Physical disability and sexuality
- A qualitative study on challenges and expectations connected to sexuality seen from the view of Tanzanian women living with physical disabilities

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Minor Field Study
SIDA
Abstract

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This thesis is a qualitative interview study with the purpose of describing how women living with physical disabilities view their experiences and expectations connected to sexuality. It also aims to highlight how the surrounding society treats these women regarding their sexuality. Through semi-structured interviews; six single- and one group interview, the data was collected during a two month long Minor Field Study in Dar es Salaam, Tanzania. An interpreter, with a degree in Kiswahili/English translation at the University of Dar es Salaam was translating the interviews from Kiswahili to English. The results of this study show that the women living with physical disabilities view themselves as capable and strong sexual beings even if they at the same time face many challenges. The challenges they face are both on an individual and a structural level. These challenges are often connected to the men they have long or short relationships with and are closely linked to both how the men and the society view physical disability and the female sex. This thesis shows that when it comes to sexuality the women all hope for a radical change towards a society that can meet their needs better and the women’s stories clearly highlight the importance of seeing the society itself as the disabling mechanism instead of seeing themselves as disabled individuals.

Keywords: Physical disability, mobility impairment, sexuality, love relationship, women, Tanzania, Africa.

Nyckelord: fysisk funktionsnedsättning/funktionshinder, sexualitet, partners, kvinnor, Tanzania, Afrika.
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Abbreviations
SIDA – The Swedish International Development Cooperation Agency
SHIA - Swedish Organisations’ of Persons’ with disabilities International Development Cooperation Association
SHIVYAWATA - Tanzania Federation of Disabled People’s Organisations
CHAWATA - Tanzania Association of the Disabled
WHO - World Health Organization
UN – United Nations
CRPD - The Convention on the Rights of Persons with Disabilities
NGO – Non Governmental Organization
DPO – Disabled Persons Organization
SIAT - The Swedish Institute of Assistive Technology
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Introduction

...since way back our society believes that disability is like a curse in the society. Because of this those men are afraid of walking together with women with disabilities. They feel shy.../...But as the days goes on the society has started to change these attitudes and nowadays thinks that even people with disabilities are our fellows, because anyone can become disabled. The people with disabilities are our relatives.../...sometimes I joke with people and I tell them that disability is like a fashion. Disability is a fashion because God created us to look different. Sometimes I think that if God had created us to be the same; same shape, same look, same height and weight, how would that have been??! We have to have respect for that God created us different, every person is created unique.../...people can have different walking styles; some persons are crawling on the floor, some are walking with sticks, some use their hands, some walk with their feet... (Majii)

The World Health Organization estimates that ten percent of the people in the world are living with a disability of some kind. Around 80 % of the population in the world lives in development countries and therefore also a big majority of all persons living with a disability. Persons living with disabilities should have the same sexual rights as people living without disabilities. But through out history they have been excluded from services and information connected to sexuality and they face negative attitudes and prejudices from the surrounding society and individuals. People often look upon persons living with disabilities as if they are not sexually active and often they are not given the choice to decide if they want to be in a relationship or not, to raise children or not. (WHO, 2009)

In a report recently conducted by The Swedish International Development Cooperation Agency, SIDA, it is explained that sexuality historically has been a missing dimension in development work. Mostly there has been a focus on the problem filled parts of the sexuality; like sexual abuse and diseases. Since sexuality contains more than these aspects the time is now urgent to put all parts of the sexuality on the agenda. It is highlighted that in development work sexuality should be seen in all different fields. This since sexuality for example is closely linked with the human rights of health, equality, education and welfare and therefore also the level of poverty in development countries. (Runeborg, 2008) WHO (2009) explains that through out history women living with disabilities in development countries have been carrying a so called double burden of discrimination. This because of their low status as the female sex and as disabled also more exposed to sexual abuse and Hiv/Aids than men. It is emphasized that an increased awareness among us all is a must for a positive change in the world. In a global world that strives towards equality; disability and sexuality is everyone’s concern.

Oliver (2009) highlights that through out history people living with disabilities haven’t talked for themselves; people living without disabilities have talked for them. Helmius (2000) underlines that women living with disabilities and their situation have often been discussed as filled with obstacles and problems. Focus has been on how to prevent stigma and exclusion towards them, this instead of highlighting the women’s unique experiences and self defined possibilities.

Nationally and globally social work can be seen as a development work that historically has had its focus on the marginalized groups in the society, which persons living with disabilities can be identified as (Meuwisse & Swärd, 2006). Hokenstad and Midgley (1997) highlight that the social work should strive towards positive changes regarding the welfare of people. A big
challenge all over the world is that persons living with disabilities are treated different when it comes to sexuality. Since sexuality is said to be an important and complex part of every human being it is also connected to the welfare of people. With this above said I believe that to not talk about disability and sexuality is like a ticking bomb world wide. There is a need of letting people living with disabilities themselves to identify their challenges and expectations when it comes to sexuality. I believe that the social work meeting with many different persons with different disabilities can play an important role in putting a wide perspective of sexuality and disability on the agenda.

During earlier travels in Tanzania, while working and studying, I have met people living with different disabilities. While being engaged in questions concerning disability in Sweden and when I newly started to work as a school informant, talking about sexuality and relationship with youths, my curiosity on disability and sexuality in Tanzania arose. My pre understanding was that disability and sexuality in Tanzania would be surrounded with many taboos and therefore also needed to be discussed. Before starting this research I was in contact with The Swedish Organisations’ of Persons’ with disabilities International Development Cooperation Association (SHIA) who are working with disabilities in Tanzania. They expressed that they feel there is a lack of literature about sexuality and disability in Tanzania while emphasising the need for an ongoing discussion concerning disability and sexuality, which all together motivated me to start this study.

Purpose

The overarching aim off this study is to examine how women living with physical disabilities in Tanzania view their experiences connected to sexuality. The study also wants to highlight the women’s experiences of how the society is treating them concerning their sexuality. To be able to examine this, the following research questions have been formulated.

Research questions

- How do women living with physical disabilities view their sexuality?
- Are the women facing any challenges and norms connected to their sexuality?
- Do women living with physical disabilities get treated as sexual beings from the surrounding society?
- Do the women living with physical disabilities have any future expectations connected to sexuality?

Definitions of concepts

Disability: The Tanzanian National Policy On Disability defines disability. It is described that; “Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to temporary or permanent physical, mental or social barriers. Such a loss or limitation could be aggravated by community’s perception of disabled people.” (National Policy On Disability, 2004, p.1)

This National Policy On Disability in Tanzania corresponds with how WHO (2009) defines disabilities; “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 (p.9)”
Corresponding to these definitions *Women living with disabilities* will be used as the main conception in this study, emphasizing that if only the society can meet both physically and psychologically the disability could be a non disability and instead be put on the society level, instead of within the individuals. The expression *Women living in a disabling world* will also be used to strongly emphasize that the society itself is the most disabling factor, not the impairment itself. When referring to earlier research the expressions used from the original literature source will be used, therefore also expressions like *disabled people* or *the disabled* can be seen in this study.

**Sexuality:** WHO (2010) highlights that sexuality and sexual rights is an important and complex part of human beings and they have a working definition of sexuality saying that: “Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors”

WHO (2010) also describes Sexual rights: “Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to:

- the highest attainable standard of sexual health, including access to sexual and reproductive health care services;
- seek, receive and impart information related to sexuality;
- sexuality education;
- respect for bodily integrity;
- choose their partner;
- decide to be sexually active or not;
- consensual sexual relations;
- consensual marriage;
- decide whether or not, and when, to have children; and
- pursue a satisfying, safe and pleasurable sexual life.” (WHO, 2010)

How WHO defines sexuality and sexual rights includes a wide perspective of sexuality which corresponds well with how the concept of sexuality will be used in this thesis.

**Stigma:** Goffman (2001) describes how the concept of stigma originates from the Greeks, who burned marks into bodies of persons that were seen as outsiders in order to advertise their exclusion from the society. The persons being stigmatized were seen to have discreditable qualities in one or several ways. This example can show how people in the society are being divided into groups of “the normal ones” (those without stigma) and the “un normal ones” seen as less human (those with stigma).

**Norms:** Norms are the implicit or explicit behavioral expectations or rules within a society or group. These norms can usually have a function of regulating the interaction between people, in order to make the behaviors predictable. Failure to act according to the rules/norms usually result in different reproofs or punishments. If you don’t act accordingly to the norms you
might be excluded from the group. Many of the existing norms in our society are stipulating the hierarchy of a group. (Angelöw & Jonsson, 2000)

**Demarcations**

This study has its focus on catching views and experiences on sexuality from women living with physical disabilities while conducting a few longer interviews. The research is taken place in the urban areas of the capital city of Tanzania, Dar es Salaam and the interviews with the women are conducted within one of the organizations for people living with physical disabilities in Tanzania.

**Background**

**The Tanzanian context**

The republic of Tanzania is located in eastern Africa and has a population of nearly 40 million people. Out of the whole population around ten percent is living with a disability of some kind. Tanzania is one among the low income countries in Africa with an economy estimated as one of the poorest in the world. The poverty is widespread in the rural areas where 80 percent of the population is living maintaining on agricultural work. Tanzania has a high dependency on foreign aid and the corruption in the country is influencing most parts of the society. To get clean water is a major issue and diseases like malaria, cholera and Hiv/Aids are some of the main reasons causing death. The expected life length in Tanzania is estimated to be around 50 years. Tanzania has English and Kiswahili as its official language, but with their around 130 different tribes in the country there is also a variety of tribe languages. About 45 percent of the population in Tanzania is Christians, 35 percent Muslims and 20 percent are adherent of different African religions. (Nationalencyklopedin, 2010; SHIA, 2010a)

**Governmental initiatives on disability**

Since Tanzania gained independence in 1961 the government, through the Department of Social Welfare, has been engaged in various national- and international initiatives providing services to people living with disabilities. Tanzania has signed a number of international documents; among these are the declaration on the Rights of People with Disabilities (1975) and the United Nation standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993). At a continental level Tanzania has also signed the Plan of Action for the African decade of Persons living with Disabilities, which was an initiative to raise awareness of the situation of people living with disabilities in Africa between the years 1999-2009. In 2004 the first national policy on disability was created and has since then been used as an instrument for providing guidelines and services connected to disability. (National Policy On Disability, 2004; Njogopa; personal communication)
The Ministry of Health and Social Welfare has the overall responsibility for the questions connected to people living with disabilities in Tanzania and their goal is to mainstream disability to be a crosscutting issue within all ministries and at all levels of the society. The Ministry of Health and Social Welfare is offering education and are networking on questions connected to disability and they are for example organizing different Disability Days during the year. They also provide money to the different organizations, among these for example the Disabled Persons Organizations, DPO:s, working with questions connected to disability. (Njogopa; personal communication)

**Civil society and disability**

In a context analysis on disability in Tanzania Seya (2009) describes how the big majority of the population in Tanzania historically has seen disability as a failure and misfortune. Because of this, most initiatives reaching people with disabilities have been based on charity. Religious- and Charity organizations have therefore been dominating when it comes to providing people living with disabilities services. Nowadays the initiatives on disability from Human rights organization and Women organisation are increasing. The disability movement itself started to be active in the late 80s and early 90s. This was a time when many organisations came together while raising their voices concerning their rights emphasizing the changes they wanted to see within the government and society. The movement had been there since many years back but in the 80s the media became more free which created an opportunity to highlight disability. Today, different challenges that people living with disabilities are facing, are not dealt with in the quiet in Tanzania.

**Living with a disability in the Tanzanian society**

SHIA (2010a) underlines that people living with disabilities are estimated to be among the most vulnerable persons in Tanzania. In general it is hard for families to afford the payment of transport to school, school fees and school uniforms and children living without disabilities are in most cases given the chances to go to school ahead of the children living with disabilities. For a person living with a physical disability it can be a great problem to access the public spheres because of the non accessible environments and the lack of transport vehicles in Tanzania. Low education and negative attitudes towards people living with disabilities often hinders them from getting a work. Also most people living with disabilities don’t own land and therefore they usually don’t get the opportunity to take loans from the bank, which could help them to start up businesses. Negative attitudes from the health care towards people living with disabilities are common, especially for pregnant living with disabilities while in need of help connected to giving birth. In Tanzania several prejudices about persons living with disabilities is circulating and some people look upon children with disabilities as a punishment for their families because of some mistakes that the family earlier have done. Among some of the tribes disabled children are left to die after the birth. If the children survive they often get isolated in the homes and they are seen as if they cannot be independent. Thanks to the handicap movements in the country these attitudes are slowly starting to change. (a.a.).

**The gender balance**

The gender balance between men and women in Tanzania is subordinating women. The man is often in control of the reproduction and decides how many children a woman should give birth to. Women living with disabilities face a double burden of discrimination, first since they as the female sex are subordinated the men and secondly as persons living with disabilities. The women are not expected to be able to have a partner or to take care of children and this makes it difficult when they find a partner. When it comes to marriage, by
tradition, the man’s family pays a bride prise for the woman. Due to this there is a great pressure emphasizing that the man’s family and relatives have to accept the women living with disabilities as good enough for their son. (Seya; personal communication)

Hiv/Aids
Hiv and Aids affect the whole county and in the age group 15-49 years, around six percent are estimated to carry Hiv, the majority is women. People living with disabilities are more vulnerable to Hiv since their participation in the society is limited and therefore also their access to health information and health care. (Seya; personal communication; SHIA, 2010a)

Knowledge overview

Now a description of how the knowledge overview has been made will follow. The overview will be presented below existing of the themes; Disability and sexuality, Disability and sexuality – international agreements, Women living with physical disabilities in a world of disabling challenges and Women living with physical disabilities in development countries.

The collection of earlier research and literature
The earlier research has been found in the databases; Libris, CSA, DIVA and on the Minor Field Study (MFS)-site. First of all the search was aiming to find relevant peer reviewed articles and treatises. In the search for literature the following words were combined (physical disabilit*), (mobility impairment), sex/sexual*, relationship, women, Tanzania, Africa and WHO + in Swedish; (fysisk* funktionsnedsättinan*), (fysisk* funktionshinder), sexualit*, relation*, kvinn*, Afrika and Tanzania. The researcher was in contact with Hjälpmedelsinstitutet - The Swedish Institute of Assistive Technology (SIAT) and the Swedish Organisations´ of Persons´ with disabilities International Development Cooperation Association (SHIA) for furthermore ideas of literature that could be relevant for the aim of this study. Useful literature has also been found in the library at the Department of Social Work at Stockholm’s university and in the library of Hjälpmedelsinstitutet. During the stay in Tanzania, a collection of different reports has also been made along the way.

Disability and sexuality
Löfgren-Mårtenson (1997) describes how sexuality is very complex since it both can give life and cause death. This since sexuality can be a life giving source through the reproduction but also something that includes abuse and sometimes sexual violence causing death. Sexuality, love and relationships are important parts in a human’s life and the questions crossing the minds of persons who experiences long lasting impairments and disease is often about whether they can still be loved or have a relationship. Professionals within the health care systems share the taboos and prejudices about sexuality that are related to their specific culture and time and people living with disabilities have often been treated as if they are asexual.

Helmius (2000) describes that today many researchers emphasize the importance of seeing sexuality in its cultural context. From a social constructive perspective both disability and sexuality are something that is social- and cultural constructed. The collaboration between individuals and society creates the sexuality. We are born with abilities to experience sexual feelings but how we should express our sexuality is decided by the cultural values of sexuality. Due to this the norms of sexuality in every specific culture is creating an “accepted sexuality” that all inhabitants in the culture are expected to act accordingly to.
Disability and sexuality has not been on the agenda historically. Parker & Aggleton (2007) highlight that throughout history sexuality has been a question for biomedical and population science and not until in the 1980s the social, political and cultural aspects of sexuality arose. The social movements, for example the feminist-, lesbian- and gay movements have from the 1960s been working for rising questions concerning sexuality. The international concern for women’s and men’s sexual- and reproductive health and the global challenge to stop the Aids epidemic have also forced the world to put sexuality on the agenda. Today there is an aim to include discussions of the social- and political perspectives on sexuality in the most important ongoing debates in our global world. (a.a.).

**Disability and sexuality – international agreements**

In present time sexuality and disability is highlighted through international documents, the latest is the Convention of the Rights of People Living with Disabilities (CRPD). Since 2008 this United Nation (UN) convention has been on the agenda and it highlights the rights of people living with disabilities on all levels in the society. In article six there is stated that women with disabilities are exposed to multiple oppression and in the article “respect for home and family” it is described that states shall ensure the people living with disabilities the same opportunities to sexual life, relationships and children as all others people have. (UN, 2010a) Several countries all over the world have ratified this convention that clearly highlights rights concerning sexuality and disability. Tanzania is among these countries and ratified the convention in September 2009. (Njogopa; personal communication)

In rule number nine of the United Nations standard rules on the Equalization of opportunities for persons with disabilities it is explained that “States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.” This is not a legally binding rule but it encourages governments to work towards equality for people living with disabilities. (UN, 2010b)

**Women living with physical disabilities in a world of disabling challenges**

In the literature of people living with disabilities in a western context there has been a struggle to see women living with disabilities as sexual beings with sexual rights. This since they often have been pictured as victims of sexual abuse and therefore seen as vulnerable and in the first hand in need of protection. There has been a struggle for women with disabilities to be seen as women in the first hand and in second hand as women living with disabilities. In the more recent literature a feministic perspective has come to take place in the disability research. This perspective highlights the patriarchal structure in the society where the men have structural power over women. (Helmius, 2000)

Basson (1998) describes that because of the society’s prejudices the sexual well-being of women with physical disabilities is neglected. There has been little written in the medical literature about disabilities and sexuality and quite recently a focus on special diagnoses like multiple sclerosis and spinal chords injuries have been investigated from the sexual aspects. Different prejudice about women living with disabilities is circulating saying; that only persons living without disabilities can be able to have sexual relationship, therefore women with disabilities is seen as different, as asexual and as if they can not be mothers. Professionals also tend to follow these attitudes. On the other hand there is also existing attitudes saying that all women living with disabilities are heterosexual and that they should be thankful for sexual relationship if they manage to have one. With these attitudes women
living with physical disabilities are in one way or another looked upon as sexual beings. (a.a.).

Zavirsek (1998) describes that earlier research on disability and sexuality shows that persons with bodies that looked different and didn’t correspond to the criteria’s of normality that were created in Europe in the beginning of the nineteenth century were treated with racism and were called names like cripples and freaks. She describes oppressions against the women living with disabilities both due to the disability itself and due to the norms of how a woman should be and act; “Many feminist disability activists have shown that disability itself reinforces discrimination against women on the structural level as well as on the everyday interpersonal level. Disabled women challenge the idea of a perfect body as part of a constructed women’s identity. The women who decide to have a baby also challenge the naturalised heterosexual matrix that connects femaleness, heterosexual sexuality, reproduction and motherhood to form a natural undivided bond. Since the ideas of sexuality are strongly connected with reproduction, the prevention from sexual activities also means protection from the danger of unwanted pregnancy (p.277).” (a.a.).

Sjöberg (2005) underlines that if we strive towards a society where everyone has the same sexual rights we are in need of big changes on how we view persons living with disabilities, there has to be a shift from seeing persons living with disabilities as patients and instead view them as citizens. Basson (1998) underlines that there is research saying that to be afraid of losing independence and to be looked upon as sick or as a patient effects the sexual self image. Studies show that women with spinal cords injuries saw themselves as less attractive and they were less confident to start a love relationship since they were afraid to be rejected and therefore never came close to a love relationship. Taleporos and Mc Cabe (2002) also describes earlier research on physical disability and sexuality which indicates that it is common to have a lower self esteem concerning sexuality when living with a physical disability. It is explainable that the negative attitudes from people make the persons living with disabilities insecure. These attitudes surrounding disability also made people living with disabilities feel less attractive and unable to conduct sexual intercourse in the way they were expected. Helmius, (2000) highlights on the other hand, that there is also examples of women with physical disabilities who have good sexual relationships, are living with a partner and are mothers of children. These women see their disability as a resource and get confident in being different and unique. She exemplifies that if their physics doesn’t work then they instead have to verbalize how they want the sexual intercourse with their partners, which is an act that can bring self esteem. (a.a.).

Zavirsek (2002) is analysing various stories of sexual abuse told by Slovenian women living with different disabilities. She highlights that the sexuality of men living with disabilities are more visible and seen as active whereas the sexuality of women living with disabilities is not highlighted. If the men living with disabilities doesn’t get the opportunity to have sex it is also feared that their mental health can be damaged. This is a sign of suppression on society level which gives the men more right to a sexual life whereas the women are associated with the passive objectified opposite. Women are seen as objects that should be ready for the man any time he needs to be satisfied. It is highlighted that “They are paradoxically objects of the sexual activities of the others, as well as persons to whom sexuality is denied (p.271)”. She emphasizes that the history of ignoring the sexual abuse of people living with disabilities is a huge discrimination. A discrimination enabling people’s misconceptions and stigma on all levels in society toward persons living with disabilities. The women living with disabilities is not expected to be sexual beings and therefore it also seems unlikely that they would be.
exposed to sexual abuse, as if the disability would protect them from being abused. These are attitudes saying; why should anyone use violence against someone seen as a victim. The dependency on other people that people living with disabilities often face also makes them more available for sexual abuse. Physically it’s also easier to take advantage of someone living with a disability. It is also described that the person who is using a person living with disabilities can emphasize that he is doing her “a favour” since she cannot have anyone else, that she should be thankful instead of afraid.

Women living with physical disabilities in development countries
Yoshida, Li and Odette (1999) underline that there is a lack of literature on women living with disabilities from different ethno-cultural communities. Since the 1980:s there has been an interest in the combination of disability and sexuality. The literature often has its focus on rehabilitation and medical concerns and the psychosocial dimension is rarely mentioned. Also the earlier research has not been pointing out the unique situation of being a woman with a disability and the literature specially lacks research on a combination of culture, sexuality and disability.

Much of the earlier research concerning disability and sexuality in Africa has its focus on sexual abuse and the women’s exposure to diseases like Hiv/Aids. Kangaude (2009) emphasises that “In contrast to the disability movements from Europe and North America the general trend in Africa is to dwell on the prevention of violence and Hiv/Aids, and less on tackling the stigma of asexuality. (p.29)” In a study of women living with disabilities in Zambia Smith et al (2004) describes how the women are not expected to be sexually active and therefore doesn’t get the health information they need which makes them more vulnerable to sexually transmitted diseases like Hiv/Aids. Wazakili, Mpofu and Devlieger (2009) which have been conducting a study on young South Africans view on sexuality and Hiv/Aids also got results showing that persons living with disabilities were excluded from the health information concerning diseases like Hiv/Aids. In a research of gender and people living with disabilities in South Africa Hanass-Hancock (2009) describes how different myths and stereotypes makes women with disabilities more exposed to sexual abuse and therefore also to Hiv/Aids. Myths like that it is possible to cure Hiv by having sex with persons living with disabilities or that these persons are special and extra willing to have sex also puts them in a difficult position. He emphasises that the unequal gender balance where the men has more power than women in the society and the lack of health information to people living with disabilities are among the reasons why women living with disabilities are more exposed to sexual abuse and also Hiv/Aids. It is also emphasizes that instead of research focusing on sexual harassment and diseases there is also a need of highlighting sexual pleasure and disability. (a.a.).

A report carried out in 2009 by the Tanzania Commission for Aids, TACAIDS, shows that people living with disabilities in Tanzania are engaged in sexual activities, many in high risk activities, for example having multiple partners without using condom. This combined with that women with disabilities often have a lack of knowledge on how Hiv is transmitted, since they face stigma from health care being seen as asexual. Kangaude (2009) describes the urgent need of seeing people with disabilities as sexual beings in order to avoid the stigma and marginalization towards them. This in order to be able to give them the same health care, since Hiv/Aids for example is a large challenge people with disabilities are facing today. “Disability does not subtract any human rights from any human being (p.24).
WHO (2009) describes that women living with disabilities don’t have the choice to decide if they want to be in a relationship or not and whether they can give birth to children or not. In the worst case forced sterilization and abortion is practised. Prejudices saying that having sex with a virgin can cure aids is affecting women living with disabilities, since they often is seen as asexual and therefore as virgins, they are exposed to these practises. (a.a.). A study of women living with physical disabilities in Cameroon shows that they faced several obstacles when starting a relationship. The attitudes from men about that their disability was contagious, hinders them from getting a partner. Being a African woman often means that you have responsibilities to get the house hold running and to take care of your husband and children, to cook, to clean and to be working on the fields. Since many women with physical disabilities weren’t able to do the traditional jobs they were rejected by men. (Kiani, 2009)

Feinstein (2009) who conducted a study on persons living with disabilities among the masaii tribe in Tanzania, describes how massaii women living with disabilities are seen as cursed and bewitched and that they due to this face a lot of stigma. They are seen as if they cannot be married, only if the disabled women can produce children. Though, the majority thinks that there are possibilities for a woman living with a disability to get married to a man in the “same situation” (a man living with a disability). Miller, Chen, Glover,Graf and Kranz, (2009) describes that studies of Hispanics’ living with disabilities shows that the negative attitudes from people without disabilities towards people with disabilities makes it hard to engage in relationships for the persons living with the different disabilities. The study highlights existing attitudes saying that the larger the physical disability is the more difficult it is to have a relationship.

**Theoretical framework**

This chapter will describe the theoretical framework used in this study. The theoretical framework is supposed to be a helpful tool which creates a broader understanding of the data in this study (Kvale, 1997). The theoretical tool that will be used for analysing the data in this study is the Social model supplemented with Crip-and parts of Disability theory. The Medical model, that in many ways are seen as an opposite pool to the Social model, will also be a helpful tool used in some parts of the analysis.

**The usefulness of the theoretical framework**

Sohlberg and Sohlberg (2009) and Payne (2008) describes the sociological theory Social constructivism as based upon an understanding of that the reality is created by social interaction and communication between people. This interaction creates knowledge and the understanding of the reality will be different depending on the context of the society. To choose to think ether from the perspective of the Social model or the Medical model are both different ways of deciding how you want to look upon the reality of disability and sexuality. By choosing these models and theory’s the data in this study will be approached from a social constructivist perspective. Sauer and Lindqvist (2007) highlight that disability is consisting of a biological, a psychological and a social dimension. Depending on the context the disabilities will mean different things to individuals and societies. Norms and values will decide what perspective the society will have on disability and the people living with disabilities will form their identity from how the society treats them. (a.a.)

This theoretical framework will be helpful in highlighting different perspective on how to look upon disability; as something existing in a human being or as something created by the
society itself. The framework will also show how norms of bodily ability and sexuality are strongly cultural decided and seen as something “true” which will lead to challenging experiences for those persons who don’t recognise themselves in these norms. With this theoretical framework norms can be made visible and therefore questioned in order to get a wider understanding of challenges connected to disability and sexuality. This with the aim to form societies more aware of their specific norms but also to highlight how these norms affect the human behaviour.

The Medical model
Historically the Medical- also called the Individual model has been the most influential in disability policy. The core of this model explains that the impairment itself is lodged within the individual, the disabled person. The disability is also seen as something that can be cured by medical treatments or rehabilitating interventions. The model therefore has its focus on symptoms’ and according to this experts so as doctor use their medical expertise to diagnose individuals in order to help them cure and rehabilitate their symptoms’ and impairments. (Oliver, 2009) Johnstone (2001) is criticising the medical model according to its focus on treating the individual. He claims that this treatment discourse creates negative feelings of failure and shame, this since not all disabilities can be treated or cured. Siebers (2008) is also expressing criticism against the Medical model highlighting that the model itself emphasises that; how the body is created should decide what quality a human being will have; “Disability has been a medical matter for as long as human beings have sought to escape the stigma of death, disease and injury. The medical model defines disability as an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being (p.4).” Johnstone (2001) agrees with the above said and highlights that the Medical model sees the able bodies, without impairments, as superior to the disabled bodies. This since the medicalization discourse sees the problem/disability as something within the individual. Able-bodied persons are therefore seen as normal, able, good and independent while disabled are seen as abnormal, dependent and not as beautiful as the non disabled. He emphasises that these categorizations can be one explanation to why it historically has been justified “to do things to” instead of “to do things with” people living with disabilities, for example to decide over their reproduction.

The Social model
In 1976 the Union of the Physically Impaired Against Segregation (UPIAS) distributed a publication of the Fundamental Principles of Disability in Great Britain. This publication described disability as a social oppression instead of an individual impairment and the aim was to give new perspectives on disability. These ideas saying that the disability is existing on a society level instead of belonging to the individuals had been flourishing around in the disability movement for years but not until in the end of the 1980s these ideas were put together and became named the Social model by the author and activist Michael Oliver. Oliver describes that a main problem concerning the way the society view disability has been that illness and impairment often have been mixed up and seen as if it were nearly the same thing. He underlines that “…illness is caused by disease and disability is caused by social organization ( p.44).” The disability itself is existing due to the fact of the societal failure of adjusting to all people’s individual needs. With the Social model Oliver (2009) wanted to highlight every persons unique experience of disability, this with the aim of making a positive social change in the society. It is emphasised that the Social model should not be seen as a theory, instead as a tool that can bring equal rights and freedom to people of all different kinds. First, it is an attempt to switch the focus away from the functional limitations of individuals with an impairment to the problems caused by disabling environments, barriers
and cultures. The Social model highlights the long history of rehabilitation discourses which emphasizes that everyone should be changed towards the norm of the able body. In other words to rehabilitate bodies instead of seeing impaired bodies as different but equal to bodies without impairments, which can be seen as a so called body fascism. Instead of viewing rehabilitation as the only option the society could be prepared to meet all kinds of different bodies. It is important to see the power that one group, the majority, is using against the minority to rehabilitate them towards the norm of able bodies. The use of power belonging to the majority is developed from an ideology of normality and are shaped by the powerful in the society, a normality that is often invisible. Exclusion from the mainstream society shows that attitudes and environments exclude people living with disabilities. It is the whole population’s responsibility to see this exclusion which causes discrimination and stigma in order to work towards an inclusive world. Oliver (2009) claims that it is important to develop a broader understanding of disability, in order to make this happen discussions of making the personal political is essential. (a.a.) Shakespeare (2006) describes the Social model as “Rather than essentializing disability, it signals that the experience of disabled people is dependent on the social context, and differs in different cultures and at different times. Rather than disability being inescapable, it becomes a product of social arrangements, and can thus be reduced, or possibly even eliminated.” (p. 29) On the other hand he is also criticizing the Social model for putting all the focus on the environments which can make one forget the individual impairments or needs. This he means can in the extension for example cause situations where we will not be able to know what kinds of impairment individuals have and how many people there are living with them. (a.a.). The Social model has also been criticized for being a model adjusted after white middleclass men living in town. In the villages where the environments are more disabling this model face a bigger challenge to meet people’s needs. Also it has been criticized for not including perspectives on sexuality, gender and disability. (Oliver, 2009)

Since a model is not better than its content it is therefore a good idea to complement it. In this study perspectives from Crip theory and The sexual culture for people living with disabilities taken from Disability theories will be used to complement the Social model.

**Crip theory**

Crip theory has many similarities with the Social model but has its focus on questioning norms in the society. It has developed from cultural studies, which has its focus on the political nature of cultures; questioning how things are created, why and how they work, and have similarities to queer theory who is also questioning norms. Queer theory is questioning the norm of heterosexuality and Crip theory is questioning the norm of able bodies, where the disabled are seen as different in the comparison with the “norm population”. The Crip theory is questioning “the natural order of things” and are criticizing the normalcy. The normalcy cannot be said to exist since all individuals are unique and should be able to create their life in a way they are comfortable with. It is important to question the often invisible norms of able bodies since these norms can be made visible within the existing social relations in order to make a positive change in the society. (Mc Ruer, 2006) Flexible- and able bodies are seen as a norm and bodies that doesn’t work in the same way is for example seen as threats. This connected to the fear of the realization that a “normal body” can easily one day become impaired. Crip theory is about to broaden up identities with the aim of a positive variety of bodies instead of letting the norm of able bodies exist. In that norm there is always a question like “wouldn’t you rather be more normal like me”, like the norm. Able bodies are seen as the natural order of things which creates hierarchies with the normal, clean and beautiful at the top. With the realization of that we all can and probably will be disabled in the end, we can strive towards an attitude change. (Mc Ruer, 2006)
A sexual culture and disability
With his book Disability theory Siebers (2009) wants to question and contribute to the field of Disability studies. So as the Social model this theory is based upon the ideas from the social constructivism. Siebers (2009) wants to include ideas and questions from Critical- and Cultural studies, Queer theory, Gender- and Race studies. He argues that disability studies for examples include ideas about identity, ideology, politics, social oppression, sexuality and the body. With the expression sexual culture he wants to put sexuality and disability on the agenda. He emphasizes that it is important to create a sexual culture for persons living with disabilities since they historically have been excluded. This culture is broader than the regular sex life and has dimension of both a private and a public sex life. This according to the fact that a lack of privacy can be the reality for many persons living with disabilities when it comes to sexuality. This sexual culture can include new ways of thinking concerning sexuality, for example new ways of having sexual intercourse adjusted to bodies with impairments. For example he wants to question the norm of penetrative sex. “If people with disabilities are to develop a sexual culture, they will need to access safe spaces where they may develop new erotic theories and modes of being.” (p. 143) By making the private public men’s power over women can also be made visible and give us a picture of all abuses towards people living with disabilities. Men have more power to decide where the line between private and public should be drawn. The women who usually are in the private spheres can therefore be sexually abused more easily than men. Siebers (2009) also discuss how people living with disabilities are not expected to be able to give birth to “quality offspring’s”, since reproduction is a matter of forwarding qualities and abilities to the next generation. According to the invisible norms in the society there are certain qualities that you are expected to have if you should be able to produce children. For example you should attract a partner, you should be able to have sexual intercourse and you should be fertile. As a person living with disabilities you are seen as an outsider and are not expected to have these qualities. To not be able to have sex and create children can be seen as a failure as a human being because then you are seen as if you cannot contribute to the future generation. To be able to give birth to your own children gives the human beings status Siebers (2009) explains.

Method

Now a method chapter will follow, introductory the chosen research method will be described and motivated. This will be followed by descriptions of the; Selection, Conducting the interviews, Processing the interviews, Ethical aspects, Validity, Reliability and Generalization.

Research method
This is a qualitative study where the aim is to highlight unique views on sexuality and disability in order to be able to create more curiosity and a wider understanding of this field. To look for persons unique experiences and to focus on the understanding of these rather than to measure- or focus on the explanations of them are important parts of the core of qualitative method (Kvale, 1997). The data in this thesis is collected from half structured interviews during six single- and one group interview. This study also includes two informant interviews. Kvale (1997) describes that qualitative interviews aims to create new knowledge while an exchange of views is taking place between the respondents or the interviewer and the respondents, while talking about an in common subject. The goal of the interview in qualitative method is to understand the chosen research question through the respondents’
point of views while catching his or her own unique experiences. The choice of method can be motivated with this study’s aim to highlight the women’s experiences and views but also for the reason that the study aims to create new knowledge during the interviews both between interviewer and respondents but also to build new knowledge between the respondents, which was enabled from the sharing of experiences during the group interview. Another reason to why this study combines single interviews with one group interview is due to that the subject sexuality can be surrounded with many taboos and it can be assumed that some persons feel more comfortable to talk freely between two eyes while others prefer to share their views more freely in larger groups. This study can be described as abductive since the data is affecting the choice of theories and vice versa. The research- and interview questions are constructed with the presence of the theories but while gathering the data and searching for the essence within the interviews the theories steps aside with the purpose of letting the researcher being open for the interview quotes. The interview material later decides what conceptions from theories that can be useful during the analysis. (Larsson, 2005) The goal to understand the women’s sayings from their point of view also correspondence with the idea of the phenomenological perspective. The Phenomenology wants to use the exact description of the interviewed persons experience at the same time as the knowledge of the interviewer should be held aside. (a.a.).

The interview form used in this study is half structured and the interview guide contains a base of themes with under questions. This relatively open way of conducting interviews enable the interviewer to adjust to the respondents’ histories and to be open for new themes and unexpected knowledge during the interviews which also this corresponds well with the abductive- and phenomenological approach. (Kvale, 1997)

Selection
The choice of conducting interviews on the theme disability and sexuality in Tanzania opened up for a contact with SHIA since they are the biggest Swedish umbrella organization working with disabilities in Tanzania. SHIA was created in 1981 and is a non-profit organization working for disabled peoples rights, equality and inclusion. SHIA consists of 29 Swedish organisations of persons with disabilities which are actively involved in international development cooperation. SHIA stands for Solidarity, Human Rights, Inclusion and Accessibility. SHIA has been having an active collaboration with Tanzania since 1986 and from SHIA:s office in Sweden information and encouraging ideas were given. Through SHIA, Sweden a connection with their coordinator in Dar es Salaam, Tanzania was enabled. By email an information letter with an introduction of the interviewer, the aim of the study and the conditions for participating in the interviews (Kvale, 1997) was sent to the coordinator of SHIA. Through this emails the coordinator of SHIA got a picture of the interviewers aim with the study. The research questions, the interview questions and the goal of sharing the women’s views and experiences were described. A dialogue on how well the plans of the study could work in a Tanzanian context started. Topics to discuss were if the interviewed would be comfortable to talk, which language to be used, how it would work to conduct the interviews with a translator. The researcher also explained the conditions for the selection of the persons to be interviewed, which were; women living with physical disabilities in Dar es Salaam, at an age where they could be expected to have experiences from different love relationship. Due to this but also for ethical reasons women at a minimum age of 18 years were considered. The representative who did the selection was also informed that the women were suppose to be interested in sharing their views on challenges connected to sexuality and relationship. The researchers also expressed her intension of using the same interview guide with all respondents. This with the demand that all women were suppose to be able to speak
for themselves and could understand the interview questions and situation. Therefore the choice of selecting women with similar impairments, physical, was outspoken.

The coordinator forwarded the email conversation and the information to a representative of one of their member organizations; The Tanzania Federation of Disabled People’s Organisations SHIVYAWATA. SHIVYAWATA is the Tanzanian umbrella for different disability organizations. With the background information of the study the representative who had a good overview of the organizations and members, contacted women that she thought could be interested in participating in the interviews. The women she contacted were all members of the organization Tanzania Association of the Disabled CHAWATA who is an organization for physical disabled. (SHIA, 2010b) She representative contacted the women through email, phone or by meeting with them.

**Organizational overview:**

<table>
<thead>
<tr>
<th>SHIA</th>
<th>SHIVYAWATA</th>
<th>CHAWATA</th>
</tr>
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<tbody>
<tr>
<td>Swedish Umbrella Organization</td>
<td>Tanzanian Umbrella Organization</td>
<td>Tanzania Association of the Disabled</td>
</tr>
</tbody>
</table>

The selection of interview persons can be describes as a selection adjusted to the circumstances given, where the researcher had limited options to participate in the selection due to the geographical distance (Kvale, 1997). When coming as a researcher from abroad it feels very important to get as much help as possible from contacts familiar with the Tanzanian context this since they for example have an overview of available interview persons in the country.

**Interpreter**

A contact with a Kiswahili/English translator, whom the interviewer knew from earlier visits in Tanzania, was established from Sweden. After arriving to Tanzania, the interviewer and the translator spent time together discussing the study and coming interviews. Preparations for the interviews were done while picturing the interview situation together in order to get a picture of how it would be to conduct the interviews working closely together. These preparations gave us a picture of how we could work to ensemble well during the interviews. Ideas of how we could establish a good contact with the women during the interviews were also shared. A translation of the interview questions to Kiswahili was done in order to make sure that the Swedish concepts were corresponding with the Tanzanian.

**Conducting the interviews**

Before leaving for Tanzania earlier research on disability and sexuality were studied and contacts with helpful ideas of where to find information concerning disability and sexuality were taken. Kvale’s (1997) ideas of how to construct an interview were helpful and one earlier interview guide on the theme sexuality and disability were gone through before creating an interview guide.
Informant interviews
Two informant interviews were conducted, the first one with the coordinator of SHIA and the second with a social welfare officer at the Ministry of Health and Social Welfare in Dar es Salaam. The purposes with these interviews were to collect background information but also to get a wide picture of disability in Tanzania. The contact with the Ministry of Health and Social Welfare was enabled through the coordinator of SHIA. The interviewer started the research in Tanzania by conducting an informant interview with the coordinator of SHIA. Then a meeting together with the representative of SHIVYAWATA was enabled, here the planning for the coming single- and group interviews was done. A discussion of where the most comfortable place for interviews would be, how long time the interviews could take and which language to be used were discussed.

Single interviews
The single interviews took place during week 15, 16 and 18 at the office of CHAWATA, a place all the women were familiar with. Before starting the interviews the interviewer and the translator introduced themselves. The interviewer described the study, how the interview would be conducted and what the conditions were. She also emphasized the women’s rights to be anonymous and also opened up for questions.

The interviews were recorded. During the interview the interviewer asked questions and the translator forwarded the question in Kiswahili, sometimes the interviewer also asked in Kiswahili and the women sometimes also used their English knowledge. After the translator interpreted the sayings in short and then the next question was asked. During the interviews both the interviewer and respondent were sometimes clarifying sayings to make sure the understanding of the questions and answers were correct. The interviews ended with opening up for questions, talking about disability in Sweden and inviting the women to the group interview a second time, this in order to make sure that the women could be able to participate.

After the first interview the interviewer and translator discussed their experiences from interviewing together, difficulties and interesting views were highlighted. Some new questions were added and some interview questions were again clarified.

Group interview
The same practical measures as during the single interviews were undertaken. In the group interview five of six earlier interviewed women participated, one was unable to participate because of changed plans. Instead a representative of a DPO participated for 20 minutes, sharing her experiences of sexuality as a woman living with physical disabilities. The discussion lasted for two hours and the participants so as the interviewer and translator did all exchange a lot of ideas and experiences, while drinking juice and eating cookies. The atmosphere was open and curious, both filled with frustration and laughter’s before the interview came to an end.

Processing the interviews
The recorded time of the single interviews varies from 46 minutes to 2 hours and 24 minutes, this depending on how the women preferred to share their experiences and views. The total interview time is 10 hours and 40 minutes which altogether gave a result of 36 transcribed pages.
The interviews were transcribed as soon as possible after the interviews, in most cases the following day. Using one headphone each, the interviewer wrote down the translation while the translator interpreted. Giggling and feelings were included to fresh up the memory if time would pass before the material would be analyzed. An ongoing discussion took place during the transcription of interviews where the translator and the interviewer took pauses discussing quotes. While discussing; a more correct understanding of the interviews was enabled despite the cultural differences and backgrounds.

The method used during the analysing of the interviews was a concentration of the essential units of the data, (Kvale, 1997). The data was read through and some overall themes were found. After this specific themes were formulated from the overall themes chosen from the women’s sayings. This was followed by findings of concepts from the theoretical framework that could be helpful in increasing the understanding of the quotes included in the different themes.

**Ethical aspects**

In an interview study ethical aspects should be considered throughout the whole study; from the early planning stage, to the contact taking, the data collection, the processing of the data and later the publishing of the study. The purpose should be to generate new scientific knowledge but also that new knowledge creates among the participants themselves which also could be transferred to the group they are representing. (Kvale, 1997) The data in this thesis can, as the first study of this kind, highlight the knowledge and experiences concerning the sexuality of women living with physical disabilities in Tanzania. This which is a field surrounded with many taboos within a group that hasn’t been listened to as much as needed historically. By using a combined interview method of singles- and a group interview the possibility of sharing views with other women with similar experiences was managed and therefore it can be assumed that new knowledge was created and shared.

This study was planned with the guidance of the research principle and the individual protection principle; including the demand for information-, consent-, confidentiality- and information giving of where the data would be spread. (Vetenskapsrådet, 2010; Kvale, 1997). The demand for information concerning the study’s aim, voluntarily participation, consent, confidentiality and how the interviews would be used was presented in the information letter which the women were forwarded by the representative of SHIVYAWATA. Before the interviews started this information was also gone through to open up for questions and to make sure that there was a common understanding. All the women were comfortable with having their name in this thesis but they were informed that the interviewer most likely would unidentified the names, this with the purpose of offering anonymity, since the subject during the interviews can be very private (Kvale, 1997). In the end the interviewer explained how the interviews would be processed and the women got the information that they had the right to regret their participation before the time of publishing.

Before the interviews started the interviewer and the interpreter were making an introduction of themselves and welcomed any break or question during the interview. The interviewer also shared thoughts on disability in Sweden. This combined with refreshments helped the atmosphere to become more welcoming and relaxed. Since some days passed between the singles- and group interview, the women were also given the chance to come up with questions or to ask the interviewer to change something from the earlier interview, if they preferred. All together these measures were undertaken in order to increase the participation and comfort with the purpose of collecting true information during the interviews.
Validity

Kvale (1997) underlines that it is of great importance trying to answer the question “why” and “where” before the question “how” is answered in the early stage of a research. This is also closely connected to the questions of ethics and helps you motivate why this study is worth to be conducted. (a.a.). Since this study is taking place in a context that the interviewer is not totally familiar with, questions of another cultural context and “going native” has to be considered in order to prevent the researcher from analysing the interviews from her cultures point of view. A way of not going native is to work close with a translator who has got knowledge of the present cultural context (Rwebangira, & Liljeström, (1998). It can be easy to misunderstand the data and to analyze it with theories from an unproductive or even devastating direction. Since the interviewer has experiences of Tanzania from earlier travels, there is an understanding of the society but though not a fully understanding. Due to this the aim of working with an interpreter was not only for the purpose of managing the interview translation but also to increase the understanding of the interview quotes. To work close to the translator during the entire data collection and transcription of the data increases the validity since the researcher have been able to discuss and understand the interviews from the Tanzanian point of view, having the questions “why” and “where” in mind. The use of theory was in the meantime held in the background, with a researcher open for that quotes of any kind could come up. This can be seen as a flexibility to avoid the mistake of trying to fit one cultural context into theories created in another. This way of working close to the translator makes the validity in this study increase.

Since coming from abroad the respondents could have expectations of the researcher being an expert, not only a student. This could possibly make the women ether uncomfortable or also more willing to participate in this study, because of curiosity or a hope of creating new contacts. In one way or another these aspects can affect the results of the interviews. The representative that invited the women could also be said to be in a powerful position with the ability to affect the women to participate in the interviews, because they felt obligated to instead of participating by own free will. The relationship between the representative and the women interviewed on the other hand seemed like a relation built upon friendship and trust.

With the instruction in Kvale (1997) combined with inspiration from earlier, similar interviews the interview guide was created due to the aim of the research questions. Since the first interview was used as sort of a pilot interview the chances of asking relevant questions increased. All these measures can together increase the relevance of the questions asked during the interviews and therefore also the validity of this study in general.

Reliability

Since the interviewer is coming from abroad and not are fluently in Kiswahili or don’t know all the social codes there is a chance of misconceptions. While working together with a translator there can also be a language barrier, since English is neither the interviewers or the translators first language. But to prevent misconceptions’ there was a translation from English to Kiswahili made and also an ongoing discussion of different conceptions used. After the first interview, feedback on what could be done better during the coming interviews was discussed, in order to improve the communication.

During the interviews, the interpreter shared concluded remarks on what the respondent just have said. This gave both the interviewer and translator a chance to reflect. If there was not a fully understanding, the quote was followed up with a clarifying question.
Before transcribing there was a discussion on how the work could be done in the best way. The data was written down word by word during most of the interviews, from speech to written words there is though a chance of changing the essence (Kvale 1997), especially since the interviewer didn’t transcribe in her first language. Giggles, silence and clarifying notes were written down during the interviews, in order to increase the correct essence in the quotes and therefore strengthened the reliability in this study.

To generalize
This study has no aim of speaking for all women living with physical disabilities but instead to spread the unique voices of the women in this study. It is important to remember that the experiences shared from the women interviewed might not be recognised by all women, especially since all of the women participating in this study come from a group of women who are engaged in organizations working for rights of people living with disabilities. On the other hand it is also important to highlight that the women have shared experiences both from rural and urban areas for women both with larger and light disabilities, which can altogether give a realistic picture of disability and sexuality in general in Tanzania and other neighbouring countries on the African continent.

Result
This chapter starts with an introduction of the interview persons. This will be followed by the results of the data collection. In this section the data has been structured into different themes; Challenges – Society, Challenges – The Partners, Challenges – the family and relatives and The self picture.

Description of the women who shared their stories
What will follow is the knowledge of what seven women shared with the researcher and translator during six single interviews and one group interview. All the women have been living with physical disabilities since they were between 2-7 years old, many got a fever, polio, and this fever or the injection against polio itself caused body damage so as paralyzed body parts. The women all move by own force, some with crutches, some without, but with problems with feet and legs which makes it difficult for them to move in a smooth way. The women are between 27 and 56 years old and even if they stressed that their names would be shown I have decided to name them Ardhi, Jua, Maji, Mvua, Upepo, Moto and Radi. These are the Kiswahili names for earth, sun, water, rain, wind, fire and thunder. These elements all symbolize power which these women have a lot of. All women are members of CHAWATA, they are engaged in organizations working for rights of people living with disabilities. Their activities varies from being a business woman, to doing jobs like tailoring, sewing, cooking, to activism in organizations. Some have been begging on the street in the past, but these days most of them have sustainable and organized lives. Most of them are mothers, a majority single mothers. Some are married, some have boyfriends and some are singles. I want to highlight that during our conversation the women were speaking both from their own and others experiences on disability and sexuality.

Challenges - Society
All the women have experiences on how women living with physical disabilities face challenges connected to their sexuality. The challenges that will be described below are divided in themes of society level, family and relatives and the partner. The sections of
Challenges are also divided into several under sections describing the different challenges under each theme. Society affects individuals and vice versa, therefore it’s no clear lines between the different themes of challenges on society, partners, family/relationships level. Most of the women think that these challenges differ from person to person but emphasizes also that all women living with physical disabilities are facing more or less similar challenges.

Most of the women describes that the society wonders a lot when they decide to be in relationship or when they decide to deliver children. They highlight that people is wondering more when you are a woman living with a disability than when you are a man living with a disability.

*I don’t know if they (the society) are wondering with negative or positive attitudes, but they are wondering a lot!! People they are not surprised if men with disabilities get children, because the men usually have women that are physically fit. But when it comes to the women with disabilities and their children they wonder a lot, maybe because we are seen to be weak....?? (Moto)*

*Since we (women with disabilities) are born our families regret us, they don’t want us because of the disability. When we grow up, because of culture and tradition, people feel in their heart that women with disabilities cannot be married.* (Moto)

The women describe how they face negative attitudes from the surrounding society when they start a relationship. People are wondering why their man with or without disability didn’t chose another woman without disabilities instead. Some people explain the man’s choice in a way saying that the man must have been bewitched from the woman living with disabilities.

*In the beginning of our relationship he faced challenges because of me, his friends were joking with him saying “didn’t you see other women on the street, why do you choose her with a disability, you must be crazy”. Others were joking with him because of the way I walk; they imitate how I walk...//...They said that I had bewitches him, hihihi. They said that I had gone to the witches to do something to make him love me.* (Moto)

Several of the women give their stories about the negative attitudes they face when they meet the employees at the hospitals. This makes women afraid of going to hospitals and it also creates a great health danger to them while delivering babies.

*We face a lot of stigma at the hospitals, the nurses can shout, “even you!!!”* (Moto)

*I got a lot of challenges at the hospital when delivering my babies; the nurses harass people with disabilities. The beds are not available for us (women with disabilities) and they (the nurses) can leave you on the floor, you can bleed a lot risking both your own life and the baby’s life. This is a common problem to many disabled...//...many people with disabilities they live far away from health services and when they get to the hospitals the nurses are not helpful, they segregate you, due to this problem many women with disabilities dies.* (Radi)

Many persons with disabilities are isolated in their house and don’t get information easily, therefore there is a big lack of education concerning Hiv/Aids and other sexually transmitted diseases among persons living with disabilities. People living with disabilities are also neglected when coming to the hospital for voluntarily counselling to take tests.
Many organizations they have meetings concerning Hiv/Aids, but they don’t call persons living with disabilities to participate. That’s why many women living with disabilities get Hiv and also they are afraid when they go to the hospitals and when they get pregnant..they keep quiet because there is no constitution that will protect them..(Moto)

Challenges - The partners

Here the women’s stories of the challenges they face from short- and long term partners will be described. When asking for partners and relationships all the women described heterosexual relationships. The relationships referred to below are therefore heterosexual love relationship with men. Before this section starts it should be highlighted that some of the women also have experiences of long lasting relationship, these relationship will not be focused on here. The women underlines that the soul of the partner, if he respects you or not, will decide how the relationship will be like.

Many women explain that the men want the relationship to be in secret and in public they don’t show that they are together, refusing to hold hands, going far behind or ahead of the women, this because they are afraid of the reactions from the society.

... It can happen that someone loves you and has a relationship with you but he wants the relationship to be in secret. The man doesn’t want the society to recognize that he has a relationship with a woman with disabilities...if the society will get to know then he will feel shy. (Jua)

Because of my disability, sometimes the men don’t want to walk close to me while we are on the street. When walking outside together the men don’t walk parallel with me, they will ether tell me to go before or to stay in the back. (Ardhi)

Most of the women they have experiences of men coming to them just with the purpose of “seeing how they are”. This they explain, is due to the men’s curiosity to know how a woman with disabilities work sexually and how her body is created. This leads to the consequence that many women are approached only for the purpose of sex and their relationships last only for a short period of time. The women don’t know if they get true love, but since they need love as everyone else they might start a relationship. Then if she becomes pregnant the man usually leaves and this makes many women living with disabilities become single mothers.

When you are a woman with a disability some men approach you just for sex. Men approach us not for the purpose of getting married because after that they have got sex then they run away/disappear...//...Because they want to know if we are the same as other women. (Jua)

Their experience is also that these challenges increase with the size of the disability, the larger disability the more challenges. The challenges are also described to be more obvious in the rural areas where the services and information connected to sexuality are less and the level of education among the people are low.

I met a woman in the rural areas, she was crawling, and I asked her about love relationship. She had children but no man. This man goes to her at night, he has sex with her and then he goes away, he waits for some years until the baby is born and then he comes again. She gets pregnant and then he runs away. That man has four children with her!! She couldn’t tell me
the name of the man because she was afraid and she said “if I tell you then he might kill me”...//...this is all happening because of shame. (Moto)

Several of the women also have stories of how women living with disabilities get approached because the men are looking for money, not for real love.

Women with disabilities sometimes get a lot of support from the government and he thought that he could get a better life through my disability. (Maji)

...first the man will approach me as if I am a source of money...//...men knows that women with disabilities get help from white people/from countries outside,. They believe that women with disabilities can travel to different countries, Sweden, Germany,... they also think that the rich people here in Tanzania usually give the disabled something..so these men they just approach you because they think that they can get something. (Upepo)

Also, the women living with disabilities highlight that they are seen as more “sweet” and special when it comes to sexual intercourse, because of their disability.

Some other men they come to us and they say that women with disabilities are very delicious and sweet because they don’t have sex with many different men. If they want the delicious part of us, but don’t think we will agree, then they can go to a witch doctor so that they can get the women easter. Sometimes you can agree because you want to have sex because you feel for it, I mean the man doesn’t get sex because he went to the witch doctors (as the man himself sometimes thinks).. (Upepo)

Superstitious misconceptions are also described. Some men think that to have sex with a women living with disabilities can bring you luck and fortune, therefore you can get economically wealthy as a man.

Some men believe that women with disabilities have blaze/wealth from GOD. They go to witch doctors so that these doctors can help them to get higher positions through women with disabilities, to succeed in the business,. The rich men afford to buy women with disabilities..Me myself as a woman with disabilities thinks that this is just foolishness and wealth has nothing to do with the disability itself this is more about a disability of the mind (on these men). (Upepo)

The women describe how men approach them just for the purpose of curiosity and after having sex they disappear. This makes it hard for the women to trust their partners and to know what goal the men have with the relationship.

Many women with disabilities they get worried when men approach them. Why should men approach me, I don’t have a normal body, why doesn’t he follow other women who are more beautiful instead. When I met with my boyfriend and he said “I love you” I was afraid. But he said “I don’t look for your disability you are a woman like all others”. (Moto)

Many women with disabilities are shy and they cannot express their feelings when they meet men. They have created something negative inside, so during sex it gets hard to feel good. (Radi)
A few of the women describe that sometimes the man doesn’t adjust to her needs, that he needs to have a certain amount of sex and that his desires comes first.

I always tell him that he should ask me for advice for how he should have sex with me/please me. Sometimes he wants sex everyday while I’m not able.../... I got the advice that I should try to give my husband the sex in order to keep the relationship safe.../...It was a time when I thought that my husband wanted to have sex with me every day because of my disability, but it wasn’t like that. I asked him and he said “I don’t have other women, I only have you and then I should get sex every time I need”. (Moto)

Some of the women highlight that the men usually decide when and where to have sex and they also control the condom use, whether to use a condom or not.

People with disabilities can get a relationship easily but it’s also easy to get Hiv, the men can attack you any time and do what they want to women with disabilities. Its easier for a man to get sex, the men decides when to have sex and with condom or not..(Radi)

There are also some local beliefs that cause a big health risk for women living in a disabling society. Some people think that they can get cured from Hiv/Aids if they have sexual intercourse with a woman living with disabilities.

When you have sex with a woman with disability they think that you can cure aids, this is a local belief. (Moto)

The men think that women living with disabilities are “safe”. Many of the women give examples of how the men talks in terms of that “it is safe” to have sex with a woman with disabilities since she doesn’t carry any disease.

Another challenge is that some men say that “it’s a bit safe to be with a woman with disabilities because most of the men don’t approach them”. If a man comes to you and say that he will be safe with you, don’t trust this because he is coming with other things, he is coming with virus. (Moto)

The women think that it is common that women living in a disabling world get raped by men. Also there are several cases in Tanzania where fathers decide to have sex with their own daughter if they (the daughters) can’t get anyone else to have a sexual relationship with, which can be a common problem if the daughter is disabled and regretted from the society. The women explain that some people believe that you can get hysterical (a hysteria) if you cannot be able to find a sex partner and the fathers are then doing their daughters “a favour”.

Men can knock your door and then you open and then he can try to rape you and you are not able to run away... (Maji)

Its very common that women with disabilities get raped, for instance here in Dar es salaam where many people are living on the streets.../...when people come and rape you they are often on alcohol or drugs. The crisis of people living with disabilities are not outspoken in the society. Even the police used to rape those women with disabilities. We are tired of being angry instead we are fighting for our rights.../...we don’t want women with disabilities to be raped in the future. (Radi)
Challenges - The men’s family and relatives

Friends of the women often think it’s a good idea to start a love relationship and often encourage this, but when it comes to the families of the men, several problems occurs. This due to that the families have an interest of that the household is run in a proper way.

He said that in his family they can’t get married to persons with disabilities...//... his family will not agree for him to get married to a woman with disabilities...//...it’s a taboo to get married to and to have children with people with disabilities. Once he said to me (concerning their common child) “the child is yours not mine”, and it’s true its mine because he has never brought the child a single thing.. (Mvua)

It’s very easy for men with disabilities to get married, they marry beautiful women...//...but for the women with disabilities, if you get married then you are a lucky person!...//...It’s easier for the disabled women with good jobs to get a husband. (Mvua)

The women also describe that it’s a big difference for men and women when they want to get married, this because of the different responsibilities they have in the household. The men’s family is afraid of the burden of disability and the responsibilities. So when the woman gets pregnant then the man runs away, because if they should start a family together then she will be a burden to him and his family since it’s expected that she cannot work like any other women; not being able to take care of the household, carry water, clean, cook. For a disabled man its different, he doesn’t stay home and he can more easily get money without hard body work.

He thought I would be a burden to him and that he would get a lot of work because of that I cannot do hard work...//...its easier for the men living with disabilities to get women than for the woman with disabilities to get men. The relatives of the man will say that this woman will not be able to fetch water and this woman will not be able to work fast like other women. Also there is some other reasons behind, its easier because the men is suppose to look for the money to the household, so its up to him if he wants to marry a disabled or not. The woman has to take care of the household. It’s the tradition that men takes care of the money while women takes care of the family. (Maji)

The men are afraid of that the disability will cost a lot of money. A big challenge is whether the men’s family and relatives will accept that the man marries you as a woman living with disabilities.

It’s like this, in our society it is like any person with a disability is a burden. There are a lot of people with disabilities but if a woman gets a disability then she will have double up with problems at the same time...//...when you get married into a family, the family will get problems because of you. Even the neighbours can for example talk like; all these women in the world and you choose this woman with disabilities. Then the men start to feel shy because they get to hear a lot of discouraging words. As a woman living with disabilities its my decision to work or not to work, I can act like a woman with disabilities and choose to employ a house girl or I can work even better than a woman without disabilities...(Upepo)

Several of the women explain that the society thinks that disability is inherited, no matter if the woman herself is born with the disability or if she for example got polio when she was a couple of years older. The men don’t face the same attitudes concerning this.
My marriage got stuck because the relatives of the man started to talk a lot of discouraging words...they said “a woman with disabilities is a curse”. ...they think that disabilities can be inherited and that the whole clan can get elements of disability (when the man didn’t propose to her she asked) “Why don’t you want to get married to me, in your family don’t you have people with living with disabilities?” And then he said that “at our place when a woman gives birth to a child with disabilities we throw them in the river”...//...then I told him “god made me come to this world and if you segregate me then you are also segregating your God”...//...and then he got more sympathy for me. In the end that man ran away from me because of my disability and I thank God that my parents were already dead because of all the shame this situation brought me. (Maji)

The self picture
All the women sharing their stories during the interviews describe experiences connected to sexuality in a way that points out that they have the same needs as anyone else when it comes to sexuality. They have the need of love and intimacy and engage in sexual intercourse, they become pregnant and deliver babies.

No there is no difference (concerning love relationship and sexuality) because even “normal” people can be loved or have problems in their relationship, we are all the same no differences. (Ardhi)

When we were having sex we adjusted to my needs (because of the impairment), if it hurt then I told him to do it in a different way... (Maji)

After I got to know that I was pregnant I was aware of that I had to get money to support myself...//...I had to plan how I would take care of the baby, I was sure that my family couldn’t support me much, so I made my own plan on how I would be able to empower myself to support my baby. (Maji)

At the same time as the women describe that they are independent women with the same needs as any one else they give examples of how they sometimes face more challenges than persons that doesn’t live with disabilities. Even if they view themselves as capable and strong they still have to prove, verbally and physically, to others that they are. Several women describes that when getting a partner and becoming pregnant the surrounding society including relatives get surprised and have negative attitudes.

The relatives thought that I would not be able to deliver, but when they saw that I was delivering my children in a safe way they were later happy...//...the society has negative attitudes but they change after a while, even Rome was not built in one day... (Radi)

The society look upon women with disabilities as if they cannot deliver babies and also that they cannot stay with a husband...//...I disagree with this since I’m a woman with disabilities that has children...//...Women with disabilities can sometimes deliver very safe even without an operation...//... and they deliver beautiful and healthy babies. The society has negative attitudes towards people with disabilities and they think that they have the correct attitudes, like as if they think they are like God. (Mvua)
One woman also experienced how her own mother didn’t expect her to live an independent life and she had to explain to her mother that she had needs of love and wanted a self-sufficient life together with a partner.

*My mum said “why do you need that man, you are disabled...//...you are my child you should be with me forever and ever. I think you can’t go anywhere”. I said “no mum, I’m a human being, I feel, I need a man, I need an own house, I need my own life”...//...Yes that’s my mum...hihihi.. (Moto)*

The women are all hoping for radical changes in the future. First of all they highlight education as a great tool; the women are talking about education as an essential way of increasing the society’s awareness concerning sexuality and disability. They are also describing the importance of employment, good infrastructure, accessible houses without stairs and better hospitals and services in order to improve their life in general. They emphasizes that the government has to be pushed through advocacy. Most of all they emphasise the importance of that women living with disabilities should come together in groups, this in order to support each other to get awareness of their own sexual rights.

*We need a lot of education so people can understand that we are human beings. (when talking about relationships challenges) (Maji)*

*You know, I want to be a good role model for the women living with disabilities and to get more support to help the people to be aware of their rights and how to live in this environment. Many people living with disabilities especially women they don’t accept to live with their condition/disability. After that they have accepted themselves, and when working together in groups, they will be aware of their disability and then they can work according to their goals and human rights (Moto)*

**Analysis**

**Challenges – Society**

The women’s stories highlight that the society historically has been having negative attitudes towards people living with disabilities in general. Since the sexuality is a central part of the identity of most human beings it is also a big oppression to a person when the sexuality can not be expressed in a preferred way. The women all give examples of that they face negative attitudes when they decide to be in a relationship so as when they take the decision to become mothers raising children. In the society there is circulating attitudes saying that disability is a curse. This creates a shame which sometimes makes the men who start relationship with women living with disabilities, to have the relation in secret. The society has difficulties to understand how a person without disabilities can choose to be together with a person living with disabilities. Some parts of the population in Tanzania have beliefs in witch craft and use these beliefs as a way of explaining these men’s choices, emphasizing that the man didn’t engage in the relation (with the disabled woman) by his own free will, he was bewitched. The norm breaking confuses and the ones breaking the norms can be punished in one way or another, by exclusion or negative attitudes. The fear of getting close to a person with disabilities can also be seen as a way of escaping the thought of that you yourself could be in the same situation as the person living with disabilities. When getting close to a person living with a disability the reality of an impairment comes closer to you and you have to face both the disabled persons stigma and also your own fear of becoming disabled (Mc Ruer, 2006)
The negative attitudes from the surrounding society stigmatizes the women living with disabilities and can be understood from the norms of flexible- and able bodies. These able bodies are, compared to the impaired bodies, seen as more able, beautiful, clean and therefore also as superior to the impaired bodies. This norm of the able bodies underlines that the bodies that doesn’t look “normal”, they should be rehabilitated in order to look alike with the able bodies. This can be seen as an ongoing body fascism that takes place in the society (McRuer, 2006)

The government of Tanzania has signed various documents and conventions emphasising the importance of every human beings equal value trying to create a gender balance in the society, decreasing the stigma and exclusion of marginalized groups. Despite this the women living with disabilities are still facing stigma from not only individuals in the society but also from the different welfare system, for example the health care. This is a sign of that these women get excluded from the mainstream society and don’t get the services they need connected to sexuality (Oliver, 2009). Earlier research also shows that prejudices and attitudes towards women living with physical disabilities assuming that they are not sexual active have neglected their sexual well being (Basson, 1998). All these negative attitudes can be seen as derived from the norm of the able body. If the body is impaired it is seen as something wrong within the person, which can be seen as a medical model way of thinking. The Medical model views the disability as a tragedy within the individuals themselves (Oliver, 2009). The more different the body is due to the norm the less attractive and sexual it is also seen to be (McRuer, 2006). The conventions signed shows that the government of Tanzania is working towards a more equal society but meanwhile the culture of the society is not yet there, instead of lifting the disability to a society level most people view disability as an individual defeat. Are the international conventions adjusted to a society where the individual rights come first and therefore they don’t apply to a context where the collective is in focus?

Challenges - The men and their families
Men’s power over women
All the women have stories of challenges connected with men. The men are approaching the women not with the purpose of real love; they are coming for several other reasons. In short the men are coming for the purpose of getting sex or money and then they usually leave, often after making the women pregnant. It is described that the men often approach the women because they think that they are virgins, not sexually active, which makes it more exciting to be with these women. Also, women living with disabilities can be more easy to abuse because of the impairment that makes them unable to run away. This shows that the men have the control of the sexual intercourse, the women also underlined that often the man also decides whether a condom will be used or not. One woman describes that the stigma is worse for women than for men living with physical disabilities when it comes to getting children, she wonders; is this because we women are weak? The stories of the women shows that the sexual need of the men comes first, which can be understood from a gender perspective where the men are superior both because of their male sex and because of their able bodies (McRuer, 2006). Earlier research highlights that a feministic perspective has been integrated in the more recent disability research, which highlights the men’s structural power over women at several levels (Helmius, 2000). In Tanzania the men’s right to the women can also be explained with the marital system, where the man pays the bride fee for the woman when getting married. With this his power over her manifests both physically and psychologically (the money).
The women also have stories of women living with disabilities being raped. This can be understood as an extreme way of oppressing the women. Here the man only cares for his own needs, seeing the woman as an object which maybe due to her physical impairments can be an easy person to rape. The rapes towards women living with disabilities have not been highlighted. Shakespeare (2006) highlights that talking about sexuality and disability have historically been neglected. This because it has been hard to discuss something that so many have been excluded from and would also make each and everyone to be confronted with the reality of the abused- and sometimes isolated lives many persons living with disabilities live. With this said a question about if the abuse of the women living with disabilities has been legitimized by the silence of the society should be asked. The earlier research also show, that there is attitudes saying that people living with disabilities should be thankful for what they can get. This attitude can be a way of letting the abuse and rape keep on happening. Earlier research shows that some rapists thinks that they are doing women living with physical disabilities a favour by “giving” them sex, instead of admitting the actual situation of rape.

Some of the women describe how they are not always able to have sexual intercourse as much as the man desires or in the way the man wants it. This can be understood by the norm of sex as penetration, with an active man and a passive woman. This norm can be disabling for a woman living with physical disabilities if the penetrative sex is not the most comfortable way of having sex due to her impairment. Instead of the norm of penetrative sex new ways of having sexual intercourse could possibly be created from a perspective of people living with different disabilities. (Siebers, 2008)

The traditional roles in household disables
Earlier research shows that the traditional roles in the household in low income countries is hindering especially for women since their physical impairments can be in the way. If you are not able to fulfil the different task you as a woman are expected to do then you can be rejected by the men. (Kiani, 2009) All the women have been highlighting that the men and their families don’t expect them to be able to take care of the household. The men’s family marries the woman into their family, by payment, which makes the whole family and relatives not wanting their son to get married to a woman living with disabilities. This gives the women living with disabilities a double burden; first because they are women living in an unequal gender balance second they are living with disabilities in a society that expects them to be able to manage the traditional works.

An interesting aspect which the women highlight is though, that in Tanzania most families have a house girl that can take care of the traditional works, which could make it easier for the women living with physical disabilities. The women explain how the men regret them anyways which can be explained with the stigma connected to the disability itself. The stigma of not having an able body which also makes you less attractive and in the end you could be seen as less human. Siebers (2008) describes that depending on how the body is created the qualities of you as a human being will be defined.

Stigma because of connection with reproduction
The women living with disabilities are also facing challenges since they as women are connected with reproduction. The men’s sexuality is not that connected with reproduction as the women’s sexuality is, since she is seen as “mother earth” giving birth to children. Some families fear that the children will inherit a disability from the mother living with disabilities, both if the woman is born with- or got the impairment later. This shows that there is a big need of educating people concerning disability, anatomy and heredity.
Siebers (2008) discuss how people living with disabilities are not expected to be able to give birth to “quality offspring’s”, since reproduction is a matter of forwarding qualities and abilities to the next generation. There are certain qualities that you should have to be able to produce children, for example you should attract a partner, you should have an able body, be able to have sexual intercourse and to be fertile. As a person living with disabilities you are seen as an outsider and are not expected to have these qualities. To not be able to have sexual intercourse and children can be seen as a failure as a human being, since you are not being able to contribute to the future generation. To be able to reproduce can give the human beings status he describes. “Sex is the action by which most people believe that ability is reproduced, by which humanity supposedly asserts its future, and ability remains the category by which sexual reproduction as such is evaluated. As a result, sex and human ability are both ideologically and inextricably linked (Siebers, 2008, s.139f).”

The self picture
The clash between the Social- and the Medical model
The interviews shows that the women view themselves as capable, strong and their goal is to empower themselves to have good lives with love relationship and children. They view themselves as “any other person” while the attitudes from the surrounding society sees them as special. The attitude from the surrounding society, individuals to structural level, is what first of all disables the women, since they have to prove that they are able, able to live independent life like any one else. The society sees the imperfections within the women instead of the women’s resources. This can be understood as a clash between the Individual- and the Social model. The women point out that they want to see changes in the society. This correspondence with the Social model way of thinking, where the environment and the attitudes are the disabling factors which should be adjusted to the persons living with disabilities, not the opposite. (Oliver, 2009) At the same time as some of the women want the attitudes and environments to change they are talking about that they are like any other person, which can be seen as they are striving to be a part of the norm, the norm of body-abled (Mc Ruer, 2006). Some of the women want to be part of the present norm, maybe by rehabilitation they could, some women are instead emphasizing that the norm must be opened up, in order to include all types of bodies, impaired or not these should be seen as equal. The women have more or less a thinking which corresponds with the core in the Social model where the aim is a change in the society towards an accessible society, seeing themselves as subjects (Oliver, 2009). This clash with the majorities views, where disability is seen from the perspective of the Individual/medical model. In the Individual model the disability is seen to be an illness within the person, an illness that makes the person unable. This medical model way of thinking from the surrounding society can be seen in earlier research, Basson (1998) where women living with disabilities are seen as different when it comes to sexuality.

Future expectations connected to sexuality
The women emphasize the need of education concerning disability at all levels in society, in order for the society to understand that the women are equal human beings. The women highlight the importance of that women living with disabilities have to come together in order to raise their own voices. This can be understood as if the women have experiences of that the services and education from the government and the leaders are not enough to meet their needs fully. Instead they know that they have to empower themselves. Shakespeare (2006) describes that all persons need education, both concerning to live with disabilities in general and about different specific disabilities. Without education exclusion and fear can create great social barriers instead of interaction between people. Also people with the experiences of the
knowledge of living with a disability have to share with others, all need to educate themselves and each other in order to be able to communicate on an equal basis. Another way of understanding these demands for change in the whole society would be to increase the understanding of disability from the Social model point of view, which put the overall responsible of disability on the society. This with the purpose of creating an awareness of how the society disables persons who doesn’t have a look like the norm/ are behaving like the norm. (Oliver, 2009). It is also important to emphasise every person unique experiences of disability and that his or her goals should be self defined. People should speak for themselves instead of as it has been historically, that majority speaks for minority (Oliver, 2009). That the society should meet the needs of people living with disabilities correspondence well with the ideas of the Social model (Oliver, 2009.) Earlier research highlight the need of including people living with different disabilities when it comes to education concerning Hiv and sexual violence. Though there is still a lack of working with the stigma towards people living with disabilities. The women in this study offer the society to be educated by them. This is a sign of very strong women facing many challenges, willing to educate people in order to make them stop giving the women themselves discriminating challenges.

**Concluding analysis**

This thesis shows that the women interviewed are facing several challenges and norms. The narrow norm of the able body and the norms connected to the female sex disables at all levels; from society- to individual level. The challenges can through the theoretical framework be understood to come through the disability itself, because of the fact that women are seen as disabled individuals instead of individuals living in a disabling society. The women don’t only face negative attitudes due to the impairment itself, also due to their female sex since it is linked with several other circumstances connected to sexuality. There is now a need for the multiple burdens within the oppression of the female sex to be highlighted. First because of that the gender balance subordinates women and they are seen as the weaker sex, with less power in private and public spheres. As women they are also connected with reproduction and since women living with disabilities are not expected to give birth to healthy children they face stigma. Also the burden of the work in the household makes men and their families think that a woman living with disabilities cannot be able to take care of these tasks. Several misconceptions, superstitious or not, also challenge the women. Despite all these challenges the women view themselves as strong and capable with control of their love lives. This they have to prove to the society and individuals all the time. For the future they want changes that can be said to be a shift from the Medical model way of thinking towards the Social model way of thinking.

**Ending discussion**

What now will follow is a summary of the findings of this study, presented in order to answer the four different research questions that were introductory formulated. Also a discussion of the method so as questions for the future will be accounted.

**Like any other but with more challenges and the need to prove ability**

One of the purposes with this study was to investigate how women living with physical disabilities view their sexuality. The results show that the women interviewed in this study view themselves as capable and strong women with the ability to have sexual intercourse, to
get both short term and long term love relationship, to become pregnant and deliver healthy children. They view themselves as “anyone else” but they are also aware of that they have to prove to all the levels of the society that they are capable sexual beings. From the theoretical framework this can be seen as if the women view themselves from the perspective of the Social model where the society is responsible for meeting their needs instead of them trying to fit in to the society. Even the abuses that the women face, that they get approached only for the purpose of sex or money, can the women turn into something positive, emphasizing that they chose to agree to the sex. This can be seen as a way of making oneself to an active subject while the men come with the purpose of treating the women as objects. This can be understood as a way of turning a situation of for granted taking or abuse to something wanted and due to the own sexual desires, which also can be seen in the earlier research discussed by Zavirsek (2002).

First of all the earlier research has its focus of other peoples view on persons living with disabilities (Oliver, 2009). Secondly historically there has been little focus of the sexual well being of women living with disabilities, mostly the research has been focusing on abuse and diseases (Basson, 1998). Though there is earlier research showing that women living with physical disabilities view themselves as strong and capable when it comes to sexuality Helmius, 2000). With this said there is a need to investigate the sexuality from a broad perspective from the women’s own point of view in order to stop the victimization of women living with disabilities.

**Multiple challenges and stigma**

Another aim with this study was to see if the women are facing any challenges and norms connected to their sexuality. The result shows that the women are all giving examples of several different challenges and norms which they themselves or other women living with disabilities face. The challenges are on all levels; partner, family, relatives and surrounding society including health care services. The men approach them not for the purpose of finding the true love or getting married. Instead they come for the purpose of getting money, they come because they are curious and for the purpose of getting sex, which can be seen as ways for the men to use their power as the male sex. This can also be recognized in the earlier research. Often they make the women pregnant and then they run away since the pressure from society says that “why do you chose a women living with disabilities when you can choose someone normal”, attitudes which is also connected to the different responsibilities the woman has in the household. Also women living with disabilities face challenges connected to reproduction since some people think that disability can be inherited. Among the challenges highlighted in this study is also the different superstitious believes which creates challenges for the women living with disabilities. The idea saying that if you have sex with a woman living with disabilities you can become rich can be seen as a finding that should be further researched. This can be interpreted as a sign of poor knowledge or/and as the witch doctors devastating way of making money on prejudices saying that women living with disabilities are getting rich from national- and international support. The society’s negative attitudes influence all levels and individuals in society and can be explained by the theoretical framework showing that the norm of the able body is very strong. The less able the body is the less you will be seen as a human being with sexual needs, which creates stigma. This stigma is devastating and it’s causing the death of persons living with disabilities. This since some new born babies get killed due only to their disability and since persons living with disabilities don’t get the health care they need when it comes to delivering babies or
concerning Hiv/Aids. To speak clearly; the disabling norms of the able bodies has historically and is still today, right now, causing an ongoing genocide of people living with disabilities.

**Sexual beings, yes and no**

Also this study wanted to investigate if the surrounding society, from individuals to structural level treats the women living with disabilities as sexual beings. The results from this study show that the women are both seen as asexual and sexual beings. Due to the challenges the women are facing there is shown that people have attitudes saying that they can’t have partners, get married or have children. Also they are excluded from health information and get stigmatized at hospitals. All these challenges show that the main problem is that they are not seen as sexual beings, the disabled body puts them in a position far from the societal norms and they are therefore seen as less human. These results correspond with the findings in earlier research (Helmius, 2000; Basson, 1998). At the other hand the women are seen as sexual beings since they get approached from men who want to have long and short sexual relationships with them. This can though be seen as if the women get objectified and are not really seen as sexual active beings, just as an easy way of pleasing needs. This objectification can be seen in the earlier research, when it highlights that people living with disabilities are expected to be thankful for any kind of relationship they can get. Also the high rates of sexual abuse so as rape, show that women living in a disabling society are often being taken for granted.

**We have to make a change together– a need for the Social model**

Finally the study also wanted to highlight the women’s future expectations connected to sexuality. The different challenges the women face make them not only to be excluded from the society, facing negative attitudes. It also creates a great health danger for them to be approached from men with more power believing in different misconceptions. They are also left as single mothers raising their children by themselves, which creates a vicious circle of struggling with the economy and often they are not able to support both themselves and their children. The women emphasizes the need for education at all levels of the society, this to get an understanding of disability corresponding with the Social model way of thinking. People also need to come together to raise their voices, for example there is a great need of creating laws protecting the sexuality of women living with disabilities. This highlights that there is a need for the thinking of the Social model to be spread in Tanzania. The women also emphasize the need of women to accept themselves in order to work towards their own human rights. This can be seen as an awareness of that many women living with disabilities have adopted the society’s stigma towards themselves; in the extension not accepting their own bodies. The women though know that you should be able to love yourself in order to have the strength to fight for your rights, since no one else will fight for them. This highlights the ongoing struggle for women living with disabilities and it also shows that the women feel that they themselves must be the leaders of the change. They can’t rely on the leaders or the government. Historically there have been to many promises made that haven’t been fulfilled and the women living with physical disabilities are used to be treated as a minority group, not being given priority in the society, at any level.

**Method discussion**

The purpose of this study was to investigate sexuality from the view of women living with physical disabilities, a field where there has been a lack of research in Tanzania. The strength
of the qualitative method used has been the possibility to meet with the women sharing their personal thoughts (Kvale, 1997). Before conducting the interviews the researcher was prepared to not be able to get a big interview material, this due to the expected taboos surrounding sexuality. This fear was not confirmed and the chosen method worked well. The women both described experiences from themselves and from their friends. To describe other persons experiences can though be seen as a way of not sharing your most private thoughts, which could be, but doesn’t have to be, a sign of that the method used was making the women feel uncomfortable. Another option of tools used for collecting data could have been to use a narrative approach in order to let the women lead the interviews more by themselves; this with the purpose of not interfering with stories the women don’t prefer to share. To observe interaction in love relationship could also have been a method, but since much of the challenges connected to sexuality are intimate and private this method would have been filled with obstacles. Another challenge with using this method can be that the women cannot be guaranteed full anonymity, both towards each other due to the group discussion and to others within the organizations. Overall the method used has though been a great tool and it’s important to raise the voices of minority groups so as women living with disabilities in patriarchal societies. This study is the first one highlighting the combination of women living with disabilities and sexuality in Tanzania. The women shared many stories and unique thoughts which is a sign of them being comfortable. If the method used is comfortable then the chance of getting realistic quotes increases which in the end will increase the validity of the research (Kvale, 1997).

Findings and concluding remarks

We are all creating our society together, every day, in our different interactions and choices. The men in the women’s stories can be seen as carriers of the stigma, but they can also be seen as forced to this behaviour from families who want to have able bodied women in their families. These men and their families can be seen as carriers of the disabling norms of the able bodies, which is an ongoing oppression. The men have to take their responsibilities not treating the women as objects but instead as the unique women they are. The men’s families influence on the women that should be the wife of their sons can be reduced by questioning the aim and importance of the bride price. With education and an increased understanding and respect for disabilities people can get the choice to slowly start to change these norms. The whole society has to think twice about the disabling norms of the able bodies and the gender norms in order to create a world with much wider norms than the ones existing today. The women have to be liberated from all the challenges which they themselves do not own. New findings that haven’t been seen in the earlier literature have been the superstitious misconceptions concerning women living with disabilities and the belief of men getting wealthy when having sexual intercourse with them. The misconceptions according to local beliefs and the witch doctors role in spreading prejudices must also be discussed and eliminated. Another finding in this thesis is that these women, despite the multiple challenges they face, have a great confidence and they view themselves as strong individuals with the right to be unique. They demand a radical change in the society. They ask for a change, which can be put into action by wider norms of bodies instead of narrow disabling ones. Due to this there is a need for the Social model to be highlighted and spread in Tanzania, for education to reach everyone and for the impairment not to be seen as tragedy and instead be put on a society level. Instead of women living with disabilities we would then talk about women living in a disabling society.
For the future
To work with highlighting disabling norms of perfect bodies and sex is one important way towards a positive change in the society, a society accessible for all individuals. For the future research it would be interesting to search for similarities and differences on sexuality from the point of view of other sexes living with disabilities.

It would also be interesting to ask persons living without disabilities about how they view the sexuality of persons living with disabilities, to see if this correspondence with the views from “inside” (in this study).

Can the self confidence of persons living in a disabling society, saying you are unique, be the most important tool in order to strive towards accessible societies that carry a great respect for all types of human beings?

In the future we might see a society that meets its inhabitants with positive attitudes and accessible environments, no matter how their bodies are created, what sex they are or where in the world they live. We are not yet there but already now we can strive towards a Sex(ual-acc)essible world!

“The society needs education, they need to learn that women living with disabilities are like others, we have the same needs as other women.../...we have to educate the society (we living with disabilities) no one else will educate them.../...What we really want is that women with disabilities should have solidarity with each other, to work together in groups in organizations and to speak up together. We must empower the women living in the villages. Women living with disabilities need to be able to make their own laws and principles.../...we need to talk with different leaders and Kikwete (the present president of Tanzania) and they need to listen to us.” (Moto)
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**Personal communication**

Njogopa Oliver, Social welfare officer at the ministry of health and social welfare. (Informant interview 100504)

Seya Neema, Tanzanian coordinator of SHIA. (Informant interview 100413)
Appendix 1

Hello, my name is Johanna Andersson and I’m a student from the institution of Social work at Stockholm’s university, Sweden. This semester I’m writing my undergraduate thesis and since I have lived and worked in Tanzania before I took the opportunity to do a so called minor field study here in Tanzania. I will be here in April and May and my aim is to collect information and make interviews on the subject sexuality.

Since there is much to say concerning sexuality but also many taboos I find it interesting to talk about questions connected to sexuality. Sexual rights; to choose your sexual identity, if you want to have a partner, if you want to have children, if you want to be sexual active, are a part of every person’s human rights. Sexuality is complex and therefore important to highlight all over the world.

SHIA, Sweden connected me with Neema and CHAWATA and I am now here to learn from you and my aim is to share your thoughts concerning sexuality and relationship. I want to highlight the challenges and norms you face and the expectations you have for the future connected to sexuality and relationship. I also want to get your view on how the society is meeting you concerning sexuality and relationship.

I turn to you since your thoughts will be the data in this study. Together with Secilia, who is an English/Kiswahili translator I would like to do single interviews so as one group interview during week 15 and 16 at the CHAWATA office. The interview time can vary from 20min-1 hour. I will record the interviews with a tape and afterwards transcribe your sayings.

It’s your own choice to decide if you would like to participate in this study and if you decide to participate you can pause during the interview anytime to regret your participation. You have the right to be anonymous and the interviews will only be used for the purpose of this study. When the paper is done the interviews will be erased.

When this study is ready the paper will be published at the databases at Stockholm University and persons/ organizations that are interested and can gain from reading this paper are welcome to get a copy.

I am happy for my chance to meet with you and I am looking forward to be able to share your thought on questions connected to sexuality and relationship. If you have any type of questions for example concerning me or Sweden don’t hesitate to ask!

Best regards Johanna Andersson

Letter of confirmation
I have got the information above and I agree to participate in this study:

Name
City
Signature
Date
Appendix 2
Interviewing the coordinator of SHIA

- Can you give me a picture of the lives of people living with disabilities in Tanzania? Historically and today?

- How do physical disabled persons organize themselves? SHIA´s work?

- Are people given different opportunities depending on their type of impairment? Rural/Urban life? Male/female?

*International human rights conventions highlight the sexual rights of all persons, no matter race, gender, bodily ability.*

- How does Tanzania work with these rights?
- In theory and practice?

- The responsibilities/activities in government/social work/organizations/disability movements concerning these questions?
- How does the organization around “disability” look like? National/international aids? Cooperation?

- Thoughts and challenges for the future?
Appendix 3
Interviewing women living in a disabling society - single and group interview
-I will introduce myself (if I haven’t been able to do it earlier) and describe what the interview is going to be like, including time, confidentiality and the aim of making this paper. In forehand I also would like to know if she is born with the disability or not and also to get a clue of how she view her disability (and sexuality).

Your “eyes” on you
Background; name, age, living, expectations on the interview..

A picture of an ordinary day
Can you tell me about an ordinary day in your life? For example; yesterday or today.
What do you do? Do you go anywhere? Who do you meet?

Social relations
What does you social situation look like? Do you have family/ friends?
What do you do together?

Love/ intimate relations
If living with a partner;
How was it when you started the relationship you have today/previous relationships? Moved in together? Got children?
Challenges?
Are you as a woman facing different challenges than a man would do?
If single living;
Can you choose to be in a relationship/ to move in with someone/ have children?
Yes/no – Why?
Challenges?
Are you as a woman facing different challenges than a man would do?
What is sexuality for you? Something else than to have a partner /intercourse/children?
Positive/negative? Risks? (Contraceptive methods?)
Who do you turn to with questions concerning this above?

Other persons/societies “eyes” on you
- How (would or do) the surrounding society react if/ when you decide to be in a relationship?
- What (will or do) they say if you; you kiss someone on the street/ decide to have a partner/ move in together with a partner/ marriage/ have children?
- Was there any difference in how the surrounding society treated you concerning these subjects before you got the impairment? / If you didn’t have the impairment, what would be different?
- How do other people look upon your sexuality? Positive/ Negative?
- People living without disabilities, are their sexuality similar to yours? Yes/No – Why?

**Human rights including sexual rights**

*International agreements’ and national conventions in Tanzania says that all persons, despite sex, age, race or bodily function, should have the same human rights including for example to have a sexual life, to start a family, have children.*

-What do you think about this? How is it in reality? How would you like to have it/ what to change?

-Can you tell me about your thought for the future connected to your sexuality? Are there any challenges? Any wishes and expectations?
Appendix 4

Interviewing the ministry of health
- Can you give me a picture of how people live with disabilities in Tanzania? Historically and today?

- Are people given different opportunities depending on impairment? Rural/Urban life? Male/female?

*International human rights conventions highlight the sexual rights of all persons, no matter race, gender, bodily ability.*

- How does Tanzania work with these rights?
- In theory and practice?

- The governmental/social work/organizations/disability movements responsibilities?
- How does the organization look like? National/international aids?

- Thoughts and challenges for the future?