REPRODUCTIVE HEALTH CHALLENGES FOR WOMEN WITH PHYSICAL DISABILITIES IN MOMBASA COUNTY

BY

FAITH REDEMTOR ATIENO

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DECLARATION

I declare that this project is my original work and has not been presented to any other institution for the award of a degree.

Sign ____________ Date 17th NOV 2011

Redemtor Faith Atieno

This project has been presented for examination with my approval as the university supervisor.

Sign ____________ Date 17th NOV. 2011

Dr. Charles Owuor Olungah

DEDICATION

To all women living with disability who struggle to access reproductive health services in public health facilities despite the challenges they continue to encounter.

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LIST OF ABBREVIATIONS AND ACRONYMS

ACHPR	African Charter for Human and People's Rights
ANC	Antenatal Care
APDK	Association for the Physically Disabled of Kenya
BPFA	Beijing Platform for Action
CBR	Community-Based Rehabilitation
CRC	Convention on the Rights of the Child
CEDAW	Convention on the Elimination of all Forms of Discrimination against Women
CPGH	Coast Provincial General Hospital
CRPD	Convention on the Rights of People with Disabilities
DDP	District Development Plan
EOC	Emergency Obstetric Care
ICESCR	International Covenant on Economic, Social and Cultural Rights
FGD	Focus Group Discussion
FHI	Family Health International
GOK	Government of Kenya
IL	Independent Living
ILO	International Labour Organization
KNBS	Kenya National Bureau of Standards
MDGs	Millennium Development Goals
MS	Multiple Sclerosis
MOH	Ministry of Health
MMR	Maternal Mortality Rate
NCPWD	National Council of Persons with Disability
NGO	Non Governmental Organisation
NHIF	National Hospital Insurance Fund
PEAP	Poverty Eradication Action Plan
PMTCT	Prevention of Mother to Child Transmission
PWD	Persons with Disability
RCN	Royal College of Nursing

RH	Reproductive Health
SAGA	Semi-autonomous Government Agency
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
STDs	Sexually Transmitted Diseases
STIs	Sexually Transmitted Infections
TSC	Teachers Service Commission
UK	United Kingdom
UN	United Nations
US	United States
UNFPA	United Nations Population Fund
UNDP	United Nations Development Programme
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
USAID	United States Agency for International Development
WHO	World Health Organisation
WWD	Women with Disabilities

ABSTRACT

This was an exploratory cross-sectional study of reproductive health challenges faced by women with physical disabilities in seeking reproductive health services in public health facilities in Mombasa County. The specific objectives of the study were to establish facts influencing reproductive health seeking practices determining accessibility challenges and identifying care provision problems faced by women with physical disabilities.

Purposive sampling was used to select three organizations dealing with persons with disabilities from where 45 respondents to survey questionnaires were conveniently sampled. Four FGDs were conducted, two of which were with older women and the remainder with younger women. The participants in these FGDs were purposively selected. Case narratives were carried out with six women purposively chosen to give insights in their lived accounts in seeking reproductive healthcare. Moreover, the study sought the experts' opinion from twelve key informants consisting of ten health workers (doctors and nurses) and two NGO officers working for disability organization.

The findings indicate that women with physical disabilities face several challenges while seeking reproductive healthcare. Some of the challenges include communication difficulties, bad experiences with healthcare providers, the physical access and mobility challenges due to built environment and the attitudes of healthcare providers which hinder many women with physical disabilities from inquiring more on contraceptive use and sexuality experiences.

The challenges presented a range of barriers to seeking and receiving satisfactory reproductive health care services. The barriers can be divided into two major categories: structural barriers related to access or physical accommodation and the socio-cultural concerning relationships with health care providers. The above barriers affect the quality of the reproductive healthcare and present major areas of concern if this group of women is to be adequately served.

This study recommends that government institutionalize and provide disability programmes and support services in the healthcare system. Equipments should be disability friendly in the health facilities to provide comfort to WWD. Proper sensitization and availing of adequate health information on contraception and STIs is urgent to this population group. Furthermore, women with disabilities should be provided with adequate information on pregnancies, birth control and other sexuality education that recognizes them as human beings with needs. The government should strengthen, facilitate and work hand in hand with disabled people's organizations and adapt educational materials that are suitable for them.

Finally, interventions should be directed at enhancing providers' understanding of how to work effectively with women who have physical disabilities. The training on how to treat disabled people be included in medical school's curriculum and in hospitals for those already practicing and the medics be sensitized on language that is not offensive when handling disabled people.

CHAPTER ONE: BACKGROUND TO THE STUDY

1.1 Introduction

Persons with disabilities are identified 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 (UNCRPD, 2006). Around 10 per cent of the world's population or 650 million people, live with a disability. They are the world's largest minority (UN, 2007).

The reproductive health care of disabled women is akin to those of all women. Women with disabilities require the same gynaecological and reproductive healthcare services as women without disabilities, yet they often experience difficulty obtaining them (Lehman 2009). Sometimes, women with disabilities have unique needs that must be understood in order to ensure effective and high quality reproductive health services. Yet the field of health promotion has yet to acknowledge the unique needs of these women. Such women often lack access to multitudinous opportunities for maintaining and improving their overall health, and disability-related barriers discourage women with physical disabilities from engaging in health-promoting behaviours (Hughes, 2006).

The foregoing scenario could result from the nature of their disability, be it physical, cognitive, or mental. For example, family planning practitioners tend to be unaware of the reproductive health needs of disabled people. In many developing countries, disabled women are not taken for routine gynaecological examinations because it is assumed that they will not have children (Best, 1999). Even in developed countries, women with paralysis, impaired motor function, and other obvious physical disabilities, are rarely offered counselling on sexuality or contraception (Best, 1999). If family reproductive health services are to be improved for people with disabilities, those providing the services must increase their awareness and acceptance of sexuality in disabled people (Best, 1999).

Twenty per cent of the world's poorest people have some kind of disability, and tend to be regarded in their own communities as the most disadvantaged (UN Enable, 2009). It is reported that women face barriers to full equality and advancement because of such factors as race, age, language, ethnicity, culture, religion or disability (UNFPA/The Center for Reproductive Rights, 2010).

In this context, women with disabilities are recognized as being doubly disadvantaged, experiencing exclusion on account of both their gender and their disability. Sixty- five to seventy per cent of women with disabilities in low and middle-income countries live in rural areas (USAID, 2009). Studies have shown that girls and women of all ages with any form of disability are among the more vulnerable and marginalized of society. There is therefore, need to take into account and to address their concerns in all policy-making and programming, thus, special measures are needed at all levels to integrate them into the mainstream of development (BPFA, 1995).

In addition, people with disabilities, irrespective of where they live, are more likely to be unemployed, illiterate and have less access to developed support networks and social capital than able-bodied people (DFID, 2000). The highest attainable standard of health is a fundamental human right enshrined in numerous international and regional human rights instruments, including the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights (ICESCR), the African

Charter for Human and People's Rights (ACHPR), the Convention on the Rights of the Child (CRC), and the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW). Article 12 (1) of the ICESCR specifies that everyone has a right "to the enjoyment of the highest attainable standard of physical and mental health," and the Convention on the Rights of People with Disabilities further clarifies that this right must be upheld "without discrimination on the basis of disability". With the entry into force of the Convention on the Rights of People with Disabilities (CRPD) came the important paradigm shift from the outdated medical model of disability, viewing persons with disabilities as objects of treatment, to persons with disabilities emerging as subjects of their own rights. Several rights of the Convention of the Rights of People with Disabilities uphold the sexual and reproductive rights of persons with disabilities (CRPD, 2008).

In Africa, the UN reports that there are at least 60 million disabled people and that these disabled people are often excluded from schools and therefore have limited opportunities to find work or a means of livelihood (UN, 2006). Factors that contribute to the growing number of persons living with disabilities include violence, HIV/AIDS, birth defects and disabilities due to pregnancy and child birth, malnutrition, ageing population, environmental degradation, injuries at home, work and accidents on roads.

In Kenya, according to the 2009 Population and Housing Census Results, at least 3.5% of the population is disabled (KNBS, 2009). This implies that there are some 1,330,312 million disabled people in the country. Disabled people in Kenya, as in most developing countries in the world, face extreme conditions of poverty, have limited opportunities for accessing education, health, and suitable housing and employment opportunities.

However, the domestic legislative framework guarantees fundamental rights to persons with disabilities and prohibits discrimination. The human rights of people with disabilities are recognised in the Kenyan Constitution. Article 54, (1) of the Constitution states that a person with any disability is entitled:

(a) To be treated with dignity and respect and to be addressed and referred to in a manner that is not demeaning;

(b) To access educational institutions and facilities for persons with disabilities that are integrated into society to the extent compatible with the interests of the person;

(c) To have reasonable access to all places, public transport and information;

(d) To use Sign language, Braille or other appropriate means of communication; and

(e) To access materials and devices to overcome constraints arising from the person's disability (Republic of Kenya, 2010).

Article 54, (2) states that The State shall ensure the progressive implementation of the principle that at least five per cent of the members of the public in elective and appointive bodies are persons with disabilities (Republic of Kenya, 2010).

1.2 Statement of the Problem

Women with physical disabilities are growing in number and increasingly interested in becoming mothers and raising children. However, healthcare providers are often unfamiliar with the health care needs of this group of women and overlook the important issues that make the difference between positive and negative experiences of these women (Smeltzer, 2007).

Lack of access to reproductive health services must be more acute for disabled women compared with their able bodied counterparts (Becker et al., 1997). Disabled mothers who seek reproductive healthcare services are two or three times more likely to suffer from poor services than other women looking for pre-natal and ante-natal services, including discrimination (UPDK, 2010). To get a clear picture of the situation, this study set out to investigate the factors that make access to adequate reproductive health services to the women with physical disability a nightmare.

Towards this end, the following set of research questions guided the study:

1. What factors influence the health seeking practices of women with physical disabilities?
2. What are the accessibility challenges faced by women with physical disabilities at the healthcare facilities?
3. What are the care provision problems faced by women with physical disabilities at the healthcare facilities?

1.3 Research Objectives

1.3.1 Overall Objective

To assess the reproductive healthcare challenges faced by women with physical disabilities in Mombasa County.

1. 3.2 Specific Objectives

1. To establish factors that influence the reproductive health seeking practices of women with physical disabilities in Mombasa County.
2. To determine accessibility challenges faced by women with physical disability at the healthcare facilities.
3. To identify care provision problems faced by women with physical disability at the healthcare facilities.

1.4 Justification of the Study

The study provides ethnographic information that has the potential to lead to evidence-based policy formulation.

A study focusing on disabled women's access to reproductive health services will no doubt highlight their experiences and provide information to direct the formulation of responsive policies geared towards meeting their health needs.

Given that there is little information on reproductive health issues of women with disabilities in Kenya, the findings of this study go a long way in laying the foundation for further research in this area and also empower advocates to press for change in service delivery systems so that they can effectively assist women with disabilities achieve healthy lives and participate fully in all spheres of life.

1.5 Scope and limitations of the study

This study was carried out in Mombasa County. It focused on the accessibility challenges faced by women with physical disability as well as the care provision problem facing this group of women in the County.

This study was limited to only a small sample particularly the women registered by the association of women with disability hence the generalizability of the study results may not be taken to represent that of the country. The data collection methods are qualitative in nature thus any quantitative trends on the challenges facing women with physical disabilities will not be captured by the study.

1.6 Definition of key terms

Disability: In the study disability was taken to refer to physical disability which include deformed limbs and hands, which impacts on one's social, economic or environmental participation.

Reproductive Health Care: the constellation of methods and techniques and services that contribute to reproductive health and solving reproductive health problems (Women's Bureau, 1997).

Health seeking practices: Active seeking (by a person in stable health) of ways to alter personal health habits and/or the environment in order to move toward a higher level of health.

Challenges: The situation of being faced with something needing great mental or physical effort in order to be done successfully and which therefore tests a person's ability

Women: an adult female person .

Physical disability: Any impairment which limits the physical function of limbs or fine or gross motor ability is a physical disability. Other physical disabilities include impairments which limit other facets of daily living.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

In this section, literature on reproductive health challenges facing women with physical disability is reviewed. The literature is reviewed using the following themes: the scope of reproductive health, health seeking practices of women with disability, constraints and problems faced by women in deciding to go to the facility and reaching the facility, problems faced by women when they arrive at the facility in terms of healthcare. The section also presents the theoretical framework and assumptions that guided this study.

2.2 Scope of Reproductive Health

Reproductive health is a state of complete physical, mental and social well being, and not merely the absence of disease or infirmity in all matters relating to the reproductive health system, its functions and processes (Kenya, 2008). The main components of reproductive health services in Kenya include: safe motherhood and child survival, family planning, management of STIs/HIV/AIDS, promotion of adolescent health, management of infertility, gender issues and reproductive rights and screening and management of cancers of reproductive organs and other reproductive health issues.

2.2.1The situation of women with disabilities in Africa

Whereas both men and women with disabilities face many challenges in their fight for equality, women with disabilities are more disadvantaged, they suffer double amounts of discrimination 'not only because they are disabled, but because they are 'disabled women'. "While women with disabilities have much in common with men with disabilities, women with disabilities have to face multiple discrimination in many cases, so that they are often more disadvantaged than men with disabilities in similar circumstances" (Kamga, 2011:2).

African women with disabilities are not at the margin of this tragedy. Poverty, joblessness, misery, and social exclusion are the plights of African women with disabilities, who are marginalized and excluded from every sphere of life -- hence the statement from women with disabilities in northern Uganda: "As if we weren't human". As in South Africa, women with disabilities in northern Uganda suffer stigma and discrimination based on their poverty, disabilities and gender. They are prevented from having employment and when they are afforded the opportunity to work, they are poorly paid, earning in general 56 percent of what men with disabilities receive. Moreover, the job market is twice as accessible to men with disabilities as to women with disabilities, who therefore are the poorest of the poor in the society (Biegon & Kamga, 2010: 16).

In Africa, women with disabilities are also prevented from creating a family, accessing information, health care and other government services, and, more importantly, from taking part in the community's activities. In terms of creating a family, women with disabilities are considered to be asexual, unable to marry, have and raise children. Research shows that women with disabilities "as compared with women without disabilities and men with disabilities, are more likely to be unmarried, married later or divorced earlier." According to Kotze 2011, African women with disabilities "tend to be shunned in the marriage 'market,' whereas more men with disabilities actually get married". In terms of health care, girls and women with disabilities are exposed to sexual violence and rape and, consequently, to HIV and AIDS. When they are infected with

HIV/AIDS, women with disabilities are not only discriminated against on the ground of the disease, but also for being women as well as for having a disability (CHR, 2009:88).

In Africa, the vulnerability of women with disabilities to sexual violence, rape and HIV is aggravated by a well known myth that sex with a disabled person will cure AIDS presumably an even more twisted version of the so-called "virgin cure" that is based on the common misconception that people with disabilities are not sexually active and therefore have to be virgins'. In addition, rapists target women with disabilities as they are unable to run away if they are physically impaired, scream if hearing impaired and unable to speak, and identify the rapist later if visually impaired. In addition, women and girls with disabilities are specifically vulnerable to marital rape (Kamga, 2011).

In South Africa, a 29 year old woman with physical disability testified: "My husband would force me [to have sex] all the time. When I tell him that I am tired today he would… force me. I would just sleep even though he would be on top of me. It was painful. It happened all the time"(Naidu et al, 2005:21). The vulnerability to sexual abuse exposes women with disabilities to risk of HIV. In Zimbabwe, a study in 2004 revealed that 87.4 percent of girls with disabilities had been sexually abused; among them, 52.4 percent tested HIV. Similarly, research in Namibia and Botswana reached the same findings, and it was also discovered that women with disabilities in several Southern African countries are excluded "from mainstream HIV/AIDS programmes and denial of access to services such as counselling, testing and treatment" (Kamga, 2011:4).

Moreover, after being victims of sexual abuse, women with disabilities do not have access to court. For example, in Kenya, after the rape of a 10 year old girl with a disability, her mother went to the police station where she was not only denied the necessary police medical forms because there were none, but was also told that "such cases cannot be properly supported in court as the girl is deaf and disabled…[and] cannot be able to give evidence in court". Eventually, when the matter reached the court, it was listed several times, but could not be discussed because of the unavailability of sign language interpreters to assist the applicant (Kamga, 2011:4).

In several African countries, the lack of significant legislation on the rights of women with disabilities is the norm. For example, there is no specific national law protecting women with disabilities in Lesotho, Namibia, and Tanzania; and in Malawi, such a law is still in draft format. In terms of policies on the rights of women with disabilities, Malawi and Lesotho have none, and this is the trend in Africa. Where such policies are found, they are "outdated and largely unimplemented" and women with disabilities thus remain invisible and are discriminated against on a daily basis. Kotze summarises in these words: "PWDs [persons with disabilities] are poor, this is particularly problematic in the case of girls and women with disabilities, as they tend often to be economically dependent on parents and/or partners and are therefore generally not in a position to negotiate about safe sex. As a result of a combination of factors, including poverty, gender inequality and lack of education, women and girls with disabilities are very often more vulnerable to sexual exploitation and violence and therefore to infection by the HIV virus" (Kotze, 2010:25).

2.2.2 Reproductive healthcare options and services availability for women with disabilities

Worldwide, the reproductive health of men and women with physical disabilities is usually given low priority or dismissed (FHI, 1999). This often arises from the myth that disabled people are not sexually active and have no need to control their fertility. Many disabled people are unable to have children and like able-bodied people may wish to use contraception temporarily. Others may seek a permanent or long-acting contraceptive method, since childbearing and child rearing may be difficult for them. Some may prefer a permanent method if they suffer from a genetic condition that could be passed to their children (Best, 1999).

Despite international human rights guarantees, states often disregard or ignore the sexuality of women with disabilities and refuse to offer the information and services to which they are entitled. This is reflected in the de jure dearth of laws and policies and the de facto exclusion of women with disabilities from reproductive health services, information, and education. For example, one US study found that only 19% of the physically disabled women surveyed had received sexuality counseling. Women with paralysis, impaired motor function or obvious physical disability were rarely offered contraceptive methods or information (Haefner et al., 1998). In India, women with very minor physical disabilities do not receive reproductive health services because they are considered to have no marriage prospects (Best, 1999). In the U.S, women with schizophrenia not only experience higher rates of unintended pregnancy than women from the general population, but they experience higher rates of obstetric complications. These women may also be more susceptible to episodes of schizophrenia during the postpartum period. In spite of these challenges, the reproductive health needs of women with psychiatric disorders are often overlooked (Best, 1999).

Lack of information and much misinformation on birth control, abortion and sexually transmitted infections persists. This is particularly true for deaf women. These women are at increased risk of STIs and pregnancy and are further marginalized as a result.

Education must be relevant to disability and sensitive to the issues that women with disabilities face. As a woman with a disability, it is not easy to obtain reproductive health care services from physicians (Grabois, 2001).

2.2.3 Government policy on reproductive healthcare in Kenya

The Government of Kenya (GOK) realizing the need to cater for the needs of women and gender concerns for people with disabilities (PWDs) established the Ministry of Gender, Sports, Culture and Social Services. In 2003, a semi-autonomous government agency (SAGA) – National Council of Persons with Disabilities (NCPWD) was also established by the Ministry of Gender, Sports, Culture and Social Services in 2006 to realign the Ministry to achieve its mandate to cater for PWDs (Kenya, 2006).

The NCPWD is responsible for providing policy guidance, coordination of programmes and mainstreaming concerns for PWD as well as implementing and operationalizing the Persons with Disabilities Act of 2003. Among its functions is to enhance the capacity of disabled person's organizations, institutions and individual PWD (Ministry of Gender, Sports, Culture and Social Services, 2006).

According to the Act, the NCPWD shall be represented in the implementation of the national health programme under the Ministry responsible for health for the purpose of; prevention of disability; early identification of disability; early rehabilitation of persons with disability; enabling PWD to receive free rehabilitation and medical services in public and privately owned institutions; availing essential health services to PWDs at an affordable cost; availing field medical personnel to local health institutions for the benefit of PWDs; and prompt attendance by medical personnel to PWDs (Kenya, 2004).

The NCPWD commissioned a baseline survey in 2007 to obtain data on challenges facing women with disabilities; develop a strategy of engagement with Government and other stakeholders; and make recommendations on the way forward for women with disabilities. The study, which was undertaken in the informal settlements of Nairobi, Kiambu, Thika and Machakos sampled and interviewed women with all forms of disabilities. These included: 48 with physical disability; 2 with cerebral palsy; 2 albinos, two with mental handicaps; four with hearing impairment and two with autism. The study respondents were selected using non-probability sampling methods, namely, convenience and snowball (Kenya, 2007).

The study established that at the national level, policy makers are not responsive to the reproductive and sexual needs of women with disabilities due to lack of institutionalized mechanisms on the use of brail in hospitals, and on contraceptives and safer sex methods (Kenya, 2007). The study recommends that the NCPWD lobby government to institutionalize and provide disability support such as braille, mobility and hearing aids to institutions dealing with disabled women; conduct massive training for language instructors, lobby policy makers to ensure that medicines and contraceptives manufactured in Kenya and imported into the country are also inscribed in braille (Kenya , 2007).

The study also interrogated the *Persons with Disabilities Act, 2003* and found that it has no specific reference to women with disabilities. This, the report says weakens support/legitimacy of persons and institutions advocating for women and girls with disability. It recommends that the NCPWD spearheads the review of the Act to make it gender sensitive towards all categories of disability and with specific focus on women with disabilities (Kenya, 2007).

2.3 Health seeking practices of women with disability

Although the full picture of SRH issues for persons with disabilities is not yet clear, it is certain that there are significant unmet needs. Like everyone else, persons with disabilities need information about SRH. In order to do so, they have the right to make reproductive decisions for themselves. They must have the same access as everyone else to programmes, services, and resources that support them in their decisions (WHO/UNFPA, 2009).

Although there are no specific healthcare seeking patterns for WWD with respect to their health seeking behaviour, health seeking practices by people are described in various literature.

A survey by Mbindyo and Mutere (1987) in Muranga district of Central province shows that a majority of disabled people require medical care. Nearly all disabled persons obtain medical treatment in government hospitals and a majority is not satisfied with the services they get.

Women report less frequently than others to health services in developing countries long queues of women wait at clinics, but they are often seeking care for their children rather than for themselves. Resource constraints limit women access to hospital since men control more esources and income within the households. Women sometimes use these visits to ask about their own health problems, but maternal and child health or 'safe motherhood' services focus primarily on reproductive health. Health workers at these services may ignore women with obvious diseases such as elephantiasis or leprosy because they are unsightly. Or they may lack the training, drugs or facilities to treat them (UNDP/World Bank/WHO, 2000).

In most developing countries, men use health services for their own health concerns more often than women do. Women are more likely to treat themselves or to seek traditional healing and advice. So even when they are affected by such diseases as malaria and schistosomiasis, women may only use the health services as a last resort. Also, many diseases, especially those that are believed to be transmitted sexually, are considered shameful, and women hesitate to ask health workers about them (UNDP/World Bank/WHO, 2000).

No matter how much women may want information about their health, there are certain times of the day, week, month or season when other needs are of a higher priority. One reason why many women do not attend health clinics regularly is that these facilities have strictly regulated working hours that conflict with women's other responsibilities. Also, women feel that time spent waiting in queues could more profitably be spent doing domestic or paid work (UNDP/World Bank/WHO, 2000).

In Kenya, Nigeria and Sierra Leone health-seeking behaviour for women is difficult to predict. In most cases women first use home remedies and traditional medicines for their illnesses. If these fail and symptoms persist, they will seek low-cost treatment in the form of painkillers, topical creams and other over-the-counter drugs. Women consider this type of treatment to be most effective for malaria, colds and coughs, and head- and stomach-aches. Sometimes, if drugs are left over from a previous illness, they will be used for a later illness, regardless of expiration dates or contraindications (UNDP/World Bank/WHO, 2000).

In all study areas formal health services were inadequate, and the shortage of doctors acute. In many cases a health clinic is 50 kilometres from villages. In the rainy seasons roads are frequently impassable on foot, and public transportation is rare and expensive.

Limited drug availability, water and electrical shortages, the lack of diagnostic equipment, poorly trained and sometimes hostile personnel, and the great distances most patients must travel constitute a health care system in crisis (UNDP/World Bank/WHO, 2000).

In Kenya, women get information from a variety of sources, including clinic talks, posters in public places, women's groups and church meetings, the radio, friends and public meetings. The most popular means of receiving and exchanging information is through discussion in women's groups. In these settings, women feel they can ask questions without being threatened or embarrassed. Health messages placed in the songs that women sing in these meetings are another popular source of information (UNDP/World Bank/WHO, 2000). In a study done in Taipei (Taiwan) two oldest and most culturally traditional districts –Lung-Shan and Yen-Ping – concerning their response to actual episodes of sickness as well as their general beliefs about different kinds of health problems confirmed the enormous extent of family treatment worldwide (Kleinman, 1980). Ninety-three per cent of all sickness episodes were first treated in the family, and 73 per cent of all sickness episodes received their only treatment from the family. Also, a smaller, if still very high, per centage of children (88 per cent) were first treated at home than adults (98 per cent) or the elderly (100 per cent) (Kleinman, 1980).

The study by Kleinmann, (1980) further outlined the various determinants of health care seeking behavior. Perceived severity of sickness by family members appeared to dominate. All sickness episodes labelled by family as "severe" received treatment from professional or folk practitioners, but fewer than one-fourth of those labelled as "minor" were so treated. Of the 56 sickness episodes evaluated by the research team as severe acute medical problems, all received treatment from Western-style doctors either at the outset or following family treatment. Forty-seven sickness episodes were labelled by the research team as serious chronic medical or psychiatric sicknesses. Of these, 45 received treatment from at least one practitioner outside the family, but only 29 were treated by Western- style doctors, as compared with 45 who received treatment from Chinese-style doctors and 40 from sacred folk healers. These findings demonstrate the influence of popular beliefs on health care seeking behavior: Western-style practitioners are selected more frequently for the treatment of acute sickness and indigenous practitioners are selected more frequently for the treatment of chronic sickness, which follows the popular culture's ideology concerning the relative efficacy of these therapeutic systems (Kleinman, 1980).

2.4 Accessibility challenges faced by women with physical disability at the healthcare facilities

Becker et al., (1997) conducted a qualitative study to determine reproductive healthcare experiences of women with physical disabilities. The objective of the study was: to explore the reproductive health care experiences of women with physical disabilities and how reproductive health care experiences could be improved.

The main findings of the study was: that the women encountered numerous barriers to quality reproductive health care services, including inaccessible equipment and facilities, limited contraceptive options, health care providers' insensitivity and lack of knowledge about disabilities, and limited information tailored to their needs. Providers sometimes appeared surprised that they would be sexually active, and did not ask about contraceptive use or assess for sexually transmitted diseases. Although most interviewees had private health insurance, some had problems seeing preferred providers. Accessing reproductive health care services is so difficult that some women avoid regular gynecologic visits. Suggestions for improving services included involving women with disabilities in teaching health care providers about their special needs and self-advocacy training to help disabled women become more knowledgeable partners in their own health care (Becker et al., 1997).

Many investigations of the experiences of women with disabilities have been reported. Krotoski et al. (1996) observe that women with disabilities may lack knowledge about their bodies and sexual function. Parents of children with disabilities are often overprotective and set up the expectation that their children will never marry, reproduce, or have intimate relationships (Mayers, 1978). A study by King et al (1993) point out that women with physical disabilities may also have low self-esteem and diminished perception of social acceptance relative to able-bodied women. With limited knowledge and low self-esteem, women with physical impairments may not have the self-efficacy to advocate for themselves in relation to their reproductive health.

Liotta (1996) confirmed that reproductive health issues have often been ignored in part because society tends to view persons with disabilities as asexual beings and therefore, not in need of reproductive health care services.

Gans et al. (1993) identified five commonly recognized reasons for inadequate health care services for people with disabilities: transportation problems, inaccessible offices, inadequate knowledge among health care providers, provider attitudes, and inadequate insurance coverage.

Nosek et al., (1995) found that patterns of interaction with the medical system are set in childhood, often based on frequent negative encounters, and that these experiences can have lifelong traumatic impacts. Women reported emotional, physical, and sexual abuses. Some reported that they lacked basic knowledge about their reproductive health, in part because they had restricted access to such information as adolescents. Women who experienced traumatic injuries later in life said they received inadequate information about the sexual impact of their disability when they were in rehabilitation facilities. Many women also had difficulties obtaining reliable contraceptive information. Women also reported encountering barriers to obtaining health insurance and to accessing offices and equipment. They reported that the most difficult barriers were the negative attitudes of health care providers. These barriers are particularly problematic, because the women reported a higher-than-average incidence of health problems, such as respiratory infections and urinary tract infections, which can have an untoward impact on their lives (Nosek et al., 1995).

Welner and Haseltine (1990) in their study argued that women with disabilities face some special issues in detecting and treating sexually transmitted diseases (STDs). Because these women may have sensory deficits, providers must be trained to recognize other possible signs of STDs, such as sensations of pressure, spasms, urinary tract infections, vaginal discharges, or decubitus ulcers. Both symptoms and findings may operate differently for women with disabilities.

In the past, women with severe physical disabilities were discouraged from having children. Consequently, there have been few studies of pregnancy among these women (Becker et al., 1997). One exception to this is a study conducted by Smelzter among 15 pregnant women with multiple sclerosis (MS). She found that the decision to become pregnant was difficult for many of the 15 because of the lack of information about pregnancy within the context of their disability, as well as the uncertainty associated with the disease itself. Some women had experienced negative reactions to their pregnancies from family members, close friends, and health care providers. Age, length of time since diagnosis, and previous course of the MS all influenced women's child-bearing decisions. For many women, childbearing had become more important to them after they were diagnosed with MS. One woman explained that the diagnosis of MS made her feel abnormal, but the prospect of motherhood made her feel normal again (Smelzter, 1994).

2.4.1 Barriers to reproductive health care

The women identified several barriers to good reproductive health care services confronting them and other women with disabilities. Some of these barriers are structural, for example, physically inaccessible tables, stirrups, and examining instruments not designed for women with impairments. Offices and parking lots are not always fully accessible for wheelchair users, and some participants reported transportation problems in traveling to providers (Becker et al., 1997).

Transport

Driving independently may not be an option for some women with a physical (or sensory) impairment so they are reliant on public transport, taxis or other individuals when travelling to and from health care facilities (Anderson and Kitchin, 2000; Lawthers et al., 2003; Prilleltensky, 2003; Scheer et al., 2003). Depending on the woman's geographic location and the availability of suitably adapted public transport, access to health care facilities and participation in other community activities may be severely curtailed. In the United States, it is estimated that 1 in 4 women with disabilities have no access to appropriate transportation (Nosek, 1992; Goodman, 1994). Inadequate transport to and from the health care facilities can pose significant challenges for women trying to get to appointments and to access reproductive care. Even when public transport is available, Smeltzer et al., (2007) posited that it is expensive, undependable and inadequately equipped to accommodate or secure women with a wheelchair. Long waiting times for suitably adapted transport to arrive is the norm and can be problematic when appointment times are inflexible. The service is generally infrequent and the distance of health care facilities from designated bus stops may be such that women still need to negotiate many other challenges in the environment before reaching the health care facility (Smeltzer et al., 2007).

Access to buildings

The design of the built environment can be another critical determinant of accessibility and impacts significantly on the social inclusion and participation of women. For some women, physical accessibility to the building is often the first and most obvious challenge encountered (House of Commons Health Committee, 2003; Thierry, 2006) and can be one of the most challenging aspects to obtaining care (Schopp et al., 2002).

Evidence suggests that a substantial proportion of health care facilities and physician's offices are inaccessible to women with a physical or sensory disability (Campion, 1997; Welner, 1997; Grabois et al., 1999; DeJong et al., 2002; Smeltzer et al., 2007). It is estimated that 2 out of 5 women with disabilities experience difficulty getting into and around the built environment of physicians' offices (Goodman, 1994) while a fifth of women in both the United Kingdom and the United States report that due to architectural barriers, health care facilities are unable to accommodate them during childbirth (Goodman, 1994; Nosek, 1996). Other obstacles that render health care facilities, physician's offices and clinics inaccessible include the physical location of facilities, offices and clinics, non availability of designated parking bays and the topography of pavements and curbs (Thomas and Curtis, 1997). For some women, the stress and physical energy generated from trying to gain access is so intense that some would 'delay appointment making' (Scheer et al., 2003) rather than try to negotiate access to an inaccessible environment (Goodman, 1994; Nosek et al., 1995; Scheer et al., 2003). This is compounded even further as health professionals are often unaware of the problems that inaccessible offices and clinics present (Smeltzer et al., 2007). Physical challenges which impede access convey the impression to women that they are unwanted, unwelcome and are a burden on health care providers (Kaplan, 2006).

Internal waiting areas and rooms pose physical challenges with inaccessible bathroom facilities, inadequate space and narrow corridors posing difficulties for women with disabilities especially when trying to manoeuvre in a wheelchair. Reception desks are at an inappropriate height or level to facilitate eye to eye contact (McKay-Moffat, 2007) and the exchange of personal and sensitive information with receptionists, who are often perceived as gatekeepers to the services. Space restriction limits any freedom of movement and limits the women's possibility to move around the built environment, which essentially restricts them to one particular area.

Inadequate collaboration of services

Women with disabilities frequently encounter fragmented and uncoordinated services (Commission on the Status of People with Disabilities, 1996; Department of Health, 1996; Baker and Cardenas, 1996; Thomas and Curtis, 1997). Services that are fragmented and uncoordinated are insensitive to individual needs and service provision is often compromised (Thomas and Curtis, 1997; D'Eath et al., 2005). Health professionals in maternity services may work in isolation from other professions or staff involved in the care of the women with a disability; there is little collaboration with other professionals to assist them to become knowledgeable about the disability, and a referral to allied health professionals, for example, physiotherapists or occupational therapists, is an uncommon occurrence (Lipson and Rogers, 2000; McGuinness, 2006). Consequently, health professionals do not offer effective, individualised and culturally sensitive care or proactive help and guidance (Tingle and Dunmore, 2005).

Lack of suitable equipment

It is also difficult for women with disabilities to use equipment that is fixed and not readily adjustable, for example, examination tables and impractical baby cots, and many women rely on health professionals to help negotiate such inaccessible equipment (Thomas and Curtis, 1997). However, these women frequently experience a lack of will, manpower and suitable equipment to help transfer them safely in order that examinations can occur or in order that they can interact with their baby. A recent study of 152 trusts providing obstetric or midwifery-led maternity services in England found that 83% of trusts reported having height-adjustable couches available at some antenatal clinics and 90% said they would provide home visits for disabled women. However, only 22% of delivery units had flexible-height cots (Commission for Healthcare Audit and Inspection, 2008).

Inappropriate training of health professionals in correct manual handling techniques exacerbates the issue of safe transfer even more and exposes women to impractical and unsafe techniques (Grabois, 2001). Diagnostic equipment can also be a source of discomfort and its use can be a daunting and traumatic experience for some women, especially those with a physical disability, and their experience may deter these women from seeking further care (Goodman, 1994; Welner, 1999).

Lack of assistance with physical environment

An inaccessible environment coupled with a lack of accessible baby equipment and inflexible hospital guidelines, procedure, policies or protocols impact on women's ability to care for their babies in a confident and independent manner. McFarlene (2004) found that health professionals are often unable or fail to suggest creative and practical solutions to overcome the challenges encountered with an inaccessible environment and equipment. They fail to provide alternative equipment solutions, or to refer the women to appropriate services from where adapted/modified equipment may be purchased (Lipson and Rogers, 2000).

Access to high quality personal care attendants could facilitate independence in women with disabilities (Lawthers et al., 2003); however, some women in the United States experience difficulty in finding suitably trained and experienced personal care attendants. Limited numbers of competent attendants impact on the women's autonomy and ability to be independent and render the individual dependent on formal and informal support structures such as partner, their children and extended family (D'Eath et al., 2005).

Access to health information

Possessing information engenders a sense of autonomy and control and is a central tenet of the decision making process; Clark (2002) suggests that it is in fact 'the fourth right of citizenship'. Insufficient access to information excludes women from the process of informed decision making and impacts significantly on their choice. Moreover, it impinges on the doctrine of informed consent where women must understand all risks and benefits associated with procedures and care (Gravois, 2001; D'Eath et al., 2005). Not having adequate explanation especially about invasive, intimate procedures renders women more vulnerable and when the procedures are conducted they may feel undignified, humiliated and degraded.

The information needs of women with disabilities are varied and dependent on the type of disability or impairment experienced (McKay-Moffat, 2007). Women with disabilities, however, do experience difficulties in receiving quality health information (Nosek, 1992; Harris and Bamford, 2001; Commission for Healthcare Audit and Inspection, 2008) and Campion (1997) and the Royal College of Nursing (RCN) (2002) found serious deficits in the provision of information in relation to pregnancy, childbirth and disability in the U.K. When provided, the information tends to be irrelevant, inadequate, unhelpful (Goodman, 1994; Commission for Healthcare Audit and Inspection, 2008) and contradictory (Thomas and Curtis, 1997). Women are forced to obtain information from other sources, e.g. support groups/networks and voluntary agencies while many parenting skills are developed through experiential learning (Thomas and Curtis, 1997).

The learning needs of expectant women with physical disabilities vary considerably more than for women without disabilities and contemporary models of antenatal education have been described as inappropriate (Conine et al., 1986; Blackford et al., 2000). The evidence suggests that the needs of women with disabilities are not being met when attending antenatal classes (Conine et al., 1986; Blackford et al., 2000; Commission for Healthcare Audit and Inspection, 2008). Some women reported that class facilitators do not advocate for women with disabilities (Blackford et al., 2000) and described them as cold and uncaring (Westbrook and Chinnery, 1995). Westbrook and Chinnery (1995) found that many facilitators lack knowledge in relation to disability and pregnancy and fail to consider the special needs of women with physical disabilities. Some facilitators consider that the provision of antenatal education classes for women with disabilities is not part of their role and function (Conine et al., 1986) and have indicated how the provision of adaptive programmes for women with disabilities is time-consuming and disruptive to normal progress (Conine et al., 1986). In a recent survey of the 152 trusts providing maternity services in England, pre-pregnancy advice clinics were available for women with a physical disability in only 19% (Commission for Healthcare Audit and Inspection, 2008).

Conine et al., (1986) found that many of the environments where antenatal classes are held are inaccessible; doors, walkways and bathroom facilities are generally inappropriate and directional guides indicating the location of appropriate facilities are non-existent. There is a lack of sufficient information in appropriate formats which could help to facilitate a state of independence (Blackford et al., 2000) and facilitators do not discuss adaptive techniques that could help women with disabilities in their parenting skills. Lipson and Rogers (2000) and McKeever (2003) found that facilitators did not routinely provide alternative equipment or refer the women to appropriate services from where adapted/modified equipment may be purchased.

Teaching and learning resources used by class facilitators are more suited to women without a disability and are inappropriate for women with a physical (or sensory) impairment. The stigma of having a disability impacts on women's sense of self and self-confidence. Consequently, women may lack the confidence to discuss their particular concerns and issues with class facilitators. This often results in many women not accessing and availing of antenatal education classes or, when they do, women are unwilling to voice concerns or simply ask a question because the educator and other women with no disability in the class cannot relate to or associate with their anxieties or fears. Women therefore, feel excluded from the class (Westbrook and Chinnery, 1995).

2.5 Care provision problems faced by women with physical disability at the healthcare facilities

Ineffective communication between health professionals and women with disabilities

Some health professionals communicate with women with disabilities in a patronising (D'Eath et al., 2005) or authoritarian (Westbrook and Chinnery, 1995) manner. Campion (1997) reports that the language used by many health professionals reflects their prejudicial attitudes and ignorance and may leave women feeling fearful, uncomfortable and degraded. Even the physical positioning of health professionals in clinic areas reduces good communication, for instance, due to lack of eye to eye contact between a wheelchair user and those standing near them (McKay-Moffat, 2007).

Attitudes of health care workers on reproductive health needs of women with disabilities

Becker et al in their study "Reproductive Health Care Experiences of Women with Physical Disabilities": done in 1997 concluded that the most commonly discussed problems concerned interactions with health care providers. Women described providers as insensitive or lacking awareness of disability issues as they impact reproductive health care. One woman, who was paralyzed in an accident, expressed surprise that providers were not more knowledgeable about how to treat women with disabilities. When she almost fell off the examining table because no one was holding her legs, she realized she had to help them understand what she needed (Becker et al., 1997).

Women, especially those with spasticity, also sense that some providers are uncomfortable or nervous about treating them. A woman with cerebral palsy described the situation: "Somebody standing over me, and they are nervous . . . which causes a downhill cycle. It gets worse and worse because the more nervous they are, the more nervous I am, which increases my spasticity." Other women believed that they were not listened to, were patronized, or were not given adequate explanations of their condition or of upcoming procedures. One woman stated, "Sometimes they are not honest about things they tell us . . . They just basically treat us like children instead of the adults that we are." Another woman who narrated her story in Becker et al exemplifies the problems women with mobility impairments have when they are not adequately prepared for the examination: "Once they put me up on this high table, with my back, I don't have control. And they say, 'Now take your shirt off.' Had I been told to take my shirt off when I'm sitting in my chair, I could do it by myself, but I nearly fell off and two people had to help me . . . . Therefore, things were harder and more complicated than they really needed to be." (Becker et al., 1997:26).

The lack of good communication leads women to avoid asking questions. According to one woman, "It's pretty difficult to continue to ask questions when you get looked at like you're coming from Mars." She observed, "They always assume that it is a disability problem instead of a real health problem and that is not just with reproductive healthcare staff. That is with everything." Another respondent stated that physicians sometimes talk down to the woman or talk to the person accompanying the woman, as if the patient herself is not in the room. To feel comfortable when asking questions is particularly important for these women, however, because they may experience symptoms that are difficult for them to interpret. For example, one woman who had fibroid tumors narrated that her physician asked if it hurt when he examined her. Her response was, "Well, how would I know?" Another respondent discussed the special problems people with speech and hearing impairments have in communicating with health care providers. Even when a translator is present, the translator 'may not accurately and completely communicate the necessary information. Other women said that they were treated as asexual beings. One woman stated that the health care provider seemed shocked that she wanted to use birth control or protect herself in any way. By contrast, one woman commented positively on a provider who asked about her partner: "He assumed I had one." (Becker et al., 1997:27).

Becket et al., (1997) study summarised that the results of these barriers are often uncomfortable, embarrassing, or painful examinations. As one woman said, "This is a very sensitive area for a woman. You feel a lot of shaming very quickly." Consequently, women tend to avoid routine examinations, and seek gynecologic services only when they are experiencing a problem or are in need of medically prescribed contraceptives.

Women also discussed what facilitates satisfactory reproductive health services. As might be expected, these factors were often contrasted with the barriers the women had encountered. A common theme was a positive attitude on the part of the health care provider and his/her office staff. One woman mentioned the favorable impact of having someone in her physician's office actually offering to help her with her wheelchair (Becker et al., 1997).

More specifically, providers who ask questions are willing to learn, and respect women as partners in decision-making about their health are viewed positively. One woman with paralysis reported that her gynecologist consulted with two physiatrists to make sure there were no contraindications before prescribing oral contraceptives (Becker et al., 1997).

The negative attitudes from health care professionals described above may stem from the health professional's lack of awareness, knowledge and expertise in relation to the disability (House of Commons Health Committee, 2003). Few health professionals seem knowledgeable about the care required by women with disabilities and many are unfamiliar with disability related complications that may develop (Westbrook and Chinnery, 1995; Lipson and Rogers, 2000; McGuinness, 2006; Thierry, 2006; Smeltzer et al., 2007). They may lack awareness of, and therefore be insensitive to, the individual needs of women. Quite often it is the woman who educates the health professional about her disability. This lack of knowledge and awareness leaves many health professionals anxious, uncomfortable and nervous about caring for a woman with a physical disability during pregnancy, childbirth and early motherhood (Baker et al., 1996), which may encourage them to refer women to another physician. This action impacts on the concept of continuity of care (Grabois et al., 1999; House of Commons Health Committee, 2003), a concept that could help alleviate the many attitudinal challenges experienced by women.

Attitudes and behaviours relating to pregnancy

Health professionals rarely consider pregnancy and disability together. Women are often defined in terms of their disability and their disability overshadows their pregnancy and new role as a mother (Lipson and Rogers, 2000; Clark, 2002; Prilleltensky, 2003). This may not be the experience of all women, for some the opposite may occur; health professionals may fail to acknowledge the physical disability and may not discuss the possible additional and unique needs the women may have (McKay-Moffat and Cunningham, 2006). An unfamiliarity with the woman's disability impacts on the provision of appropriate care (Fiduccia, 2000). Welner (1999) found that the casual attitude of some health professionals towards complications that may occur can instill a lack of confidence and facilitate a state of discomfort between health professionals and the woman. Many health professionals make a conscious effort to avoid discussing the reproductive concerns and issues of women with disabilities because they are overwhelmed by their workload and unable to manage additional problems (Welner, 1999).

Women with physical disabilities have described health professionals as aloof, authoritarian and domineering (Westbrook and Chinnery, 1995) or patronising, hostile and unable or unwilling to accommodate diversity (D'Eath et al., 2005). The hypervisibility of the woman's disability may result in the woman being shunned or ignored (Zitzelsberger, 2005), although this may be due, in part, to health professionals' nervousness at the different challenges that women with disabilities present (Goodman, 1994).

Policy barriers

Policy barriers may be imposed by hospital or clinic regulations; by insurance companies; or by other third-party payers. Some insurance providers discriminate against individuals with disabilities, by barring coverage for pre-existing conditions, or by cost-capping services which may be essential for managing a disability. Another major barrier is that some necessary services such as in-home personal assistance services, prescription medications, durable medical equipment, holistic health services, assistive technology, preventive care, certain therapies, or abortion services may not be covered by private or government-funded insurance plans. Government and private policies may also have an institutional bias i.e., they offer services primarily in nursing homes, rehabilitation hospitals, and other large long-term care facilities; but not in the disabled woman's own home, where she can be part of her family and community. Ending this institutional bias, and securing more support for independent living (IL) and community-based rehabilitation (CBR), is a major focus of disability-rights advocates in many countries (Hershey, 2000).

2.6 Theoretical Framework

2.6.1 Critical Medical Anthropology

Critical Medical Anthropology theory as an analytical perspective in healthcare has been influenced by Marxist theory and dependency theory (Ember and Levinson, 1996). This approach analyses the impact of global economic systems, particularly capitalism, on local and national health (Singer and Baer, 1995:3). The central foci of analysis in CMA are imbalances in power relations and differential access to health with the primary objective of CMA being the transformation of social relations. Critical medical anthropology "emphasizes the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience and health care" (Singer and Baer 1995:5). It looks "toward a more holistic understanding of the causes of sickness, the classist, racist and sexist characteristics of biomedicine as a hegemonic system, the interrelationship of medical systems with political structures, the contested character of provider-patient relations and the localization of sufferer experience and action within their encompassing political-economic contexts" (Singer and Baer 1995:6). CMA is concerned with the phenomenology of illness and pain, and the social construction of the individual.

Health is also considered to be socially constructed, rather than organic, and is defined as "access to and control over the basic material and nonmaterial resources that sustain and promote life at a high level of satisfaction" (Baer et al. 1986:95).

The theoretical underpinnings of critical medical anthropology can provide comprehensive support and enlightenment to intervention programming, with its focus on political economy, the social relations of health and disease, and commitment to social action. Applied critical medical anthropological theory can bring a variety of attributes to critical praxis: cultural relativism; concern with insider perspective; support for self-determination; a desire to work with communities to respond to their felt needs; an appreciation of research as a "potent weapon in social struggle" (Singer, 1995:99); holistic orientation and understanding of local customs; recognition that culture shapes and is shaped by social relations and human behaviour; an awareness of the social origin of disease, and the ideological aspects of science and medicine; and an orientation to "consciousness raising and empowerment through the unmasking of the structural roots of suffering and ill health" (Singer 1995:99).

Critical clinical medical anthropology is an adjunct of political economy. This approach analyses biomedical practice and the differentials in power and authoritative knowledge of practitioner and patient. Clinical anthropology has been influenced by Michel Foucault's writings on the historical production of medical knowledge and the notion that the body can become an arena in which social control issues are played out. Usually focused on medical communication, the approach has been used particularly in relation to women's reproductive health and has developed a controversial literature on the lexicalisation of women’s bodies.

Relevance of the theory to the study

CMA focuses on the economic perspective of health through the lens of capitalism and the state’s role. This aspect is important in explaining the economic challenges faced by women with physical disabilities in accessing reproductive healthcare in centres without any state subsidies. The phenomenon may result into women minimizing health centre visits given the high costs or seeking cheaper alternatives irrespective of the quality of healthcare provided.

CMA examines the contested character of provider-patient relations and the localization of sufferer experience and action within their encompassing political-economic contexts. In this case it helps to explain the challenges women with physical disabilities face at the health centres in terms of attention by the care-providers which has been labelled discriminatory. The situation has led to overlooking the patients' explanations and conditions within the health centres by the medical attendants. This approach therefore analyses the biomedical practice and the differentials in power and authoritative knowledge of practitioner and patient which is critical in understanding challenges faced by women with physical disabilities in seeking reproductive healthcare.

CMA is concerned with the phenomenology of illness and pain, and the social construction of the individual. In this context, it explains the society's view of women with physical disabilities as asexual hence no need for reproductive healthcare information and services to this group of persons. It therefore advocates for the structural unmasking of the suffering and ill health.

2.7 Assumptions

- The reproductive health seeking practices of women with disabilities are informed by several factors.
- Women with disability face a lot of challenges in assessing services in a health facility.

- Women with disability face a lot of constraints in service delivery in health facilities.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter describes the study site, study design, study population, sample size and sampling procedures, methods of data collection, data processing and analysis. The chapter finally presents ethical considerations that guided the study.

3.2 Research Site

This study was carried out in Mombasa County. Mombasa is an Island in the Coast province and the second largest town in Kenya after Nairobi. Mombasa town is located on the East-Coast of Kenya some 500kms from Nairobi the capital of Kenya. Mombasa town sits on the island totaling some 13km² and on the mainland sections of the Mainland North (Kisauni), Mainland South (Likoni) and Mainland West (Changamwe). All these sections combined are some 275km²; however, the total area of the town including the territorial waters is 867km² of area (Mombasa District Strategic Plan 2005 – 2010).

Coast province has a population of about 3,325,307 people with 1,656,679 males and 1,668,628 females (KNBS, 2010). It is a cosmopolitan town and the heart of tourism in the country. Mombasa County has a population of about 939,370 people with 486,924 males and 452,446 females. The number of people with disabilities in the country per sex stands at 647,689 (3.4%) males and 682,623 (3.5%) females (KNBS, 2010).

Mombasa's health service infrastructure includes both private and public health facilities. The County is serviced by 23 public facilities and a couple of private facilities (DDP, 2005). The provincial referral hospital, the Coast General Hospital, is at the apex of the health care system and provides diagnostic, therapeutic and rehabilitative services.

3.3 Research Design

This was an exploratory cross-sectional study that used both quantitative and qualitative methods of data collection. The quantitative data was collected through survey questionnaires while qualitative data was collected through key informant interviews, focus group discussions and case narratives. Quantitative data was cleaned, coded and analysed using the Statistical Package for Social Sciences (SPSS) software and the results presented in tabular forms, graphs and charts.

Qualitative data from key informants, FGDs and case narratives was analysed thematically and used to enrich the quantitative results and draw conclusions as guided by the objectives and assumptions of the study.

3.4 Study Population

The study population was women with physical disabilities of reproductive age and living in Mombasa County. The unit of analysis was the individual woman with physical disability.

3.5 Sample Population

A sample of 45 women was drawn from the County as respondents in the survey questionnaires. In addition, the study had twelve key informants whereby ten health workers and two NGO officers working for disability organization were drawn for expert opinions.

3.6 Sampling Procedures

The study employed purposive sampling technique to select the sample. The study purposively selected a disability group in Bombolulu, an Association of Persons with Disabilities (APDK) situated in Bombolulu and Portreitz Special School for the disabled.

In each of the centres, a sample frame that consisted of the names of the registered members was used to guide the sampling process. Respondents to the survey questionnaires were conveniently sampled from the lists. Respondents for the survey included 8 from Portreitz Special School, 15 from Twaweza women group in Bombolulu and 22 from APDK - Bombolulu. Six women who appeared experienced and ready to volunteer more information were purposively drawn for case narratives. Four focus group discussions (FGDs) were conducted; one with older and another with young women in APDK-Bombolulu. Another FGD was conducted with young women and older women respectively in Twaweza. Young women were between the ages of 20-35 years while older women ranged between 36 – 60 years. The key informants were purposively selected based on their expertise and interest to participate in the study.

3.7 Data Collection Methods

3.7.1 Survey

Questionnaires were administered to 45 women and were important in eliciting information on access to reproductive health and experiences of disabled women, attitudes of health workers, and the attitudes of the women with disabilities to seeking reproductive health. Their views on the means of improving reproductive health services for women with disabilities were also sought. A survey questionnaire (Appendix, 1) was used to collect data.

3.7.2 Focus group discussions (FGDs)

FGDs were carried out with four groups of physically disabled women. These were two groups of younger women (18-35 years) and two groups of older women (36-60) years to gauge the different experiences that women undergo in seeking reproductive health services. The FGDs with younger women had 6 participants at APDK-Bombolulu and 8 participants at Twaweza while the FGD with older women at APDK-Bombolulu had 12 participants. Similarly, the FGD with older women at Twaweza had 9 participants. These discussions were important in yielding important challenges women experience while seeking reproductive health services in public health facilities and recommendations for improved services were a key factor in the FGDs among other issues. An FGD guide (Appendix, 2) was used to collect data.

3.7.3 Key informant Interviews

These interviews were held with ten health care providers and two NGO workers. These key informants helped to explain the reproductive health needs of women with physical disabilities, the accessibility and the care provision challenges faced by this group of women at the healthcare facilities. The research further explored the kind of training they receive for such special cases and the level of healthcare access, both medical and structural for such women. A key informant interview guide (Appendix, 3) was used to collect the data.

3.7.4 Narratives

Case narratives were carried out with 6 women purposively sampled with physical disabilities of different ages to get the deeper voices of disabled women on their experiences during a specific reproductive health episode. The information collected from case narratives covered areas such as personal experiences of the informants while seeking reproductive health services and how social factors such as age, class, income, marital status affected their access to services. These women also provided information on any form of discrimination suffered due to their condition or if it was a consideration before accessing the services. A case narrative guide (Appendix, 4) was used to collect data.

3.8 Data Processing and Analysis

The data collected was cleaned and checked for consistency and accuracy of responses. Completed questionnaires were reviewed daily for completeness and were accessible only to the researcher and research assistants. Completed questionnaires were entered into the Statistical Package for Social Sciences (SPSS) computer programme for analysis.

Qualitative data from key informant interviews, case narratives, and FGDs were analysed thematically and used to enrich quantitative derived results and conclusions drawn guided by the objectives and assumptions of the study.

3.9 Ethical Considerations

Permission from relevant authorities was sought before embarking on the fieldwork. Ministry of Higher Education's authority was sought through the National Council for Science and Technology.

During data collection, the researcher introduced herself to the respondents, explained the importance of the research and sought permission to carry out the interview. Consent from the respondents was sought and assurance of confidentiality was given and kept. Respect for the respondent's views and culture was of paramount importance. The information collected from participants was kept confidential and was only accessible to the research team. During the training of research assistants, the issue of confidentiality was a key factor. Any breach in confidentiality would result in instant dismissal of the responsible member of the research team. The answered questionnaires were kept in the custody of the overall researcher as soon as they are collected and were not released to any other party not concerned with the research. In the write-up, pseudonyms have been used to conceal the identity of the respondents.

CHAPTER FOUR: DATA PRESENTATION AND ANALYSIS

4.1 Introduction

This chapter presents the findings of the study based on the data collected from the field. The study sought to assess the reproductive healthcare challenges of women with disabilities in Mombasa County. The study focused on responses from members of Bombolulu Association for the Physically Disabled of Kenya (APDK), Portreitz Special School and Twaweza Women group. The data has been analyzed and presented in form of graphs and tables and the qualitative information presented in prose and in some certain circumstances, verbatim quotes used to amplify the voices of informants and participants.

4.2. Demographic information of the respondents

Table 4.1: Demographic characteristics of the informants

Variable	**Percentage**
Age	
20-30 years	15
31-40 years	34
41-50	47
51-60	4
Marital status	
Single	55
Married	40.4
Divorced/separated	2.3
Widowed	2.3
Children	
Yes	78
No	22
No of children	
1-2	55.8
3-4	26.4
5-7	17.8
Educational level	
Primary	39.4
Secondary	21
College	36.6
Diploma	3
Employment status	
Yes	76
No	24

In terms of age, 47% of the respondents were between the ages of 41 and 50 years while 34% were between the ages of 31-40 years. On the other hand, 15% were between the age brackets of 20-30 years while 4% were between the ages of 51-60 years. On marital status, 55% of the respondents were single while 40.4% were married. Further, 2.3% indicated that they were divorced while a similar percentage pointed out that they were widowed. Most (78%) of the respondents indicated that they had children while 22% of the respondents reported to have no children. On education levels attained, 39.4% of the respondents indicated that they had attained primary education while 21% indicated that they had attained secondary education. Further, 39.6% revealed that they had attained college education. On occupation, 76% of the respondents indicated that they were employed while 24% were not employed. They were engaged in different forms of employment such as teaching, clerical work, tailoring, and supervision. Others worked in the warehouses as casual laborers.

On the amount of money earned, the respondents indicated as follows: 80% earned below Ksh 10,000; 15% earned between Ksh 10,000 to 20,000 while the remaining 5% earned above Ksh 30,000. A detailed breakdown of the salaries are shown on Table 4.2 that shows that employees at Portreitz Special School who are staff of the Teachers Service Commission (TSC) were paid as follows: a head teacher who had a salary of above Ksh 30,000, a teacher who had a salary of between Ksh 11,000-20,000 and a secretary who had a salary scale of below Ksh 10,000. On the other hand, the APDK Bombolulu had permanent employees such as supervisors who had a salary of Ksh 12,000. The casual workers (those paid per hour) like jewellery staff had a salary of Ksh 9000, warehouse staff earned Ksh 6000, tailors had a salary of Ksh 9000 and casuals (paid per hour and no other benefits) who were paid between Ksh 280 and 312 per day. In addition, the

Twaweza group had permanent employees such as a Coordinator who had a salary of Ksh 20,000 and tailors who earned Ksh 10,000 as summarised in table 4.2 below:

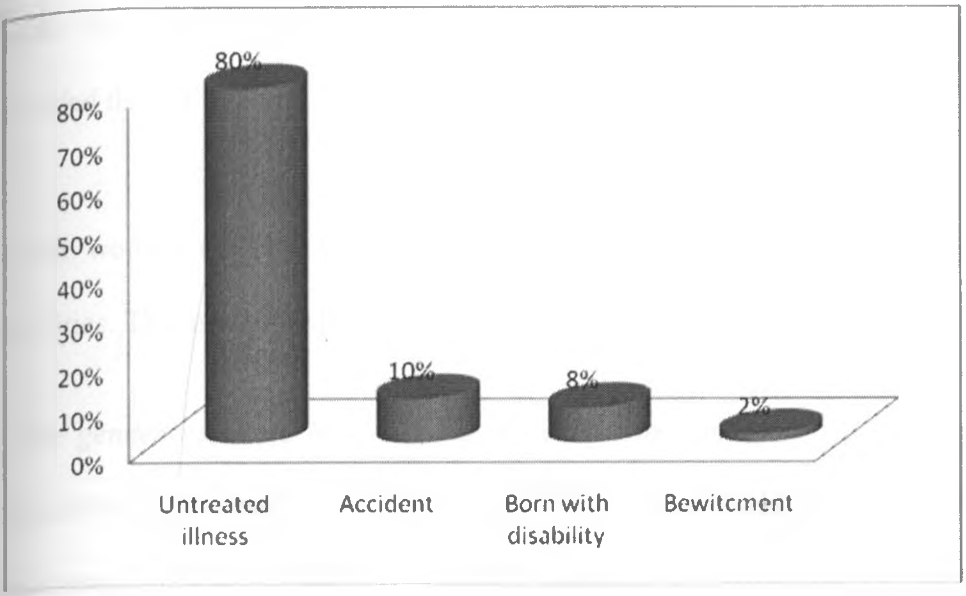
Table 4.2: Income levels

Employer	Nature of Employment	Designation	Salary scale
TSC(Portreitz)	Teaching	Head Teacher	Above 30,000
		Teacher	Between 11,000-20,000
		Secretary	Below 10,000
APDK Bombolulu	Permanent	Supervisor	12,000
	Casual	Jewellery	9000
		Warehouse	6000
		Tailoring	9000
		Casual	280 or 312 per day
Twaweza group	Permanent	Coordinator	20,000
	Casual	Tailor	10,000

4.2.1 Nature and causes of the disability

Most of the respondents (80%) indicated that their disability was physical in nature and it came about as a result of untreated illness suffered in childhood (0 – 5 years) such as polio because they were not vaccinated. On the other hand, 10% reported that their disabilities were due to accidents while 8% reported being born with disability. Finally, one respondent reported bewitchment as a source of her disability. The findings are summarised in figure 4.1 below:

Figure 4.1: Causes of disability among respondents



4.2.2 RH services provided at health facilities

The services the disabled were provided with included breast examination, PMTCT, family planning services, delivery, antenatal care, post natal care, repair of vaginal fistula, rehabilitative and palliative health care.

4.3 Reproductive health seeking practices of women with physical disabilities in Mombasa County

The study shows responses on whether the respondents went to the hospital whenever they had reproductive related illnesses.

The study established that 83.3% indicated that they went to hospitals whenever they had a reproductive related illness while 16.7% reported that they did not go to hospitals whenever they had a reproductive health problem. Those who did not go to the hospital noted that they practiced self medication and some were tired of going to hospitals every month due to menstrual pains. Some of the respondents noted that theydid not suffer from reproductive health illnesses while others indicated that they felt rejected and despised when they visited the hospital and clinics because of their conditions and they therefore avoided them altogether.

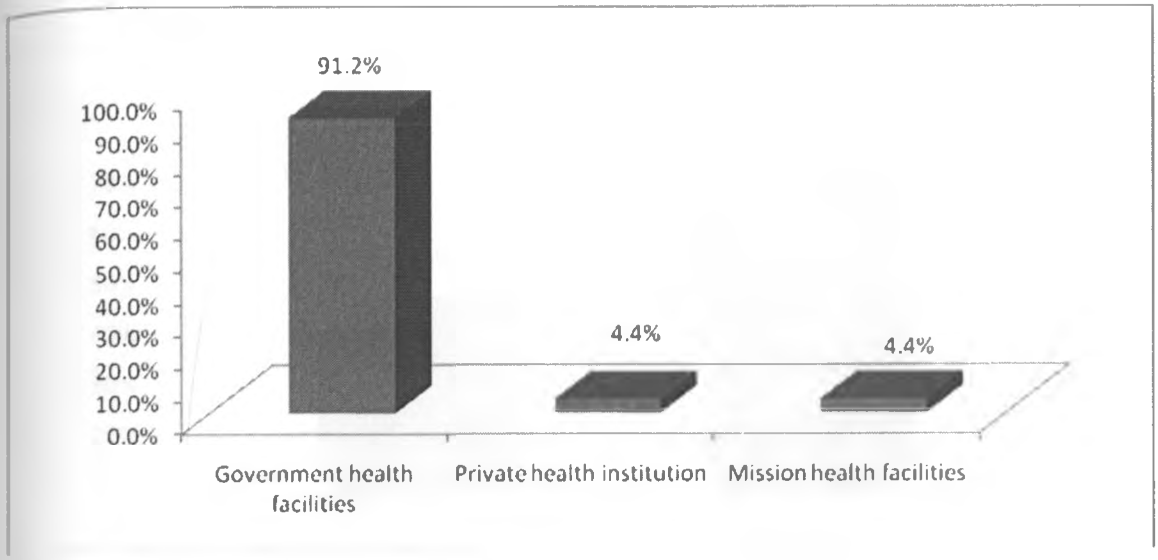
Other women indicate that the work load they have bars them from accessing the facilities. This is summed up by a participant in an FGD who said:

"The gender roles we have to play as women are immense more so for women with disabilities. This in essence makes it hard for us to seek treatment for conditions that can be treated at home as the hospitals are normally expensive and characterized by long queues." (Interview with FGD participants at Twaweza women group). This is in line with a UNDP/World Bank/WHO (2000) study that stated that one reason why many women do not attend health clinics regularly is that these facilities have strictly regulated working hours that conflict with women's other responsibilities. Also, women feel that time spent waiting in queues could more profitably be spent doing domestic or paid work.

The issue of self medication among the FGD participants featured prominently. In most cases, women first use home remedies and traditional medicines for their illnesses. If these fail and symptoms persist, they will seek low-cost treatment in the form of painkillers, topical creams and other over-the-counter drugs. This concurs with previous a previous study done in Taipei (Taiwan) two oldest and most culturally traditional districts –Lung-Shan and Yen-Ping – concerning their response to actual episodes of sickness as well as their general beliefs about different kinds of health problems confirmed the enormous extent of family treatment worldwide (Kleinman, 1980).

On reproductive health services sought, women patronized several health facilities as shown below on Table 4.3.

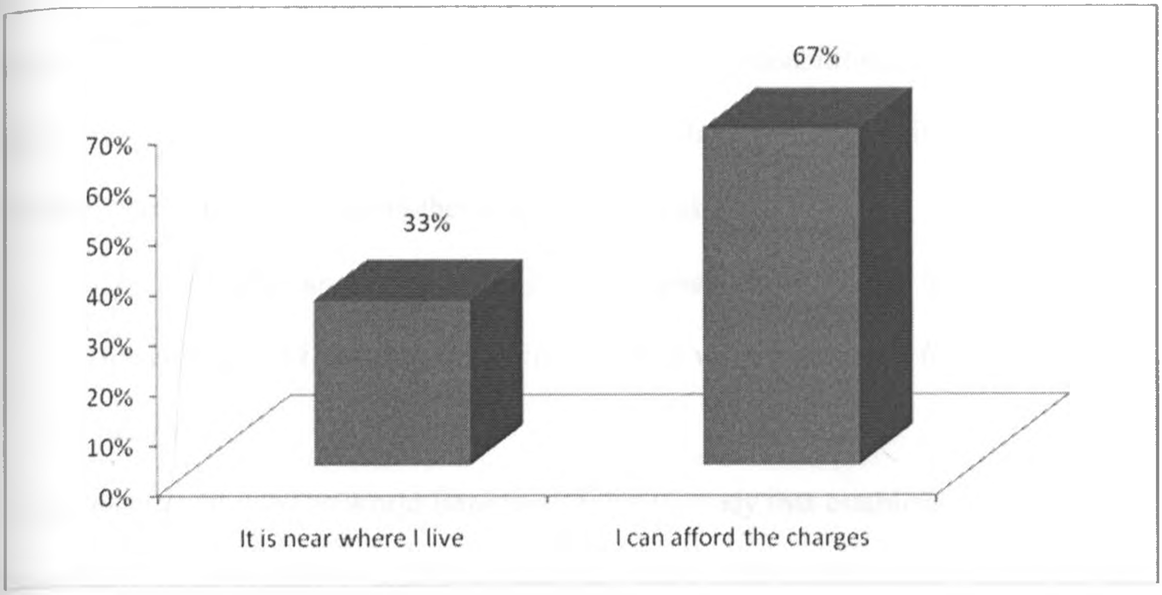
Figure 4.2 Places where women seek reproductive Health Services



The study shows that majority of the respondents indicated that they went to government health institutions; this was 91.2% while 4.4% revealed that they went to private health institutions and another 4.4% went to mission health facilities. Further, they indicated that they went to hospitals such as Coast Provincial General Hospital (CPGH), Guru Nanak, St Mary's Saba Saba, Jamii, Mkomani, Portreitz and Agha Khan Hospital. The respondents cited that they went to government health institutions because they were cheap and easily accessible. CPGH and Portreitz were situated close to most of their residence.

The reasons for attending the CPGH were varied ranging from distance, cost and others as documented on table 4.5. The table shows the reasons for attending government facilities. The respondents (33%) chose the reproductive health facilities because it was near where they live. Further (67%) indicated that they choose the nearby reproductive facility since it was affordable.

Figure 4.3 Reasons for attending a particular reproductive health facility



The key informants indicated that accessing healthcare was a big challenge because for each service you receive at a health facility, you have to pay for it. One of the healthcare providers noted that most of the physically challenged women are poor and connot afford expensive health care. He commented thus:

> *"Most of these people have difficulty paying for healthcare services because of their low income levels. Consequently they are not able to access some services at the hospital".* (A doctor from CPGH).

Women with disability continue to face financial obstacles in seeking RH services at health institutions despite provisions provided for in the Persons with Disabilities Act 2003, that stipulate that the national health programme under the ministry of health shall enable PWD to receive free rehabilitation and medical services in public and privately owned institutions; availing essential health services to PWDs at an affordable cost; availing field medical personnel to local health institutions for the benefit of PWDs; and prompt attendance by medical personnel to PWDs (Kenya, 2004).

In addition, the disabled women in the FGDs revealed that they cannot engage in meaningful labour intensive employment due to their disabilities. Most of them are therefore, left to rely on their husbands, partners or relatives to foot their medical bills. As Rukiya Ahmed a 38 year old mother of three observed:

> *"We rely on our husbands to give us money to go to the hospital and they sometimes don't see this as a priority unless we are very sick like when you are bed ridden."*

This concurs with UNDP/World Bank/WHO (2000) study that established that resources constraints limit women's access to hospital since men control more resources and income within the households.

The disabled face stigmatization and discrimination in the community and at work. The discussants also indicated that no matter how much a disabled person was educated, they could not hold a senior position in their company. In addition, the disabled suffer sexual harassment and gender based violence's such as rape.

> *Even if we are educated we are not given senior positions because of our disability. We are consistently harassed sexually and are victims of Gender Based Violence* (FGD with women in APDK Bombolulu).

As stated earlier, the FGD inclusion criteria was based on age with young women being between the ages of 20 – 35 years while the older women were from 36 – 60 years. It is worthy to note that the older women's FGD seemed knowledgeable about their rights as women living with disability and experienced in reproduction matters. The younger women had no experience on reproduction but were more knowledgeable on sexuality issues and cited being excluded from youth initiatives. In terms of educational level, majority of the younger women were more educated than the older women although some older women were well educated and held senior positions in their places of work. The older women who were well educated had high self esteem, were assertive, independent, were exposed and knew about their rights. The younger women who were educated were well exposed and assertive.

Experiences of pregnancy and reproduction

The delivery experiences of the women with physical disabilities were varied. About 33% of these women said they delivered at home while 67% said they delivered in hospital. The reasons for delivering at home ranged from cost, long distance to the hospital, abrupt delivery while at home and some did not see the reason why they must go to hospital for delivery.

The study sought to find out these women's dating, pregnancy and reproduction experience. A 48 year old Racheal Oluoko narrated her experience thus:

> *"I was dating this guy whom I thought was the man of my dreams. We dated for three years while I was still in college then one day, he tricked me to spend the night in his house and that is when I became pregnant. The man later abandoned me when I told him that I had conceived."*

She notes that she later decided to forget about him and take care of her child on her own since she had a job. Her experience with the second baby was a bit different. She narrated thus:

> *"Five years later, another man came into my life and confused me with 'love'. We stayed together for two years though we were not officially married. The man had a wife and three kids but his family knew about me and the wife did not object. I later realized that the man was a womanizer and not responsible so when I gave birth to my son, I had to take care of the child alone."*

These two experiences with men made her get discouraged about marriage and more so, what society expects of an African woman in marriage to do (work) which is hard for a woman living with disability.

Most of these women reported that they experienced betrayal and deceit in their relationships. June Omondi 52 year old noted that although her pregnancy was by accident as she did not intend to get pregnant at the time, she was glad that it happened. She said:

> *"I was just having a good time with my boyfriend but fell pregnant. However things did not go well as I discovered he was dating my girlfriend behind my back. This made me very bitter and I never told him that I had his son till when my baby was 9 years old. My two sons have never known their fathers; I tell them that God is the head of our home."*

Christine Mwalado 49 years old said that women with disability continue to experience stigma in family, speculation and misjudgment. She observed that:

> *"You are looked like you are not a human being and men don't want to have a relationship with you. It is difficult for a man to come your way maybe just for sex. Men want to experiment with you and to find out if you really have a*

> *genitalia. They want to see where the metals (calipers) reach! There is a lot of stigma associated with disability and men feel that you can affect them. You crave for sex but there is no one to do it with. If you get a man who express interest, you quickly run to them."*

She says that her pregnancy was by accident and explains thus:

> *"My dad is a staunch Christian and getting pregnant out of wedlock was a nightmare. Nobody knew I was pregnant even when it was 8 months. I waited till I was due for caesarean section then gathered courage to tell my dad about it. I told my father if he refused to sign my consent form for c-section I would do it myself"*

She said the father was shocked to hear that and asked:

> *"Who is this man who does not have a heart of a human being and has done this to you?" "The man who impregnated me was married with children but was not committed to me. I wasn't interested in the man but in getting my two beautiful girls who would call me 'mama'. I told God that I have finally proven that I am a woman."*

The women described experiences of motherhood as being exciting, sweet, joyous frightening and challenging. Christine Mwalado said:

> *"Motherhood is sweet but there are lots of challenges that go with it. Maids are a constant problem because they think you are desperate."*

She is however, a proud mother and says that her children are her source of joy. She comments thus:

> *"My children have a positive look of me and see me as a mother and not a disabled woman. Children of disabled people grow faster than expected; they*

> *know your expectations and come in handy. My girls would give me my crutches when they were small and I would send them around the house. The children learn to be independent at a very early age; it is like compensation for your disability. As a woman living with disability I believe God takes care of the bit I cannot do."* She explains.

Rebecca Muluka 48 years old on the other hand noted that motherhood is challenging because bringing up children is so demanding more so for a disabled person. She commented thus:

> *"It is very challenging because of the high cost of living notably high cost of education, food, clothing, shelter and medical expenses especially for a single mother."*

Rose Oluoko 52 year old concurs that motherhood is exciting because it is unbelievable that as a disabled you can bring a child to life. She was however, quick to add that it is at the same time frightening because during sickness, when a child is injured or during emergencies you cannot handle them alone as a disabled. She sees the disabled predicament as emanating from the views of society. She said:

> *"Although society sees us as half a woman, we strive to be a better mother everyday"* She explains.

The women said the experience of motherhood for those around them was mostly positive as relatives, neighbours and friends would sometimes help, love, care, support and give them advice. This is summed up by an informant who said:

> *"They admire and are proud of me as a mother and would encourage and support me" (*said Millicent Oluoko).

Another woman Jennipher Akinyi said:

> *"Relatives and villagers came to see the child to confirm that I had really given birth! They were really happy for me and amazed that I could deliver a healthy, normal and beautiful girl! However, they were sorrowful that I am not married which also sometimes makes me feel sad and lonely."* She explained.

One woman with cerebral palsy and visual impairment mentioned that other people express concerns about a woman with disabilities having children and believe that they should have their tubes tied. She narrated that health care professionals discouraged her from becoming pregnant because they were concerned about her size and ability to take care of a baby. When asked how she felt about that advice, she stated:

> *"In a way, I feel cheated. I would have liked to at least have had the chance."*

Another woman stated that she would like to have children, but would not discuss a possible pregnancy with her physician because she feared she would not get support.

Emily Sifuna a 38 year old, a mother with arthritis described the conflicts she experienced between her need for medication to control her symptoms while she was pregnant and her concerns about the effects of this medication on her foetus. Her physician, she said, respected her decision to forego medication to ensure a healthy baby:

> *"When I had my third pregnancy it was debilitating. It got quite out of control, and the doctor sat down with me on several occasions and said, 'You need to consider what's going on here . . . If I can promise you that I could give you medication that would relieve the symptoms and wouldn't hurt the baby, would*

> *you take it?' . . . I said no, I can't believe the promise.., and he respected that, and... I appreciated that."*

Some of the emerging issues were about STDs and reproductive healthcare for women with disabilities. Most of the FGD participants indicated that they did not have information about how much of a problem STIs were for women with disabilities. As one woman said:

> *"That's another area that wouldn't be easily talked about. I think you would have to build rapport before you could even address some issues."*

None of these women reported that they had been diagnosed with an STI, although one did discuss problems with vaginal infections. While some women thought STIs were not a problem, one asserted that they could be a big problem since some of them have intercourse with so many men. She commented thus:

> *"Because I've seen a lot of women who have very low self-esteem. . , go with anybody that want to have them."*

It was also suggested that some women with disabilities may go through a promiscuous phase to prove they are sexually attractive. During this time, they may be at particular risk for STIs.

One woman pointed out that the barrier methods that are most effective at preventing STIs are difficult for women who lack muscle integrity in the pelvic area to use. Women with disabilities appear to be at special risk for STIs, because some women are unable to use the contraceptive methods that would afford them the most protection, while others who lack sensation are unable to detect the signs of STIs. Even more problematic is the fact that providers often do not discuss birth control and sexual issues with them.

4.4 Accessibility challenges faced by women with physical disability at the healthcare facilities

This section reports on the problems faced by women when they arrive at the facility while seeking reproductive healthcare.

4.4.1 Difficulties faced in terms of the physical environment

The women in this study identified several challenges to good reproductive health care services confronting them and other women with disabilities. Some of these barriers are structural, for example, physically inaccessible tables, stirrups, and examining instruments not designed for women with impairments. Offices and parking lots are not always fully accessible for wheelchair users, and some participants reported transportation problems in traveling to providers.

Depending on the woman's geographic location and the availability of suitably adapted public transport, access to health care facilities and participation in other community activities may be severely curtailed. Inadequate transport to and from the health care facilities can pose significant challenges for women trying to get to appointments and to access reproductive care. Even when public transport is available, Smeltzer et al., (2007) posited that it is expensive, undependable and inadequately equipped to accommodate or secure women with a wheelchair.

In addition, there were long queues, services were not disability friendly because the physical environment was not adaptable to the disabled due to lack of ramps everywhere and lifts were not available. Also some of the facilities were far apart like the laboratory, cashiers and wards. In addition to this, the waiting rooms had inadequate space to manoeuvre in a wheelchair. Consensus from the FGD participants identified poor physical facilities in accessing the hospital service points specifically for the disabled persons as a source of concern. As one of the FGD participant observed:

> *"The services are not disability friendly and it is a hussle to manouvre in the hospital as ramps and lifts are lacking".* (Mwanaisha Juma 23).

The design of the built environment can be another critical determinant of accessibility and impacts significantly on the social inclusion and participation of women. For some women, physical accessibility to the building is often the first and most obvious challenge encountered (House of Commons Health Committee, 2003; Thierry, 2006) Other obstacles that render health care facilities, physician's offices and clinics inaccessible include the physical location of facilities, offices and clinics, non availability of designated parking bays and the topography of pavements and curbs (Thomas and Curtis, 1997).

The majority of the respondents (90%) indicated that the health facilities were not adaptable enough to cater for disabled women needs since there was no special unit designed for the people with special needs. On the other hand, the key informants indicated that access to facilities was a problem because hospitals lacked access passages and beds were too high for the PWDs. In addition, WWD were made to share beds two or three people and this would make them fall down worsening their condition. The women also reported that the doctor's office was not spacious enough and one could not fit in a wheelchair. One commented thus:

> *"I once fell from the bed because it was too high and we were made to sleep two people. This made my condition worse and I took longer than expected to come out of hospital which caused a strain in my finances".* (said Chiriku Mkanze, 38 a mother of two).

Another woman complains of the beds and facilities floors thus:

> '*When you look at the beds around here, they are meant for people without any physical deformities, it is hard to get to these beds, and the floor needs extra-caution and makes it difficult for those disabled women who cannot easily keep their balance*". (Amina Ahmed, 52 years old).

A physical check at the facilities revealed that they are not disability friendly. Although the hospitals had ramps, there were some sections which lacked the same and disabled women found mobility to certain areas difficult using staircases.

Despite the long queues in the public facilities, disabled women were not offered special treatment due to their condition but had to wait like everyone else. This made them too tired and at times, avoided going to the facilities all together unless it was extremely necessary.

In all the study areas formal health services were inadequate, and the shortage of doctors acute. There was also a problem of distance and this was made worse during the rainy seasons since roads are frequently impassable. In addition, public transportation is rare and expensive. In similar studies... Gans et al. (1993) identified five commonly recognized reasons for inadequate health care services for people with disabilities: transportation problems, inaccessible offices, inadequate knowledge among health care providers, provider attitudes, and inadequate insurance coverage.

4.4.2 Difficulties faced by the CPGH while attending to WWD

The CPGH pointed out that their physical facilities are inadequate to cater for the women with disabilities. Although they realize the financial constraints facing the disabled women, they are not able to waive the charges. They also noted that the CPGH lacked funds to create awareness among the disabled people and the community at large to reduce stigma and discrimination. The CPGH medics interviewed also cited communication barrier while addressing the deaf and dumb and lack of medical equipments to do their jobs effectively. One doctor commented thus:

> "*Even if we are moved by the plight of the disabled people, we can only do so much. We are constrained by the tight budget and lack of the necessary medical equipment to do our jobs effectively*".

A nurse said that it is difficult to explain the procedure to the patients especially the deaf and the dumb. Most of the nurses cited staff shortage leading to high workload as a big challenge that the hospital experiences in providing health services to disabled women as they cannot give full and proper attention to them because of the workload. They also cited lack of privacy during treatment as the disabled are treated with other patients.

The healthcare professionals reported that they do not receive special training to handle disabled people but learned how to handle the disabled while on the job. They also lacked sign language skills to communicate with the deaf and dumb. The health practioners, at the same time indicated that they lacked equipments. A doctor at the hospital said:

> *"we do not receive special training to treat PWD's and therefore, are limited in that regard. We also do not take risks by allowing WWD to deliver normally as their pelvic bones cannot expand to allow for a baby."*

The medics also cited certain challenges that come from the patient themselves such as language barrier, self stigma, illiteracy, lack of cooperation, irritability, patient not free to disclose illness or other pertinent information and patient not being able to afford to pay for treatment. Sometimes underage disabled patients may not have consent from their relatives making it difficult to treat them. The disabled patients may delay to seek treatment thereby compromising their care and treatment. Some disabled people may also not have relatives who can buy medicine for them or help them when seeking admission. One nurse at the CPGH commented thus:

> *"The hyper visibility of the woman's disability may result in the woman believing that they are being shunned or ignored although this may be due, in part, to health professionals' nervousness at the different challenges that women with disabilities present. WWD sometime stigmatise and feel pity on themselves and any comment to them is taken negatively, observed a matron at the hospital".*

A study by King et al (1993) pointed out that women with physical disabilities may also have low self-esteem and diminished perception of social acceptance relative to able-bodied women. With limited knowledge and low self-esteem, women with physical impairments may not have the self-efficacy to advocate for themselves in relation to their reproductive health.

4.5 Care provision problems faced by women with physical disability at the healthcare facilities

This section of the study shows the care provision problems faced by women when they are at the facility while seeking reproductive healthcare services.

4.5.1 Treatment of disabled women as they seek reproductive health services

The representatives of NGO's working for WWD interviewed felt that the health workers lacked knowledge/skills to handle physically disabled women. There was also lack of communication and the health workers failed to empathize with WWD. The respondents reported that the doctors were mostly sympathetic to them while the nurses generally felt that the disabled were problematic and needed much attention. The WWDs indicated that most doctors/nurses did not allow them to labour and have a normal delivery but would quickly rush them to the theatre for a caesarean section. They like all women indicated their desire to labour and have a normal delivery. About 90% of the respondent said this is the joy of motherhood which they feel the medics have largely denied them.

> *"When I went into labour, the doctors did not give me time to dilate the required centimeter in order to deliver normally but quickly rushed me into theatre and did a c-section. I was determined to have a normal delivery like most women but I was not given a chance to"* (lamented Jannete Akinyi a 52 year old mother of two).

The women reported that the negative treatment by healthcare workers often make them uncomfortable, embarrassed and result to painful examinations. As one woman said:

> *"The examination of the private parts is very painful. This is a very sensitive area for a woman, you feel a lot of shaming very quickly."*(Lewa Chidzi, 37 years old and a mother of three).

Consequently, women with physical disabilities tend to avoid routine examinations, and seek gynecologic services only when they are experiencing a problem or are in need of medically prescribed contraceptives. The case points to the need to train the reproductive healthcare providers on issues of confidentiality, sensitivity of sharing some information with people accompanying the patients without seeking the consent from the patients.

The study participants suggested that health care providers need to spend longer time with women who are disabled during examinations. Conine et al., (1986) pointed out that some facilitators consider that the provision of antenatal education classes for women with disabilities is not part of their role and function and have indicated how the provision of adaptive programmes for women with disabilities is time-consuming and disruptive to normal progress.

Some of the frustrations voiced by the women point to the lack of good-quality, appropriate information for this population. Their concerns reflect on areas where additional research is needed. As Welner (1999) pointed out, there is limited information about the health care needs of women during menopause or the detection and treatment of STIs for this population. The women noted that general information may be of limited value, unless it reflects the specific concerns of this population. One of the experts interviewed stated that many women feel like pioneers, because they are the first generation to survive into adulthood with such severe disabilities and live independently in the community. Consequently, they are frequently confronting health care providers with new issues about their health care needs.

These results indicate that a limited range of contraceptive options are discussed with women with disabilities. Oral contraceptives seem to be the most frequently discussed, but many women who used oral contraceptives experienced side effects or health-related concerns that made this method less desirable for them. Women whose manual dexterity is limited are unable to use various barrier methods. The problems experienced by these women echo what has been previously reported in the literature by Haefner et al., (1998): Best (1999) and Becker et al., (1997) and further validate the need for additional research to develop acceptable and efficacious alternative contraceptive methods for use by this population.

Two issues raised by the women have been previously reported: the discouragement women face when they want to have children and the ways pregnancy can interact with the medications women are taking to control their disability. As pointed out in Becker et al., (1997), in the past, women with severe physical disabilities were discouraged from having children. A study conducted by Smelzter (1994) among 15 pregnant women with multiple sclerosis (MS) found that the decision to become pregnant was difficult for many of the 15 because of the lack of information about pregnancy within the context of their disability, as well as the uncertainty associated with the disease itself. Some women had experienced negative reactions to their pregnancies from family members, close friends, and health care providers. Age, length of time since diagnosis, and previous course of the MS all influenced women's child-bearing decisions.

4.5.2 Attitude of health professionals when treating disabled women

The most commonly discussed problems concerned interactions with health care providers. Women described providers as insensitive or lacking awareness of disability issues as they affect reproductive health care. Sara Abdallah 40 years of age who had suffered multiple injuries in previous crashes, explained that healthcare providers are not sensitive to the locomotive needs and difficulties experienced by women with physical disabilities and expressed surprise that providers were not knowledgeable on how to treat women with disabilities.

On the other hand, the key informants indicated that health professionals do not understand that disabled people have sexual feelings so they tend to feel pity when a disabled person is pregnant. A respondent Naomi Kazungu 29 years old, narrated her ordeal in the hands of a medical practitioner at the hospital who told her that;

> "*You can die, we have seen many and you will not be the first one*".

Further, they said that some nurses could not comprehend how they acquired sexually transmitted diseases (STDs) because they saw them as asexual. They lament that some nurses have bad attitude towards them and feel that the hospital is not for disabled persons thus the nurses feel bothered whenever the women go for services.

The women reported that most of the medical personnel in the health facilities were arrogant and looked down upon them whenever they go to seek delivery services at the health facilities. One disabled woman noted that the medical practioners pity them when they get pregnant and then scold them, when they seek for services. She reported how some nurses treated her thus:

> "*Who has done this to you? You don't even sympathise with yourself in your condition? Go and get the man who impregnated you and bring him here*!"

These sentiments were expressed by some nurses who fail to realize that most of these women get pregnant by choice because they want to be mothers.

The women also complained that the nurses at the hospital do not look at you as a mother.

"They would rather talk to your house help than you."

Sometimes they say:

*"Look at this one, she doesn't even sympathise with herself. Is it a must that you must give birth?" (*said Furaha Mudzo a 38 year old woman).

Another woman explains how she was demeaned by the nurses when she visited the hospital for reproductive health services. They asked me:

"How did this husband of yours sleep with you? They talk in English thinking that we don't understand." (Cheupe Kenga 43 years old).

The woman also said when they ask questions about sexuality and/or family planning, they are answered arrogantly.

"Why are you looking for things you can handle (so many problems)? Don't give birth again, take your baby to your mother to take care of him." (Rehema Mohammed 29 years old recounts).

She further laments thus:

"They think you will infect your child with disability. This negative reaction made me so worried until my child walked, that is when I was sure I had not infected my son with my disability."

This arrogant and inhuman treatment has put her off from government hospitals and only goes to hospital when she is very sick. She says that she prefers to go to private hospital if she gets money as the staffs are social and helpful and if the doctor's office is not accessible he/she comes to you. The women also complained that instead of treating the child during an emergency the nurses instead scold them first.

The disabled women also complained that for one to be treated, you had to know someone else before you get admitted. You also needed to be accompanied by a friend or relative who will take care of you before you are admitted because you will not be able to seek admission on your own, climb the beds which are so high or do other things for yourself. The WWD also complained that they had no place to air their grievances as the administrators in the health facilities were out of reach.

Women also spoke of the importance of providers who consider the whole person, not just the disability, in their treatment. One woman with multiple sclerosis (MS) Esther Mumbi 36 years old, said of her provider;

> *"He treats me as a whole person who has this disease. He doesn't treat one specific area. I mean, he really sees the big picture and I am really comfortable that if there were a problem, he would refer me for special care...*"

The women described health professionals as aloof, authoritarian and domineering or patronising, hostile and unable or unwilling to accommodate people of different conditions. The second major category of barriers concerns relationships with health care providers. Providers were described as uncomfortable treating women with disabilities, insensitive to their needs, and reticent and/or reluctant to discuss key reproductive health issues such as birth control or sexually transmitted diseases. Physicians' attitudes were identified as the most difficult barrier faced by the women. The consequence of these barriers is that many women with disabilities avoid routine gynaecological examinations. Since many women lack sensation in their pelvic areas, and may therefore, be unable to detect signs of problems that should be treated, their avoidance of routine physical examinations is particularly troubling considering the negative impact this may have on their health.

As Lehman (2009) pointed out, women with disabilities require the same gynaecological and reproductive healthcare services as women without disabilities, yet they often experience difficulty obtaining them. Such women often lack access to multitudinous opportunities for maintaining and improving their overall health, and disability-related barriers discourage women with physical disabilities from engaging in health-promoting behaviours (Hughes, 2006).

The set of extracts below as told by women with disabilities seeking reproductive health services from public health institutions in Mombasa raise interconnected problems around the meaning of effective communication and these are strongly linked to disability on the one hand and on the other to the intersection between disability and sexuality

On the other hand, the health care providers tend to have overriding decisions and rulings on the aliments affecting the women with physical disabilities without taking the women's explanations seriously:

> *"I consistently told them that my bleeding started when I conceived but they thought my condition was different, all these time they exposed me to other tests for over two months, I endured the pain but finally they found the solution based on my account, I felt treated like a child but I had no option but to oblige to medical tests and the people I considered professional"* (Khadija, 33 years old).

These accounts illustrate not only insensitivity to women's conditions, but the fact that the information women give about their health is often ignored by health care providers. There may be several reasons why providers fail to work with these women around common women's health issues. Health care providers are well steeped in clinical training that focuses on treatment and cure of illness. When these providers treat women who have chronic and disabling conditions, they may focus on the disability and fail to see that these women face the same, if not greater, health risks as women in the general population. Health care problems stemming from untreated infections, for example, may cause even greater problems for women with disabilities and chronic conditions than for non-disabled women.

Some of the women whose conditions require constant change of position in bed also expressed the sentiments that some healthcare providers are reluctant to attend to them but in case they do, they always want relatives to be around to take care of their locomotive needs on the bed since they see such as extra work beyond the duties of the medical fraternity. Chanzu Kazungu, a 35 year old woman who had reported to the hospital with obstetric complications' case point to the attitude of healthcare providers:

> *"You need to have someone from home to attend to you since your condition requires constant changing and we do not have time to do that. I had to bring someone to be with me at the hospital because I had an obstetrics complication so that meant my stay in the hospital was not going to be any short either."*

This situation points to the nervousness of the health providers to attend to women with deep-seated injuries alongside the reproductive health complications that the women experience.

Communicating with health providers

Communication between health providers and service seekers particularly the disabled women in this study was established to be wanting. Some of the women who had sought healthcare reported not being listened to, being patronized, or not being given adequate explanations of their condition or of upcoming procedures. Khalima Khahiya 28 year old and second time mother is among mothers with physical disabilities who stated her dissatisfaction with the healthcare providers. She said:

> *"It is quite frustrating when you ask about contraception, ante natal care and some one cannot take her eyes off your wheel chair because they think you have no need for that kind of information. Sometimes, they feel the problems afflicting you are more of your disabled status rather than health per se, so they tend to either ignore or develop a prejudice."*

This kind of treatment concurs with studies carried out by Becker et al., (1997) that found that providers sometimes appeared surprised that they would be sexually active, and did not ask about contraceptive use or assess for sexually transmitted diseases. This concurs with the previous studies that indicated that accessing reproductive health care services is so difficult that some women avoid regular gynecologic visits.

Information held and shared with women with physical disabilities is a determinant on what therapeutic process they undergo besides the context in which it is shared as exemplified by the cases of two women in this study. Riziki Labi 35 years old, feared having a mammogram, because it had never been explained to her and she did not know what to expect. Yet Mildred Ngesa a 38 year old, stated that information is not necessarily individualized or takes into account the functional limitations experienced by people with disabilities. She notes that proper communication has to take into account issues of confidentiality and individual lived experiences for them to be given effective treatment and for the whole treatment episode to have meaning to the patient. Liotta (1996) confirmed that reproductive health issues have often been ignored in part because society tends to view persons with disabilities as asexual beings and therefore, not in need of reproductive health care services. Nosek et al., (1995) in his study reported that WWD lacked basic knowledge about their reproductive health, in part because they had restricted access to such information as adolescents. Women who experienced traumatic injuries later in life said they received inadequate information about the sexual impact of their disability when they were in rehabilitation facilities

Dr Zablon Maina, a key informant discussed the special problems people with speech and hearing impairments have in communicating with health care providers. Even when a translator is present, the translator may not accurately and completely communicate the necessary information.

> *"We sometime are not able to understand what the patient is saying because they are deaf or dumb. In most cases they come with translators who may also not be able to translate accurately, in such cases diagnosis becomes very difficult."*

4.5.3 Female views on how to improve reproductive health care services

When women were asked what would ease their burden and improve the services they receive in public health facilities and their views were as follows: These were suggestions for providers and suggestions for women themselves.

Women indicated that providers should be better prepared to work with women who have disabilities. Some suggested disability awareness training, with disabled women involved in the training, so that providers could become sensitive to these issues from the perspective of disabled women themselves. Better communication skills on the part of providers were identified as a major area for improvement. As one woman stated, "*. . . even if they don't know, if they could ask' "what can I do to make this easier for you?' "*

One woman, who works with other women with disabilities, stated that providers must "*purposely plan to have a discussion with them and stop treating them as kids who do not know what their problem is.*" She said that this discussion should be done in a sensitive way that allows a woman to overcome what are very natural reserves - about talking about that very private part of your life - which many people find hard to share.

> *"Issues about sex and sexuality are taboo in our culture and medics need to be sensitive about them to enable the WWD open up."*

She and others suggested that providers need to be prepared to spend more time with these patients, establishing rapport, providing information and individualizing care to their special needs, and giving the women--particularly those who experience spasticity--more time to relax before initiating the physical examination.

Providers must also recognize that many women with disabilities bring to the examination a history of negative health care experiences. One woman stated:

> *"I had a lot of operations growing up . . . . I was always being poked and prodded so that really brought a whole lot of baggage into any kind of exam, like a pelvic, because it's so like being prodded over once again."* Since positioning during a pelvic examination is difficult for many women with physical disabilities, providers should be prepared to help women find positions that are most comfortable for them.

Improved accessibility, both in terms of affordable health care and physically accessible locations and equipment, was also mentioned by many respondents. One woman suggested that a brochure be disseminated to health care providers outlining their responsibilities to provide accessible facilities under their conditions of health care provisions.

Further, they proposed interventions directed at women themselves, such as educating them about what questions to ask. One woman suggested that information networks be established for women with disabilities about health issues. Women need criteria they can use in selecting a health care provider. Assertiveness training was also suggested by both the health care providers and care recipients. Others stated that women with disabilities need to be better educated about sexuality issues, perhaps through support groups. One woman proposed that programs that individualize sexuality issues for teenage women be explored. A related suggestion was for interventions to build women's self-esteem. One woman pointed out that many women with disabilities are not comfortable with their bodies, and interventions need to be focused at enhancing their self-image in this area.

Efforts should also be directed at preparing women with disabilities to be informed consumers about their health care needs. The women interviewed here offered several suggestions in this area. Health advocacy training and networks that link women together are ideas that merit further exploration. Informational support groups that target teenage women with disabilities could build self-efficacy for health-promoting behaviors at an early age and could also address vitally important sexual self-esteem issues. National advocacy groups could make available reproductive health care information targeted to the special needs and concerns of their female consumers. Alternative formats for information that bypass barriers should be utilized, including Braille and other non-print media, as well as on-line health information. Many routine prescriptions for health screening and self-care can and should be adapted for women with disabilities. For example, a woman who lacks sensation in the genital area may need to visually inspect her genitalia for signs of redness, discharge, or growth. An attendant or partner might be taught to assist in this, or other routine examinations, such as breast self-examination.

Oral contraceptives might need to be repackaged so that women can self-administer these pills more easily. Additional time should be spent educating women with mobility impairments about the side effects of various contraceptive options. It is vitally important to individualize these adaptations, not all women with disabilities are affected in the same ways or need the same accommodations.

Finally, a couple of women mentioned that educational efforts should be directed at two other key groups: partners and personal attendants (helpers). One woman proposed a forum on attendant care services, related to health care issues.

The providers proposed interventions such as: community outreach services and mobile clinics, counseling WWD about their rights to seek health care and involving men in reproductive health in order to succeed in provision of reproductive health services.

4.5.4 Training of healthcare providers

Interventions should be directed at enhancing providers' understanding of how to work effectively with women who have physical disabilities. Just as Nosek et al., (1995) reported, we found that direct communication was highly valued by the women we interviewed, Saxton (1996) has pointed out that although women with physical disabilities and chronic illnesses are major users of medical services, few health care providers are trained to be sensitive to their specific needs. Recognizing that the quality of health care is related to the quality of patient-provider relationships, Saxton created the Project on Women and Disability to address the health care system's treatment of women with disabilities. They found that few medical schools provide comprehensive training in disability awareness that includes social and political aspects of disability. Physicians and other health care providers tend to interact only with disabled people who are having medical difficulties. This exposure reinforces their perception of people with disabilities as patients who are passive recipients of health care services. The fact that people with disabilities and chronic conditions cannot be "cured" is often perceived as a failure by health care professionals. Many are genuinely puzzled by the anger directed toward them by people with disabilities, who have frequently experienced well-meaning but misdirected attempts to meet their health care needs. Saxton's group has partnered with medical schools to provide disability awareness training for medical students and open communication between health care providers from various disciplines and people with disabilities. They argue that increasing the number of women with disabilities who are themselves health care providers will lead to change both within and without the traditional health care system. One of the women we interviewed has conducted training with the staff of Planned Parenthood to raise awareness of disability issues. Nosek has also undertaken a project that trains health care providers to work more effectively with women with disabilities. Additional interventions of this kind are warranted, both while providers are in training and on a continuing education basis for those now practicing, and should include a rigorous evaluation of their impacts.

5.0 CHAPTER FIVE: SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1 Summary of findings

This section of study gives a summary of the key findings, conclusions and recommendations.

The study established that there are various factors that influence the reproductive health seeking practices of women with physical disabilities in Mombasa County. These include cost, distance and transportation challenges to health facilities.

Most WWD visited government health facilities because they are cheap while a few visited private and mission hospitals. A majority of the respondents indicated that they go to health facilities when they are sick while a few others self-medicate and only go to hospital when they are seriously ill.

In terms of accessibility challenges faced by women with physical disability at the healthcare facilities, two major barriers were identified. The first one was structural related to access or physical accommodations for example inaccessible tables, stirrups, and examining instruments not designed for women with impairments.

The physical environment of most facilities was not disability friendly as some sections lacked ramps, toilets were not designed for the disabled and were so dirty, beds were so high and the disabled could not climb them, counters had inappropriate height to facilitate eye contact with receptionist.

The health facilities were not adaptable enough to cater for disabled women needs since there was no special unit designed for people with special needs. The second barrier to access RH services concerned relationships with health care providers who are said to be unfriendly and have a bad attitude.

The care provision problems faced by women with physical disability at the healthcare facilities were identified as the most difficult barrier faced by WWD. They relate to attitudinal challenges which the WWD experience from the healthcare providers. Their attitude was said to be negative and the medical personnel mostly nurses were said to be insensitive, arrogant, aloof, authoritarian, domineering, hostile and unwilling to accommodate women with disabilities. They are reported to mistreat WWD who visit the health facilities and scold them because of their condition making them feel uncomfortable, fearful and degraded.

The medical personnel see WWD as asexual and are amazed when they seek antenatal or post-natal care or family planning services. The nurses were surprised when women with disabilities asked about sexuality, contraception and STD/HIV. The nurses were identified as worse in terms of bad treatment to WWD as they failed to realize that WWD have sexual feelings like everyone else and most of them get pregnant by choice because they want to be mothers.

Health workers lacked knowledge and skills to handle physically disabled women at the health facility and poor/lack of communication characterized their interaction. On the other hand, healthcare providers lack appropriate equipment for offering ante-natal and maternity services to WWD.

Health professionals on the other hand said the hypervisibility of the woman's disability may result in the woman believing that they are being shunned. Most health professionals said they lacked training and skills to handle disabled women and may be nervous at the different challenges the women with disabilities present. They also lack communication skills to deal with the deaf and dumb.

5.2 Conclusions

This study is focused on assessing the reproductive healthcare challenges faced by women with physical disabilities in Mombasa County. For the primary data, the researcher opted to conduct a survey, use narratives and FGD's questionnaires with women with disabilities. A questionnaire consisting of open ended and closed ended questions was used for data gathering. The answers of the respondents were then processed through SPSS. The results were then used as a basis for the data analysis. Secondary resources derived from various publications including researches, books, journals among others were integrated to support the findings.

Based on the results of the survey, cost of health services, distance to the health facility and transportation challenges were the key determinant to health seeking behavior of women with disabilities. The difficulties WWD faces were found to be structural - physical environment – being disability unfriendly and attitudinal – attitude of health workers being negative. The study has also revealed how negative attitude of healthcare providers and ineffective communication between the service providers and women with physical disabilities affect the quality of reproductive healthcare.

From the findings, it can be concluded that WWD are sexually active and are able to have children just like their able bodied counterparts. They therefore require reproductive health services like everyone else.

5.3 Recommendations

- Government should provide free treatment to disabled people in public health facilities and provide necessary equipments and drugs needed during treatment.
- Build health facilities that are disability friendly and designing sections that are adaptable to disabled people.
- Sensitize women with disabilities on information on pregnancies, use of contraceptives and HIV/AIDs. There is need to develop HIV/Aids awareness programmes and ensure the information reaches people with disabilities by working with disabled people's organizations. Prior counseling of all disabled women on the same needs to take place.
- Training on how to treat disabled people should be included in medical school's curriculum and in hospitals. For those already practicing they should be sensitized on language and treatment that is not offensive when handling disabled people. They need to show respect and value the women with disability.
- Trainees should not be allowed to treat disabled people as they are not experienced enough to do so and may worsen their situation.
- NGOs and other stakeholders should sensitize the public on accepting and supporting the disabled so that they feel part and parcel of the community and enjoy a normal life. They should make the public know that it is not the wish of the disabled to be the way they are and make the society accept disability as part of life.
- The Persons with Disabilities Act 2003 lacks specific reference to women with disabilities. This weakens support/legitimacy of persons and institutions advocating for women and girls with disabilities. Thus, the study recommends that the National Council of persons with Disabilities (NCPWD) spearheads the

review of the Act to make it gender sensitive towards all categories of disability and with specific focus on women with disabilities. The NCPWD should lobby government to institutionalize and provide disability support such as braille, mobility and hearing aids to institutions dealing with disabled women.

- The government should look into some of the policies by the insurance companies that put a limit to services which may be essential for managing a disability. Services such as in-house personal assistance services, prescription medications, durable medical equipment, holistic health services and certain therapies should be covered by government funded insurance plans. This will aid in making the services more affordable and securing more support for independent living among the women with disabilities. There should be improved accessibility, both in terms of affordable healthcare and physically accessible locations and equipments.
- Sensitisation programmes and motivational talks need to be organized to help build self esteem and acceptance of the disabled.
- There is obviously a need for continuing research and development of accessible examination equipment that can be made easily available to health care providers. Research should also be directed at understanding why providers do not use the modified equipment that is currently available or seek the modified equipment to take care of the needs of women with disabilities in health care facilities where they lack. Efforts must also be directed at making providers understand what accommodations are required under the People With Disability Act (2003), this includes not only building ramps, but also accessible bathrooms and examining rooms.

5.4 Suggestions for further studies

The researcher recommends the following areas for future studies. Additional research should be conducted to establish why women with disabilities are more prone to reproductive diseases such as fibroids. There is also need to conduct further research in bigger cities in order to compare and contrast findings on Reproductive Health Challenges for Women with Physical Disabilities in the various cities. Finally, the study recommends future studies to understand the barriers faced by people with different disabilities that make them vulnerable to HIV that will enable the inclusion of this population in HIV/AIDS programmes.

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APPENDICES

ANNEX 1: Questionnaire for Disabled Women

My name is Redemtor Atieno and I am a student from the University of Nairobi Institute of Anthropology, Gender and African Studies (IAGAS).) I am conducting a research on Reproductive Health Seeking Experiences of Women with Disabilities in Mombasa County as an academic undertaking for a masters project. The research aims at generating information to help service providers improve their services and disabled women make maximum use and benefit from these services. All the information that you will provide shall be used for this study and will be treated with STRICT CONFIDENTIALITY. However, if there is any question you are not comfortable with you are free not to answer. You can also terminate this interview at any point. There will be no consequences for turning down the interview. With your permission, I would like to record our interview as it will help me better focus on our conversation.

A. Personal Information

Please tick and fill where appropriate

A1.Name optional)

....

A2. How old are you?

....

A3. What is your marital status? 1. Married .... 2. Single .... 3. Separated ....

4. Divorced .... 5. Widowed ....

A4. Do you have any children? 1. Yes...... 2. No......

A5. If yes how many? ....

A6. What is your level of education?..................................

A7. Are you employed? 1. Yes .... 2. No ....

A8. If yes what form of employment are you engaged in?

....

A9. If yes how much do you earn per month? 1. Below Ksh 10,000....... 2. Between Ksh 11,000 – 20,000 .... 3. Between Ksh 21,000 – 30,000 ...... 4. Above Ksh 30,000

A10. If no, what is the source of your livelihood?..

A11. What is the nature of your disability

....

A12. How did it come about? 1. Birth .... 2. Accident .... 3. Untreated illness .... 4. Other.....................

B. Access to reproductive health services

B1. Please indicate the most common reproductive health illnesses that affect you?

....

B2. Please indicate the various reproductive health needs that you have (probe for contraceptives, health information, maternal child health, pregnancy and child birth)

....

B3. How do you meet these needs?

....

B4. Do you always go to hospital whenever you have a reproductive related illness? 1. Yes................2. No ....

B5. If no,

why?...

B6. Where do you go for reproductive health services? 1 . Government health institution

2. Private health institution ………………… 3. Missionary health institution …………(probe for others)…………………..

B7. How far is the nearest reproductive health facility?

……………………………………………………………………………...

B8. Why do you go to the particular service provider you indicated above? (can tick more than one)

1. It is near where I live……. 2. I can afford the charges……. 3. The staff are friendly to help me ……… 4. I am able to use physical facilities easily …………….. 5. Others (Specify)……………………

B9. Who pays for the health services that you receive (including buying drugs)? 1. Self….. 2. Family member (specify relationship)……… 3. Friends ………….. 4. Other…………..

B10. How would you rate the kind of services you receive wherever you go there?

1. Very good……… 2. Good ……… 3. Average ……….. 4. Poor ……………… 5. Very poor …………..

B11. What difficulties do you face when you go to the reproductive health service provider in terms of

Facilities?..

Medical personnel………………………………………………………………..

Waiting time……………………………………………………………………...

Physical environment…………………………………………………………….

Others(specify)……………………………………………………………

………………………………………………………………………………

B12. How have the above difficulties affected

you?...

....

B13. Where do you get information on reproductive health issuesfrom?

....

C. Improving access to reproductive health services

C1. What do you think can be done to make the reproductive health services more accessible to disabled women?

....

C2. What other comments and suggestions can you make regarding access to reproductive health services by disabled women?

....

Do you know anyone else I should talk to (Woman with disability?)

THANK YOU FOR FINDING TIME TO RESPOND TO THIS QUESTIONNAIRE

Questionnaire 1b: Questionnaire for Evaluating Feelings of Physically Disabled Women

A. How do you feel about your disability?

....

Do you think it contributes to any reproductive health illness that affects you?

....

B. If so how?

....

C. What do you think about the service you receive as a disabled woman in a heath facility?

....

D. Do you think health professionals treat you differently as a result of disability?

....

E. Have you been denied a medical service because you were disabled?

....

F. If yes how did that make you feel?

....

G. What kind of reactions do you get from health service providers when seeking information on sexuality?..

H. What about for family planning services?

....

I. What are your feelings, thoughts and expectations before going to seek health services?

....

J. What are you most concerned about as regards to your reproductive health?

....

THANK YOU FOR FINDING TIME TO RESPOND TO THIS QUESTIONNAIRE

ANNEX 2: Key informant interview guide (Reproductive Health Service Providers)

My name is Redemtor Atieno and I am a student from the University of Nairobi Institute of Anthropology, Gender and African Studies (IAGAS). I am doing a research on Reproductive Health Seeking Experiences of Women with Disabilities in Mombasa County as an academic undertaking for a master's project. The research aims at generating information to help service providers improve their services and physically disabled women make maximum use of these services. All the information that you will provide shall only be used for this study and will be treated with STRICT CONFIDENTIALITY. However, if there is any question you are not comfortable with you are free not to answer. You can also terminate this interview at any point. There will be no consequences for turning down the interview. With your permission, I would like to record our interview as it will help me better focus on our conversation. You have been chosen as informants because your role in health service provision is key and will be useful for the study analysis, findings and recommendations.

Name:__________________________________Date_________________________

Signature:___________________________

ID Code	
Date	
Time	
Interviewer	
Interview Length	

A. Background information

Basic Demographic Questions

Age	
Sex	
Education	
Occupation	
Name of the organization	
Your designation	

B. Reproductive health services provision

B1. State the nature of reproductive health services that your organization provides to physically disabled women

....

B2. From your experience, what would you say are the common reproductive health related illnesses and needs among disabled women? (Probe according to age, nature of disability, and services most commonly rendered)

....

B3. What in your opinion hinders disabled women from accessing reproductive health services?

....

B4. What challenges do you experience in providing health services to disabled women? As an institution?

....

....

As amedical professional?...

....

B5. What difficulties do you face when providing services to disabled women that are patient specific?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

B6. In your opinion, are health service providers trained and equipped to deal with disabled women?

……………………………………………………………………………………………………

B7. How adaptable is your system to providing services to disabled women?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

B8. Is the physical environment of your health facility conducive for disabled women?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

C. Potential measures to enhance access to reproductive health services

C1. From your experience, what can reproductive health service providers do to enhance access to reproductive health services for disabled women?

……………………………………………………………………………………………………

C2. Are there any suggestions that you can make to enhance the provision of reproductive health care services to the disabled women?

THANK YOU FOR FINDING TIME TO RESPOND TO THESE QUESTIONS

ANNEX 3: Key informant interview guide (Non Governmental Organisations)

My name is Redemtor Atieno and I am a student from the University of Nairobi Institute of Anthropology, Gender and African Studies (IAGAS). I am doing a research on Reproductive Health Seeking Experiences of Women with Disabilities in Mombasa County as an academic undertaking for a master's project. The research aims at generating information to help service providers improve their services and physically disabled women make maximum use of these services. All the information that you will provide shall only be used for this study and will be treated with STRICT CONFIDENTIALITY. However, if there is any question you are not comfortable with you are free not to answer. You can also terminate this interview at any point. There will be no consequences for turning down the interview. With your permission, I would like to record our interview as it will help me better focus on our conversation. You have been chosen to participate in the study since you deal with rights of disabled women and the interview will seek to establish how disabled women are being treated as they seek reproductive health services among other issues pertinent to the study. The findings of the study will be availed to you once complete and will assist greatly in your lobbying and advocating for reproductive rights of disabled women as you will be having current and credible data to back your claim.

Name: ______________________________ Date______________________________

Signature: __________________________________

ID Code	
Date	
Time	
Interviewer	
Interview Length	

D. Background information

Basic Demographic Information

Age	
Sex	
Education	
Occupation	
Name of the Organization	
Nature of Organization	
Your designation	

A. Reproductive health services for disabled women

1. How are disabled women treated as they seek reproductive health services?

2. What are the attitudes of health care professionals when treating disabled women?

3. In your opinion are health care professionals properly trained to handle disabled women?

4. Are health facilities adaptable enough to cater for disabled women's needs?

5. Do you think the existing government policies sufficiently cater for the reproductive health needs of people with disabilities?

B. Constraints to access to reproductive health services

1. What sort of problems do disabled women encounter as they seek reproductive health services?
2. List some of the barriers to reproductive healthcare for women with disabilities

3. Does your organization assist disabled women in accessing reproductive health care?
4. What difficulties do you face while assisting women with disabilities in accessing reproductive health care?

C. Potential measures to enhance access to reproductive health services

1. What do you think can be done to make reproductive health services more accessible to disabled women?

2. What other comments and suggestions can you make regarding access to reproductive health services by disabled women?

THANK YOU FOR FINDING TIME TO RESPOND TO THESE QUESTIONS

ANNEX 4: Focus Group Discussion Guide for women with disabilities

My name is Redemtor Atieno and I am a student from the University of Nairobi Institute of Anthropology, Gender and African Studies (IAGAS). I am doing a research on Reproductive Health Seeking Experiences of Women with Disabilities in Mombasa County as an academic undertaking for a master's project. The research aims at generating information to help service providers improve their services and disabled women make maximum use and benefit from these services. All the information that you will provide shall be used for this study and will be treated with STRICT CONFIDENTIALITY. However, if there is any question you are not comfortable with, you are free not to answer. You can also terminate this interview at any point. There will be no consequences for turning down the interview. With your permission, I would like to record our interview as it will help me better focus on our conversation.

Name: ______________________________ Date________________________________

Signature ___________________________________

ID Code	
Date	
Time	
Interviewer	
Interview Length	

Name	Age	Sex	Marital status	No of children	Nature of disability	Education level	Employed Yes/No	Name of organization	D a

A. Reproductive health seeking practices

1. What are the various reproductive health needs that you have (Probe for contraceptives, health information, maternal child health, pregnancy and child birth)?
2. Where do you go for reproductive health services? (Probe for all the options either in the official health sector or the unofficial health sector (Folk, professional and popular sectors and the reasons for their choices)

B. Reproductive health care options and availability of services

1. How far is the nearest reproductive health facility from your home?
2. Why do you go to the particular service provider you indicated above?
3. Who pays for the health services that you receive (including buying drugs, tests, scans etc)?
4. How would you rate the kind of services you receive whenever you go there?

5. What would you term as a disability friendly health facility?

C. Constraints experienced in accessing reproductive health services

1. What difficulties do you face when you go to the reproductive health service provider? (Probe in terms of facilities, distance, provider attitude and any other constraints be it physical, environmental, socio-economic etc)
2. How have the above difficulties affected you?
3. What are the attitudes of health care professions when treating you?
4. In your opinion are health care professionals properly trained to handle disabled women?
5. Are health facilities adaptable enough to cater for disabled women's needs?
6. List some of the barriers to reproductive healthcare for women with disabilities

D. Recommendations for improved access to reproductive health services

C. What do you think can be done to make the reproductive health care services more accessible to disabled women?

D. What other comments and suggestions can you make regarding access to reproductive health services by disabled women?

Thank you very much for your time.

ANNEX 5: Narrative Guide

My name is Redemtor Atieno and I am a student from the University of Nairobi Institute of Anthropology, Gender and African Studies (IAGAS). I am doing a research on Reproductive Health Seeking Experiences of Women with Disabilities in Mombasa County as an academic undertaking for a master's project. The research aims at generating information to help service providers improve their services and disabled women make maximum use and benefit from these services. All the information that you will provide shall be used for this study and will be treated with STRICT CONFIDENTIALITY. However, if there is any question you are not comfortable with you are free not to answer. You can also terminate this interview at any point. There will be no consequences for turning down the interview. With your permission, I would like to record our interview as it will help me better focus on our conversation. You have been chosen again to recount your reproductive health seeking experience as your story is insightful and gives a detailed view of your life.

Name: ______________________________ Date______________________________

Signature: ___________________________________

ID Code	
Date	
Time	
Interviewer	
Interview Length	

Background information

Basic Demographic Questions

Age	
Sex	
Education	
Are you employed?	
If yes name of the organization	
Your designation	

I want to enter with you into a conversation about your health seeking behavior.

- What are some of the most common reproductive health illnesses that affect you?
- Where do you go to whenever you have a reproductive related illness?
- What are the various reproductive health needs that you have (probe for contraceptives, health information, maternal child health, pregnancy and child birth)
- Narrate to me your experience of reproduction
- How did the pregnancy come about? Was it by your consent, rape etc?
- Who delivered you and where?
- What is the experience of motherhood for yourself and those around you?
- What are some of the burden/challenges that you face concerning reproductive health issues?

Thank you very much for your time.