cannot use their arms, because if you want to go for a blood test you might need to be accompanied by three people and if you test positive they would know about it and they might say things that might hurt you. And for people, who are blind, especially women if by mistake you fell pregnant and you want to have an abortion but now the challenge is that you might have to disclose to someone why you need to go to the hospital”. (IDI#11, female)

4.8.1.2 Transportation costs

Costs, including fees for transportation, were cited as another barrier to access sexual and reproductive health services by a few respondents with physical disabilities and visual impairments. Respondents indicated that each time they need services they have to pay high transport costs as they have to hire a meter taxi to take them to the hospital or clinic or pay for someone to accompany them. The transport costs them around R100 a return trip.

“If you are disabled you cannot go to the clinic as you wish. You have to plan ahead, if you know that at this date you have to attend antenatal clinic. It is not easy to use public taxis. You have to phone a meter taxi to come and fetch you here at the yard and it has to bring you back here. That is the only easy option we have and it is very

expensive, it costs me R50 to go there and R50 to come back that means I pay R100”.
(IDI#6, female)

4.8.1.3 Inaccessible buildings

Another barrier mentioned by the respondents in the study is that the clinic buildings are disability unfriendly. There are cases of stairs which makes it difficult for a person using crutches or in a wheelchair to maneuver without some assistance. Respondents mentioned that the elevators are usually out of service and buildings do not have facilities that blind people can use themselves. Respondents with visual impairments said that it is difficult to find consultation rooms alone and that the nurses are not willing to assist them, and that the nurses would complain that it is not their responsibility.

“As a blind person, having a child is not an issue. However, we encounter a lot of challenges during pregnancy because you have to attend antenatal clinic so you need someone to assist you...I remember it was my date to go to the hospital for antenatal care clinic and I could not find someone to accompany me. So I had to go there alone. I know the directions to the hospital. When I get there, I met a nurse and I asked her to show me the antenatal care clinic and she said go up the stairs and I indicated to her that I am blind so I cannot see the stairs you are refereeing to. She said, “How could you fall pregnant if you are blind?” (IDI#2, female)

“The nurses at Addington hospital where I go to collect my treatments [antiretroviral], are negligent, they ask why you come alone. You see, I tell them please help me and they would say can’t you see I am busy. Then I will tell them, even those people told me the same thing, that they are busy that is why I came alone. The Addington hospital, has many passages, no matter how smart you are with directions, you will get lost. The passages inside the hospital are very confusing so you need someone to escort you through the building. Also their lift is very bad. They do not have lifts that talk, that tell you are you are on the ground floor or whichever floor you are at. I complained at the Addington hospital that they have to make talking elevators. Previously, they used to talk but now I am not sure what happened. A long time ago, I heard it saying, second floor but now they do not talk. You see, it is a real problem for us”. (IDI#12, male)

4.8.1.4 Inaccessible hospital equipments

A few respondents reported that the suspension heights on hospitals examining equipments are too high and not adjustable making it difficult for persons with disabilities to use easily. In addition to this, respondents stated that the nurses are impatient, they expect them to climb onto the bed quickly. Respondents also made examples that condoms are placed in areas that

are out of reach for persons in wheel chairs as a result they are sometimes reluctant to take them and this increases the possibilities of engaging in unprotected sex.

“They are just bad. Their beds are too high. You struggle for a long time to get onto the bed and you find that the nurse is scolding you. She scolds and says hurry up, you see and you can not climb onto it quickly. It is not properly planned. There is nothing that that was designed for a disabled person. There is nothing adjusted to their height, that you can climb easily. You really have to work to get onto the examination bed”. (IDI#3, female)

if you are on the wheel chair and you want to have some few condoms, you find that they are up there and then as a result, you will have to say sorry sister, can you please give me a packet of condoms, and you will start to be the talk of the day. You see, so you end up not able to protect yourself”. (IDI#16, female)

4.8. 2 Communication barriers

Respondents also reported communication barriers. A few respondents with visual impairments mentioned that persons with disabilities are being treated as a homogeneous group. They felt that the the needs of the physically disabled are take into account by government to the neglect of the blind and deaf. The main aspect of this barrier that the respondents raised is that all available information on reproductive health is available in a format that is inaccessible to persons with sensory impairments. Respondents said the healthcare services providers do not communicate properly to them other available options in case condoms rapture, they are not told about pregnancy preventing options such as the morning after pill. Respondents reflected that the lack of information in alternative formats indicate that the department of health does not yet consider and cater for the sexual and reproductive health needs of persons with disabilities.

“People who are totally blind, they do not have things on Braille. I think when the government talks about disability, they are more concerned about people who are physically disabled not people who are totally blind or partially sighted”. (IDI#7, female)

4.8.3 Functional barriers

Another barrier to access sexual and reproductive health service was the operational hours. Many persons with disabilities travel long distances to reach health facilities, particularly the clinics where SRH services are available, but because of the limited number of patients taken per day they are often unable to access these services. This implies that they have to come

back the following day. Respondents indicated that this is not possible since they would have to accrue more transportation costs.

“Sometimes, they tell you that they have closed and you must come back the following day. You see that the cost is high because you have to pay for the person who is accompanying you as well” (IDI#14, female)

As a result, a few respondents indicated that they often have to demand to be treated and access services.

“I visited Lancers clinic, for immunization of my twins, and then I was like a little bit late, and the security outside there she told me, no you cannot go in now, you are already late and I said you do not understand why I am late and you don’t want to even understand. Then I said to her can you call a sister in charge to come at the gate or can you please inform the sister in charge to tell me if I did not get this immunization today, is there any shop or chemist that might have, that I might be able to buy the immunization for my children. Then the sister decided to say, no let her in and then I said no, it is my fault I came late because I am struggling. I have got twins and I could not come alone to the clinic. I really need another person, a person to help me get there”. (IDI#16, female)

“You find that the hospital is so full, there are many people. As a result, at times I feel neglected but what I can say as a disabled person is other patients really sympathise with us. In such a way, when you arrive late they do not mind to allow you to see the doctor first or whatever service you need at that time”. (IDI#13, male)

Respondents indicated that they were unhappy with the opening hours because they have to wake up very early and go and wait for the clinic to open. They also remarked that the queues are long which lead to extended waiting hours. Respondents expected to be given priority in the health facilities to get treatment or receive services. However, this was not happening in all of the public health facilities due to a lack of communication.

“You see, they open at their own time however you have to get there early and wait for hours. When they open, you have to stand in the queue even though you are disabled and you are not supposed to wait in the queue. They do not attend to you first, sometimes; you have to ask other people who are there to help you. The nurses even if they see that you are disabled, they do not come to you to and attend to you first. The rule says, if a disabled person comes to the clinic, he must be helped first and leave early”. (IDI#12, male)

“You find that the clinic opens at 7am but you have to be there at least at 5am so that you will be at least number 30 on the queue. Because if you arrive at 7:30m the male or female [security guard] at the gate will tell you that they are no longer issuing tickets. They do not understand that I’ve got a disability I am physically challenged,

even those who are blind, and I cannot come alone, I need somebody else to accompany me to the clinic. They do not understand that a person with disability cannot stand in the queue. I am unable to stand for 4 hours waiting for the clinic to open. You have to be stubborn and push your way through until they allow you that right that you do not have to stand on the queue. You see a disabled person, is waiting on the queue with her big belly, or she is on the wheel chair and she is pregnant, they do not understand that she cannot be standing on the queue because she has a disability. It is like they are punishing her, why did she fall pregnant while being disabled". (IDI#15, female)

4.8.4 Health service providers' negative attitudes

By far, the most commonly reported barriers to access sexual and reproductive health was the attitudes and behaviours of health service providers. Respondents described their relationship with the service providers as unfriendly and the vast majority of women had stories to tell about their negative experiences. Respondents said often they were treated as asexual beings by the health service providers. They felt that the health providers need to change their mind sets with respect to persons with disabilities and their sexual and reproductive health. The public health workers need to acknowledge and accept that people with disabilities are sexual human beings therefore they need services. Respondents said that healthcare providers must recognize that disability does not imply that their sexual organs are also disabled.

"Health workers are not ready to accept people with disabilities as sexually human being. The biggest barrier is the mind set that is of the community, of the public health workers". (IDI#16, female)

"The difficulties that we face as disabled people from this flat, is that the people who work at the clinics and the hospitals, it is hard for them to understand that a person with disability are also able to engage in sex. Disability has nothing to do with sex. Disability is a disability. It is a challenge, because everybody has got their own challenge of which others cannot see but for us you can see it. So at the clinics, accessibility is the main problem and communication. They do not understand that a person with disability has a right to have sex". (IDI#15, female)

Additionally, it was interesting how some women described how they have learnt to deal with the negative attitudes showed by health service providers when they seek such services. For example one female respondent said,

"When I went to give birth, I told them, listen please be careful and check if my child is in the right position. When I was having my first child, they said, "gosh you like men" and I told her, you are wearing a ring that indicates that you have a man, I am also applying for marriage and children like you. I told her, now that I have borne a

child my man is going to marry me. Then she laughed. When growing up, we knew that, after having children, you were supposed to get married. We did not believe that you can give birth outside of wedlock and leave those children behind at home when you get married to another man. We believed that someone who has impregnated you will marry you, he cannot abandon you. That is what I was telling them, I also want marriage that is why I am here to give birth". (IDI#11, female)

However, what is also evident from the above quote is the respondent's perception and purporting that childbearing somehow increases women's opportunities of marriage.

4.8.9 Coping strategies regarding lack of access

Respondents were also asked about the strategies persons with disabilities use to cope with the lack of access to services. The respondents reported that these barriers often lead persons with disabilities to seek alternative methods outside the public health sector which are often not affordable considering that most respondents depend on social grants. Worse they avoid or delay seeking services which has serious implications for their sexual and reproductive health. For women with disabilities delaying to seek antenatal care puts their health and that of their unborn at risk, suggesting that persons with disabilities may endure unmet needs to sexual and reproductive health services mostly because of the negative and stereotypical attitudes they often experience.

"Those [persons with disabilities] who want to do contraception they end up going to private hospitals. They end up going to chemist to buy pills. They end up there because the public health services are not yet ready to give them proper dignity. So those are the strategies that they are using. Maybe others, I can say end up terminating their pregnancy which they were not planning to do". (IDI#16, female)

"Some prefer to stay at home or delay to seek help until they are seriously ill. Sometimes the friends or those close to her or him take him to the hospital" (IDI#12, male)

4.10 Suggestions for improving access to SRH services

It was apparent that the respondent felt that SRH services were inaccessible for persons with disabilities. The respondents were then asked to share how services could be improved to increase accessibility. The results suggest that it takes more than ramps to solve the crisis of inaccessibility of services for persons with disabilities. Respondents indicated that healthcare providers should be better prepared to work with persons with disabilities. Some suggested disability awareness training, with persons with disabilities involved in the training, so that

providers could become sensitive to these issues from the perspective of persons with disabilities themselves. Respondents believed that government should make an effort to employ HIV and AID counsellors with disabilities because they are more likely to understand the needs of persons with disabilities better than providers without disabilities.

“Clinic staff must be told that they must treat disabled people with respect. They must give them time if they have questions. They must stop neglecting them. Usually if you ask questions as a disabled person, they just look at you and leave you standing there alone. This really discourages us as disabled people because they undermine us. As a blind person, I need you to inform me that, that you are leaving otherwise I will continue talking because I would not know that you have left. Nurses need to be informed that they must learn how to talk to people with disabilities. They must be educated on how to interact with people who are blind”. (IDI#12, male)

“I feel that the department of health when they hire counsellors they should consider including people with disabilities, for instance when I find that I am HIV positive that would encourage me to visit public facilities. They will also educate their colleagues about disability and make them understand how to treat us on sex issues”. (IDI#5, male)

The vast majority of the respondents commented that there should be mobile clinics in order to address the issues of distance and inaccessible buildings. The mobile clinics should visit the places where people with disabilities live and educate them about contraceptive methods. Also, they should be encouraged to undergo HIV counseling and testing. Respondents commented that persons with disabilities should start their own support groups which will encourage them to talk openly about sexual and reproductive health matters.

“They should bring a clinic at least once a month in places like this for instance Lancers because it is close by, they should come here at least once to do HIV testing and other diseases not related to HIV but that facilitate the spread of HIV”. (IDI#1, male)

“There should be mobile clinics closer to place like this, where we live. For instance, for family planning, the nurses should come at least once a month to provide us with contraceptive methods. They should conduct meetings with males or females once or at least twice a month. They should bring the services near to people with disabilities. This will make a huge difference. Currently, the hospitals are not friendly towards us at all; I am talking from my own experience”. (IDI#16, female)

Summary

The findings reveal that access to sexual and reproductive health services is complex and involve a variety of factors. The majority of respondents revealed that sexual and reproductive health services are a big part of their lives. However, there seemed to be a huge gap between their need for services and their right to access these services. The general consensus was that persons with disabilities face challenges and multiple barriers to access SRH services. Significantly these barriers are not raised by the disability itself but are related to specific contexts or instances of persons with disabilities trying to access services. From the discussions it was apparent that respondents rights to be treated with dignity and to access sexual and reproductive health services is often overshadowed by social isolation, discrimination and other stereotypical assumptions that the society holds about the sexuality of persons with disabilities. The preconception that persons with disabilities are incapable of sexual relations seemed to be the underlying factor to all the barriers mentioned by the respondents in the sample. They are perceived as not sexually active hence information on sexual and reproductive health matters is not widely available in formats accessible to them. Health providers appeared surprised that person with disabilities will require assistant with family planning services and they are not given choices about suitable birth control methods rather often the nurses suggested that they terminate their pregnancies or undergo sterilization. This is short sighted. Not only does it violate their rights to decide on the number of children they may wish to have: because while it may protect them against future pregnancies it does not promote safe sexual behaviours which put them in danger of contracting STIs and HIV and AIDS. This reveals a need to address access to SRH services for persons with disabilities especially, through public health facilities in South Africa.

Chapter 5

Discussion and Conclusions

This chapter discusses the findings of the study. The aim of this study was to explore experiences of persons with disabilities in obtaining sexual and reproductive health services in Durban. The study is framed around rights-based approach to access to services. While the study is based on a relatively small sample of persons with disabilities and is not generalizable to an entire population of persons with disabilities, it has revealed several notable results. South Africa has one of the most progressive policies when it comes to sexual and reproductive health rights as the clause in the Constitution provides that everyone has the right to access sexual and reproductive health services, yet many obstacles remain for many persons with disabilities to access SRH services.

The majority of respondents in this study were aware about sexual and reproductive health matters and where to access services. They showed a working knowledge of HIV and AIDS which seemed to influence the usage of male condoms. The study discovered that persons with disabilities received information through various sources including the radio, healthcare facilities and schools. However, parents do not inform their children with disabilities about sexual and reproductive health matters. This is similar to the findings of the study by Ashani (2009) though it was conducted among students with physical disabilities in an urban university. It illustrated that education can contribute to awareness about HIV transmission and improve person with disabilities' life skills to protect themselves and that parents tend not to discuss sexual matters with children with disabilities (Ashani 2009).

The findings of this study contrasts with the findings from studies conducted in Swaziland and Nigeria which reflected low knowledge of HIV transmission and the low level of awareness of contraception and where to access sexual and reproductive health services, respectively (Yousafzai et al. 2004; Olaleye et al. 2007). Yousafzai et al. (2004) reported that persons with disabilities in Swaziland listed many incorrect examples of modes of HIV transmission. Better education is reported to improve ones awareness, empower them to assert their rights to services and increase their employment opportunities (World Bank 2010) but in this study there was no visible relationship between educational levels and levels of

knowledge on sexual and reproductive health matters. It was apparent that illness prompted the use of services.

However, consistent with other findings, this study found that knowledge of sexual and reproductive health services did not translate into use of services (Swartz et al. 2009; Smith et al. 2004; Mulindwa 2003). Access to service is an important but complex element of quality of care, since it determines whether a client even gets to the service provider. While a few females reported that they were comfortable visiting the clinic for sexual and reproductive health matters, the majority of the respondents reported difficulties in accessing services. In general, the main barriers to accessing sexual and reproductive health services noted in this study were: geographical barriers; transportation; discrimination which induced feelings of fear and hurt which prevented persons with disabilities from seeking services; inconvenient opening hours; lack of alternative communicating devices such as Braille for those with sensory disabilities and negative attitudes of healthcare providers, which are all consistent with findings in the literature.

The respondents in this study were dissatisfied with the geographical location of health care facilities. The distance to the clinic or hospitals rendered sexual and reproductive health services inaccessible for persons with disabilities. Swartz et al. (2009) reported similar findings that persons with disabilities faced geographical barriers and this was more so in findings especially in rural areas because there are no tarred roads which makes it even more difficult to travel by foot for persons using mobility tools such as wheel chairs and white cane for blind people. Although clinics and hospitals were available and accessible by public transport in urban areas in the present study, many respondents reported difficulty in accessing public transport since it does not pass by their homes. As a result sometimes they have to bear the costs of hiring private transportation. This study adds to the growing number of studies from other countries such as Cameroon, Zambia, Uganda, USA, India and Nigeria. In this study, a few women indicated they had to discontinue with contraceptives methods because of these challenges. This finding on the cost of transportation in this study is similar to the findings of other studies (Swartz et al. 2009; Mulindwa 2003). Many respondents mentioned they have to bear the costs of either hiring a private car or paying for someone to accompany them to the healthcare centres since services are inaccessible by foot. This

suggests that if persons with disabilities cannot afford to pay for transportation to access services, their needs for sexual and reproductive health remain unmet.

Findings also revealed that persons with disabilities face physical barriers which included inaccessible buildings and lack of disability friendly equipments, that is, tables are too high for persons in wheel chairs or those of short stature which negatively affected their access to services.

A few respondents avoided attending health care facilities for sexual matters and advice on family planning because of the attitudes of the nurses. They feared nurses' reactions and judgmental attitudes. Nurses often suggested that they either sterilise or terminate their pregnancy. Findings revealed that the clinics were mostly used for STI treatments, to collect ARVs medications and antenatal checkups, delivery and child birth immunization. The study by Olaleye et al. (2007), confirms this by discussing that persons with disabilities, especially women avoid utilizing the clinics for sexual matters and reproductive health due to fear of discrimination by nurses. It illustrates that persons with disabilities only used or get to know about sexual and reproductive health services during pregnancy. This implies that they avoid routine visit to the clinic or hospitals for sexual and reproductive health care services which might put their health and that of their children in danger.

South Africa has one of the most progressive sexual and reproductive health services. However from the results of this study it seems that sexual and reproductive health services are not yet fully accessible, affordable, and available to all segments of the population, in particular persons with disabilities. This is something that needs to be addressed by the government, the Department of Health in particular, to not only mitigate the spread of STIs, including HIV and AIDS and low uptake of contraceptives, but also to uphold the sexual and reproductive health rights of persons with disabilities as stipulated in the Constitution of the country.

The study revealed low usage of sexual and reproductive health services, especially by men with disabilities. The reason for this is that male condoms are widely available. Respondents indicated that they obtain them free in government' places such as schools, police stations

and also at the health facilities. The study also argues that the focus of sexual and reproductive health and HIV prevention programs is directed mainly towards women. Thus sexual and reproductive health campaigns should also focus and target men with disabilities so that they will take the responsibilities for protecting their partners against unwanted pregnancies.

Recommendations

In light of the findings of this study more effort is still needed to ensure that awareness raising programmes about sexual and reproductive health reach persons with disabilities. There are a number of factors that should be addressed in order to increase access to sexual and reproductive health services for persons with disabilities. A notable finding in this study was that persons with disabilities reported having no sexual education in special schools and their families do not communicate to them about sexual matters. They only learned about sex from health care facilities when they are ill. Also a few said they received information about HIV through media sources and friends. Sexual education is an important aspect of giving people knowledge about safe and unsafe sexual behaviors. A lack of sex education is often cited in the literature as a reason for the spread of STIs and unwanted pregnancies (Bremer et al. 2009). Bremer et al. (2009, 213), assert that “providing sex information and access to contraceptive methods reduces fear, anxiety, and unwanted pregnancies”. Without any sexual education there is a high risk of spreading incorrect information and misperceptions about sexual and reproductive health of persons with disabilities. The community awareness raising groups can play important roles in making relevant information available to persons with disabilities who are usually isolated. These may include peer educators that will visit places where persons with disabilities live with their families. Mobile clinics with professional nurses must be brought closer to the community with disabilities to ensure that they have sufficient information on contraceptive methods in order to be able to make informed choices.

Most of the barriers to access services are related to negative providers’ attitudes and basic lack of general knowledge about disabilities. The respondents reported that health care providers often advise them to be sterilized instead of assisting them explore other contraceptive methods. Efforts should be made to change the stereotypical views that persons

with disabilities are incapable of sexual activities and taking care of their children. The view that they are virgins therefore they do not get HIV and AIDS also needs to be addressed.

Training healthcare service providers is an important part of improving access to sexual and reproductive health services for persons with disabilities which should be provided through the public health system. The training of service providers should include value clarification workshops, as suggested by Groce et al. (2009), because persons with disabilities repeatedly noted the negative attitudes of service providers as a barrier to access SRH services. More studies should be done in South Africa to assess providers' attitudes towards the needs of persons living with disabilities for sexual and reproductive health, as they are an important part of its success.

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Appendix I: Interview Guide

The aim of the study is to gain understanding on experiences and perspectives of persons with disabilities in accessing sexual and reproductive health services, commonly known as family planning and HIV and AIDS services. My focus is more on the following services, Contraception methods, HIV/AIDS and STI education and prevention, Voluntary Counselling and HIV Testing; Antenatal services/post natal services (pregnancy and childbirth) and Termination of pregnancy.

Demographic information and sexual reproductive history:

Gender

Race

How old are you?

Marital status:

Married

Divorced /Separated

Widow/ widower

Cohabiting

Single

Never been married

Do you have children of your own? (How many?)

Have you attended formal education?

Level of education obtained:

Never attended school or only attended preschool (reason)

Primary school

Secondary School

Some college of technical school

College graduate

Employment Status: are you currently?

Employed

Self-employed

Unemployed

Retired

Unable to work

- What is your main source of income?

- Type or nature of disability?
- What do you understand by sexuality or having sex?
- Have you ever been engaged in sexual activity?
- Currently, would you regard yourself as sexually active?
- Are you using any contraception methods?

1. Knowledge/awareness on sexual and reproductive health?

- Have you ever heard of the following services?
 - Family planning / Contraception methods
 - HIV/AIDS and STI education and prevention
 - Voluntary Counseling and HIV Testing
 - Antenatal services/post natal services
 - Termination of pregnancy
 - Other, please explain?

Have you ever been provided any information or material concerning the following:

Condoms and Family planning (Contraception methods)

HIV/AIDS and STI education and prevention

Voluntary Counseling and Testing

Antenatal services/post natal services

Termination of pregnancy or abortion

Other, please explain?

- If yes, where did you receive this information?
- Is it important for you to know about sexual and reproductive health services
- Do you feel that you have sufficient information regarding sexual and reproductive health: why or why not? (could be prevention of STIs including HIV, condoms birth control choices and prevention unwanted pregnancy)
- Do you think that you need to know more about sexual and reproductive health ? (
- What information would you like to receive on sexual and reproductive health? (Why?)
- Who do you think should tell or teach you about sexual and reproductive health? (Why?)

2. Sexual and reproductive health services

- Have you ever visited the clinic/hospital specifically to seek sexual and reproductive health services? (condoms or family planning, STI or HIV/AIDS or abortion)
 - Can you tell me about the reasons for visiting the service?
 - Which health facility do you usually use for sexual and reproductive health services?
 - How did you get to know about sexual and reproductive health service?
 - Please describe how you get to and from your service provider for sexual and reproductive health?
 - How often do you visit the clinic or hospital for sexual and reproductive health services?
 - What type of transport do you use to get to the sexual and reproductive health services?
 - Do you have any difficulty in reaching clinic/hospital for sexual and reproductive health services of your choice? (kindly explain)

- In your experience, how accessible are sexual and reproductive health services to persons with disabilities? (Kindly explain)
 - Hours and days of operation
 - Ramps or lifts
 - Cost
 - Location
- Do you find it easier to communicate with the health service providers when you visiting sexual and reproductive services? **Probe:** (language).
- Are you satisfied with the services provided? (explain/ provide example)

3. Need for SRH services for persons with disabilities?

- What do you think people with disabilities need to know about their sexual and reproductive health?
- Would you say persons with disabilities are at increased risk of unplanned pregnancy, STIs and HIV? (Why or why not)?
-
- Tell me about your experiences in accessing sexual and reproductive health services?
 - Do you feel comfortable visiting the sexual and reproductive health services? (Kindly explain?)
 - Do you feel comfortable talking to the health provider about sex, sexuality and reproduction issues including, HIV/AIDS? (Kindly explain, examples)

- Would you feel comfortable asking the provider any questions you may have about sex and birth control methods, or STIs and HIV?
- Is your privacy respected during your consultation at the sexual and reproductive health services? (Kindly explain)
- What has been your experience in receiving services from clinics/hospital for your sexual and reproductive health?
- What do you think people with disabilities need to know about sexual and reproductive health services?
- Are there any problems you may encounter in discussing sexual and reproductive health with the provider at the clinic/hospital?

4. Factors that may hinder access to SRH service

- Please describe the degree to which your providers office/ clinic is accessible to you and other people with disabilities.
 - Ramps?
 - Accessible bathrooms?
 - Examination tables?
 - Alternate format for educational information?
- Do you have any experience that you encountered in the SRH service that you would like to share?
- Had there have ever been times when you wanted to get sexual and reproductive health services, but you encountered some difficulties?
- What are some of the difficulties that you have encountered in accessing sexual and reproductive health services as a person with disability?
- Are you satisfied with the service provided (why, why not)
- Please comment on the attitude of the nurses during your visit?
- Is there anything you are unhappy about when you visiting sexual and reproductive health services?
- Do you feel comfortable about the environment in which services are offered?
- Is there anything you are unhappy about when visiting sexual and reproductive health services?
- Are there any reasons that would discourage you from visiting the clinic for sexual and reproductive health services?
- Do you feel SRHS cater for the needs of persons with disabilities?
- What do you think are the barriers (physical, social, cultural) to accessing family planning and HIV/AIDS services?

- What strategies do persons with disabilities use in coping with lack of access to sexual and reproductive health services?
- What roles do you think persons with physical disabilities should play in providing awareness campaigns, protection and prevention services for persons with disabilities about sexual and reproductive health?
- Do you have any suggestions for improvement of the sexual and reproductive services? (**Probe**) like what things you would like to be included in terms of addressing your sexual and reproductive health needs?

Appendix II: Informed Consent

(to be read out by researcher before the beginning of the interview. one copy of the form to be left with the respondent; one copy to be signed by the respondent and kept by the researcher.)

My name is Sibusisiwe Sipehelele Mavuso (student number 205508990). I am doing research on a project entitled: "Access to sexual and reproductive health services for persons with disabilities: a case study of Clarendon home for persons with disabilities, Durban, KwaZulu-Natal"

This project is supervised by Prof. Pranitha Maharaj at the School of Development Studies, University of KwaZulu-Natal, in Durban, South Africa. I am managing the project and should you have any questions or concerns my contact details are:

School of Development Studies, University of KwaZulu-Natal, Durban 4041, South Africa
Mobile: 0732814175

Email: 205508990@stu.ukzn.ac.za

Thank you for agreeing to take part in the project. Before we start I would like to emphasize that:

- Your participation is entirely voluntary;
- You are free to refuse to answer any question;
- You are free to withdraw at any time.

All interviews will be recorded. The interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from the interview may be made part of the final research report. Do you give your consent for: *(please tick one of the options below)*

Your name, position, and organisation, or	
Your position and organisation, or	
Your organisation or type of organisation <i>(please specify)</i> , or	
None of the above	

Please sign this form to show that I have read the contents to you.

----- (signed) ----- (date)

----- (print name)

Write your address below if you wish to receive a copy of the research report: