Access to sexual and reproductive health services: experiences and perspectives of persons with disabilities in Durban, South Africa

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### **Abstract**

Sexual and reproductive health is recognized as an essential component of good health and personal development. However, a number of studies suggest that persons with disabilities are often marginalised by sexual and reproductive health programmes. In this study, interviews were conducted with sexually active women and men of reproductive ages with different types of disabilities in order to examine access to sexual and reproductive health services in Durban, South Africa. The majority of respondents revealed that sexual and reproductive health services are a big part of their lives. However, there seemed to be a huge gap between their need for services and their rights to access these services. Gender compounded the negative experiences for women with disabilities. Women mentioned that health providers appeared surprised that they will need family planning services and they are not given choices about suitable birth control methods. The findings revealed a need to address access to sexual and reproductive health services for persons with disabilities.

Keywords: persons with disabilities, sexual and reproductive health services, access, South Africa.

### Introduction

Sexual and reproductive health are an integral part of the health and well-being of every human being, however they remain sensitive and controversial issues, particularly when they concern persons with disabilities and women in particular. Many studies report that persons with disabilities lack access to sexual and reproductive health services, especially in low-income countries (Swartz et al. 2009; Groce et al. 2009). In fact, these studies suggest that their sexuality has been largely overlooked or actively suppressed and reproductive rights denied (Swartz et al. 2009; Groce et al. 2009).

In most societies, and South Africa is no exception, on the one hand, persons with disabilities are assumed to be hypersexual, and therefore it is argued that discussions about sex will trigger uncontrolled sexual behaviours (Anderson & Kitchin 2000). On the other hand, they have been erroneously perceived as unable to perform the physical act of sexual intercourse and hence they are not often thought of as sexually active (Hunt & De Mesquit 2006). Persons with disabilities are often viewed as sick or childlike therefore they are perceived as asexual; incapable of meaningful sexual relationships; unable to carry a pregnancy and not interested in establishing families (Mgwili & Watermeyer 2006).

According to the World Health Organization (2011), persons with disabilities make up more than a billion of the global population-constituting about 15% of the world's population and about 80% live in low-income countries. According to the 2011 census, there were 2870130 persons with disabilities in South Africa (Statistic SA, 2014). Disaggregation of data by province shows that the province of KwaZulu Natal had the highest number of persons with disabilities in comparison to other provinces. In South Africa, persons with disabilities are disproportionately represented among the poor and women (Statistics SA 2014).

The issue of the sexual and reproductive health of persons with disabilities is evoking considerable concern especially due to their

continuing vulnerability to sexually transmitted infections (STIs) including HIV and AIDS (Groce 2004), yet without access to essential services. Persons with disabilities may actually "have greater needs for sexual and reproductive health education and services than non-disabled people due to their increased vulnerability to abuse" (Groce et al. 2009: 5). A study by Groce et al. (2009) found that women with disabilities are three times more likely to be victims of sexual, emotional and physical abuse. However, they are less likely to access police intervention, legal protection or prophylactic care (Groce & Trasi 2004).

Addressing sexual and reproductive health is recognized as key in mitigating the spread of HIV and AIDS by preventing new infections (Bankole & Malarcher 2010). Realizing the serious nature of the problem, the need for sexual and reproductive health services for persons with disabilities should be treated as a priority by governments. One of the United Nation's Millennium goals is to achieve universal access to sexual and reproductive health services by 2015 (Groce et al. 2009). In 2007, the executive director for UNFPA, Thoraya Obaid argued that this goal cannot be achieved unless "persons with disabilities are brought into the mainstream and included in programmes to improve sexual and reproductive health" (UNFPA 2007).

Since the advent of democracy in 1994, South Africa has been identified as one of the most progressive countries in the world in terms of policy and recognition of sexual and reproductive health rights (Cooper et al. 2004). Policies and laws have been put into place to entrench the rights of persons with disabilities and their access to essential services, including sexual and reproductive health services. Despite these advances, some advocates argue that "significant efforts are still needed to put policies and laws into practice on a personal level, and to continue projects where disabled persons speak on their own behalf" (Bleazard 2010:2). The aim of this study is to shed insights into the experiences and perspectives of persons with disabilities regarding their access to sexual and reproductive health services. In order to document this, the study draws on in-depth

interviews conducted with men and women with disabilities in a residential home in Durban, South Africa.

# Methodology Study context and design

The study was conducted at a residential building for people with various disabilities. The home is located in the Durban central business district in the province of KwaZulu-Natal in South Africa and is owned by the municipality. It was primarily chosen for the study because it is a residence for persons with disabilities. The home accommodates approximately 100 persons with different disabilities, including persons with physical, visual and hearing disabilities. It is not run as an institution and the residents live independently with their companions and children.

For the study, qualitative data was collected. The qualitative data was derived from in-depth interviews. A total of 16 in-depth interviews were completed with sexually active women and men of reproductive ages with different forms of disabilities. The majority of respondents were females. Only 6 respondents were males. An attempt was made to ensure that interviews were conducted with persons with a range of disabilities including the physically and visually (blind and partially sighted) disabled. Persons with physical disabilities constituted more than half of the sample. The respondents with physical disabilities were using assisted devices such as crutches, wheelchairs and calliper shoes.

The ages of respondents ranged from 27 to 46 years. Even though the respondents reported that they were single, a few were living with their partners at the time of interviews. Only one respondent was married. All the respondents were black South Africans with 14 Zulu speaking and 2 Xhosa speaking. They were all recipients of the state disability grant, with the exception of two who were formally employed in professional positions. The level of education of respondents was high. All, with the exception of two respondents, had at least some secondary education. Most had at least some secondary

education. There were also two university graduates in the sample. One male respondent and one female respondent with visual disabilities reported that they had never attended formal schooling and attributed this to the lack of education opportunities for black South Africans with visual disabilities, especially in rural areas.

Sexual and reproductive health and disability remain sensitive and taboo subjects thus in-depth interviews were deemed most suitable as this study required a detailed account of the subjective experiences of accessing sexual and reproductive health services. For the study, nonprobability sampling was used to recruit persons with disabilities. Before the study was undertaken, there was a preliminary meeting with one of the committee members in order to seek permission to conduct the study and to assess the possibility of getting respondents who might be willing to share in-depth information on sexual and reproductive health matters. Respondents were approached directly and given detailed information about the purpose of the study, and asked if they would be willing to participate in the study. Some persons with disabilities, after they have understood the objectives of the study, also suggested others who might be willing to participate in the study and share their unique experiences as well. Ethical approval for the study was obtained from the University of KwaZulu Natal. Prior to every interview, each respondent was informed that his or her participation is entirely voluntary and is able to withdraw from the study at any time. At all times, confidentiality and anonymity of the respondents was maintained.

All interviews were conducted in the local language of the respondent over a three month period. The interviews were digitally recorded and field notes were taken during the interviews with the consent of the respondents. All interviews were then transcribed and translated verbatim to English. Each interview session lasted on average 30 minutes to one-hour.

After interviews were transcribed, passages were extracted from the transcripts and key themes and concepts were identified and coded to provide a rich framework for analysis, comparisons and presentation

of the data. Individual's experiences, comments and opinions were then categorized according to recurring selected themes from all the interview transcripts.

#### **Results**

## Attitudes towards sex and sexual health

In the interviews it is clear that men and women hold quite different attitudes to sex and their sexual health. Women tend to associate sex with an expression of their love and affection for their partner. However, men tend to equate sex with self-gratification. Women are interested in sex as a means of establishing emotional attachment while men are interested in sex for the sake of obtaining pleasure. This is clear in the following comments:

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

Some of us love sex so much that we go and look for sex like with sex workers (IDI=5, Male).

Women with disabilities sometimes find it difficult to form intimate relationships, mostly because of societal discriminatory attitudes towards persons with disabilities. The misconception that they are not sexually active may subject them to sexual exploitation thereby increasing their vulnerability to STIs including HIV and AIDS. Women with disabilities expressed concerns that they are often mistakenly perceived as 'virgins'. From their experiences, a few women mentioned that sometimes men approach them with the intention of having sexual relationships with them not because they have real affection for them but as a result of the assumption that they are at low risk of HIV infection. Women stated that they face the risk of verbal abuse once their sexual partner finds out that they are not virgins. On the other hand, some women mentioned that men take advantage of them because they use them sexually until they find another partner without disabilities. Some men engage in multiple

sexual relationships with them as well as other women. As a result, they feel at heightened risk of STIs and HIV/AIDS.

Some men they look at your disability, and then they pretend as if they love you whereas this is not really the case. He only wants to use your body. After some time he abandons you just like that and gets a new girlfriend. In some cases, men look at your disability and date you just to pass time...He will also have other girlfriends on the side and because of his mischievous behaviour; he ends up getting sexually transmitted diseases and infects you as well (IDI=8, Female).

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

# Knowledge, awareness and sources of information

Men and women indicated that they have obtained information on sexual and reproductive health matters from various sources including health facilities, schools and peers with disabilities. In addition, a few respondents mentioned that they received information about sexual and reproductive health issues from organizations working directly with persons with disabilities in Durban, for example the Natal Society for the Blind.

A few respondents mentioned that there have been poor efforts in educating men and women with disabilities about the range of reproductive health services. In addition, they felt that while they had heard of a particular type of service they would like to receive detailed information about the services. The visually impaired indicated that there is no information on sexual and reproductive

health, to their knowledge, available in alternative formats such as Braille or audio compact discs which would be accessible to them. They reported that they often do not have anyone to read pamphlets that contain information on sexual and reproductive health for them. One respondent noted:

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

Men and women with disabilities expressed concerns that they have never received information on sexual and reproductive health matters from their immediate family members. They reported limited communication with their parents. They stated that sexuality is often regarded as a very sensitive matter and in general they are viewed as not engaging in sexual activities by their families. Persons with disabilities are often viewed as children and as a result marginalized in terms of sexual and reproductive health matters. Their families are often silent about reproductive health matters which make it difficult especially for women with disabilities to understand even their first menstrual period. This has many implications for their risk of pregnancy and STIs.

When I was growing up, as a young woman, no one was willing to tell me about sexual issues, because these are very sensitive matters for us. Also it is very difficult for me because I am disabled to reveal that I desire sex. When you start your menstrual period, you are not told that are now entering puberty and you can fall pregnant at any time. When I fell pregnant it was like I have killed a 100 people. No one was willing to stand behind me and understand my position. You are not accepted in the community (IDI#16, Female).

I once told my mother that I was raped and my mother did not believe me and she said: who will rape you? I stayed with that wound, with that pain; you know with that bleeding wound that no one would believe me. At home they do not make us ready for the outside world, because you are seen as a child (IDI#11, female).

The failure of parents and families to understand that children with disabilities are sexual beings might put persons with disabilities at risk of being sexually abused without even able to report the perpetrators, because of the fear that no one would believe them. One woman stated that she had been a victim of rape and her family refused to believe her. Parents' silence on sexual health matters may increase their vulnerability to sexual abuse and negative reproductive health outcomes. Sexual education is an important part of giving people knowledge and creating awareness about safe sexual behaviours.

# **Experiences at Health Facilities**

In the study, respondents reported visiting public health facilities for a range of reproductive health services including HIV counselling and testing, STIs treatment, contraceptives, AIDS treatment and antenatal and postnatal care services. Women were more likely than men to report going to health facilities for reproductive health services. Men stated that health services are not well-equipped to deal with the reproductive health needs of men. They complained about poor interpersonal relationship with nurses who were often female and judgemental. While they acknowledge that men in general experience poor treatment at health facilities they felt that the situation was much worse for men with disabilities.

Men tend to stay away from sexual health services because you find that most nurses are females and they do not have a way of talking to us in the manner that encourages us to visit health services. For people with disabilities it is worse than people without disabilities. Image if a man who is not disabled gets scolded like that and is spoken to in an irresponsible fashion how much worse it is if I am disabled (IDI#5, Male).

Men report that they rarely visit health facilities for reproductive health services. One of the reasons mentioned for this is that male condoms are widely available. The male condom was the only contraceptive method mentioned and used by men in the sample. Men said they can access condoms either from schools, public places or the pharmacists. Two men who were HIV positive reported that they go to the health facility for the AIDS treatment.

While females seemed more likely than males to seek sexual and reproductive health services, many women with disabilities reported that they were dissatisfied with services in general and felt discouraged to seek services, particularly from public health facilities. The level of satisfaction was largely attributed to health providers' attitudes and behaviours during consultation, examination and treatment. Women stated that they are afraid of being perceived as sexually active and they do not feel comfortable talking about sexual matters with health providers. For them, sex is regarded as a taboo subject thus they are not able to ask for condoms at health facilities.

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

Some women said they were satisfied with the services because their reproductive health needs were met during their visit. They were very satisfied that their personal needs and health information was kept confidential. However, women with visual disabilities report different experiences. They mentioned that they are subjected to lots of questions, such as, how and why they engage in sexual activities, why

they need contraceptives, and how they select their sexual partners, suggesting that health providers are not yet understanding that persons with disabilities are sexually active with abilities to establish romantic relationships.

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

In addition, men and women who were visually impaired noted they were given prescriptions without any instructions. The health providers assumed that they will not understand the instructions. This was perceived as a violation of their right to respect and dignity.

In the interviews, women shared horrendous experiences they endured at government hospitals when they went to deliver their babies. A few women who were dissatisfied with the treatment received during their pregnancy indicated that they had opted to seek services from private health facilities for their subsequent pregnancies. They felt that the public health facilities do not adequately cater for the needs of persons with disabilities.

In public hospitals it is very difficult. In my last pregnancy I utilized the private one. They treat you with dignity because they know you paid. But in the public hospital after my last birth, I felt that I will never come back again because at that time it was even difficult for me to visit the toilet you know, because no one will take you there. No one will think that at least your bed should be closer to the toilet so that you will be able to go and do whatever. It was very difficult, it was not easy (IDI#16, Female).

Women reported that nurses appeared surprised that they had a sexual partner. They reported that nurses were shocked that they were in need of family planning services. The women reported that they were

sometimes scolded for asking the nurses about contraceptives. They complained that the nurses did not counsel them on a range of available and suitable birth control options instead the nurses suggested that they undergo female sterilization or opt for an abortion. Women mentioned that nurses at the hospitals found it difficult to accept that persons with disabilities want to have children and asked them who would look after their children. They reported that for instance, when they go to the clinic to deliver, the nurses asked them how many children they have and felt that they had many children already. They believed that having more children would increase the burden on their families. In fact, nurses seemed to be 'angry' as to why a woman with disability would be sexually active and fall pregnant.

When you come to the clinic, and tell them I am here for family planning, they jump and say what: What? She wants family planning! Does she have a man? You see that is the problem. They react with shock. They would ask: why you do not sterilize? We are not being encouraged to use other methods. The other thing which affects women with disabilities, when it comes to contraception, our public health workers, are not well enlightened about us (IDI#16, Female).

When you get to the antenatal clinic, they tell you about abortion, especially when you are blind like me. When I went to the hospital and they discovered that I was two months pregnant with this child, my last born, they said I must terminate the pregnancy because I am blind. A nurse tells you to just go to that side and make an appointment to do an abortion. The nurses said the pregnancy will create problems for you, and also you are causing problems for your family (IDI#14, Female).

Women with physical disabilities further mentioned that nurses assumed that delivering a baby would be complicated which was not the case for the women in the study. Women indicated that they delivered naturally and did not need to undergo a caesarean section.

Men and women emphasized their disability in general does not impact on their sexual and reproductive lives. But the negative attitudes they receive from the public health providers creates uncertainty in them and discourages them from seeking services. One woman described her delivery experience:

For us, people who are physically disabled, the nurses ask questions such as: How are you going to give birth since you are pregnant? How are you going to deliver? Let me share this with you, most people who are physically disabled, they deliver naturally without caesarean section. They deliver naturally, no operation whatsoever. So if you ask me, how I am going to deliver, I feel so bad. I have four children, all of them I delivered naturally without any operation (IDI#15, Female).

Women with disabilities feel that the nurses ask too many unnecessary questions and they are not sensitive. They feel that they do not have the opportunity to ask for (more) information about their sexual and reproductive health. The less than welcoming behaviours of nurses leave men and women feeling neglected, denied their rights to access quality services and to be treated with dignity and discriminated against on the basis of their disabilities. Consequently, the fear of discrimination discourages them from utilizing public health facilities for sexual and reproductive health services as the negative attitudes of the nurses gives them the impression that such services are not meant for persons with disabilities.

## **Barriers to access**

Men and women identified a number of barriers to accessing services ranging from physical to functional and attitudinal factors. Health facilities that offer sexual and reproductive services are located in areas difficult to easily access especially for pregnant women. Many respondents rely on public taxis for transportation to reach sexual and reproductive health services, which is very challenging for them. Respondents reported that the public transport is not only unfriendly for persons with disabilities, but also they have to walk a long

distance before they get transportation because it does not come close to their place of residence. Even if public transportation is available, travelling alone may be a challenge so they need someone to accompany them to access services and if there is no one available to assist, they are not able to access services alone. Some women indicated they had to discontinue using contraceptives because, when it is their date to collect contraceptives, they could not find someone to accompany them to the clinic. Women said going to the clinic or hospital alone is a challenge and reported that the nurses scold them if they are not accompanied by anyone.

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

Costs, including fees for transportation, were cited as another barrier to accessing sexual and reproductive health services by a few respondents. Respondents indicated that each time they need services they have to pay high transport costs as they have to hire a meter taxi to take them to the hospital or clinic or pay for someone to accompany them. Respondents indicated that they were unhappy with the opening hours because they have to wake up very early and go and wait for the clinic to open. The queues are long which leads to extended waiting hours.

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

Men and women reported that there are stairs which makes it difficult for persons with physical disabilities to manoeuvre without some assistance. Respondents mentioned that the elevators are usually out of service. Men and women with visual disabilities also complained that health facilities do not cater for their needs. They said it is difficult to locate consultation rooms alone and the nurses are not willing to assist them. The nurses complain that it is not their responsibilities.

The nurses at the hospital where I go to collect my treatment are negligent. They ask: why do come alone? You see, I tell them please help me and they would say: Can't you see I am busy? The hospital has many passages, and no matter how smart you are with directions, you will get lost. The passages inside the hospital are very confusing so you need someone to escort you through the building. Also their lift is very bad. They do not have lifts that talk, that tell you where you are. You see, it is a real problem for us (IDI#12, male).

Men and women complain that equipment in the health facilities are not adjustable making it difficult for persons with disabilities to use easily. In addition to this, respondents stated that the nurses are impatient; they expect them to climb onto the bed quickly. Respondents also noted that condoms are placed in areas that are out of reach for persons in wheel chairs as a result they are sometimes reluctant to take them and this increases their risk of engaging in unprotected sex.

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

Persons with physical and visual disabilities indicated that their dependence on others for assistance inhibits their use of such services.

They fear that having to disclose to those accompanying them their need for services might lead to them being stigmatised.

Both men and women described nurses as unfriendly and the vast majority of women had many stories to tell about their negative experiences at health facilities. Respondents said often they were treated as asexual beings by the health service providers. They felt that the health providers need to change their mind sets with respect to persons with disabilities and their sexual and reproductive health. The health providers need to acknowledge and accept that people with disabilities are sexual human beings and therefore they need services.

Health workers are not ready to accept people with disabilities as sexual human beings. The biggest barrier is the mind-set of the public health providers (IDI#16, Female).

The respondents reported that these barriers often lead persons with disabilities to seek private health facilities which are often not affordable considering that most respondents depend on social grants. Worse they avoid or delay seeking services which has serious implications for their sexual and reproductive health. For example the negative and discriminatory attitudes of nurse may encourage women with disabilities to delay seeking antenatal care which is likely to put their health and that of their unborn at risk.

## **Discussion**

The study revealed that persons with disabilities face various sexual and reproductive health problems including STIs, unmet need for contraceptives, sexual abuse and HIV and AIDS. From the interviews, there seemed to be a huge gap between their need for services and their rights to access these services. Individual's right to be treated with dignity, respect and to access sexual and reproductive health services is often overshadowed by the stereotypical assumptions that society holds about the sexuality of persons with disabilities.

The preconception that persons with disabilities are incapable of sexual relations seemed to create barriers mentioned by the respondents in the study. They are often viewed as not sexually active hence information on sexual and reproductive health matters is not widely available in formats accessible to them such as large prints, Braille and audio compact discs for those with visual disabilities. The myths and misperceptions surrounding the sexuality of persons with disabilities enforce the exclusion of persons with disabilities in sexual and reproductive health services. Foremost it means that they are often left without support and information to make informed decisions about their sexual and reproductive health. Ample evidence has been generated that establishes that these barriers are not necessarily part of having a disability, instead, arise from society's stereotypical attitudes and ignorance (including the attitudes of the services providers), harsh social isolation, stigmatization, and discrimination experienced within communities owing to having disabilities (Swartz et al. 2009; Groce et al. 2009).

According to Anderson & Kitchin (2000), the planning and design of most sexual and reproductive health services, family planning clinics in particular, reflect that persons with disabilities were not expected to be using the services. For example, most clinics do not have ramped entrances and elevators to accommodate wheelchairs. Doorways are too narrow making it difficult to access freely. This study found that although clinics and hospitals were available and accessible by public transport, many respondents reported difficulty in accessing public transport since it does not pass by their homes. In addition, the clinic opening hours and long queues presented challenges.

Women with disabilities mentioned that health providers appeared surprised that persons with disabilities will need family planning services and they are not given choices about suitable birth control methods instead nurses often suggest that they terminate their pregnancies and strongly encouraged them to be sterilised. This is short sighted and a public health matter. Sterilisation without proper counselling violates the rights of women with disabilities to decide on the number and spacing of their children. It is assumed that a parent

with a disability will give birth to a disabled child therefore women with disabilities are discouraged from falling pregnant and reproducing (Waxman-Fidducia 1997). Scientific evidence shows that genetic disabilities occur in a small number of births and this is not unique to child-bearers with disabilities (UNFPA 2007).

In light of the findings of this study more effort is needed to ensure greater awareness about the various contraceptive methods. Providing sex information and access to contraceptive methods reduces fear, anxiety, and unwanted pregnancies. Mobile clinics with professional nurses must be brought closer to the community with disabilities to ensure easy access in order to be able to make informed choices.

#### Conclusion

More effort is needed to change the stereotypical views that persons with disabilities are incapable of sexual activities and taking care of their children. And the view that they are virgins therefore they do not get HIV and AIDS. Training healthcare service providers is an important part of improving access to sexual and reproductive health services for persons with disabilities provided through the public health system. Ensuring that persons with disabilities have access to sexual and reproductive health services contributes to fulfilling women's sexual and reproductive rights, providing them with more choices to best suit their needs and empowering them.

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