

**EXPERIENCES OF THE DISABLED WOMEN ATTENDING THE  
STATE-PROVIDED REPRODUCTIVE HEALTH CARE SERVICES  
REGARDING THE QUALITY OF CARE RENDERED  
BY HEALTH CARE PROFESSIONALS  
IN THE EASTERN CAPE**

**By**

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## ABSTRACT

The purpose of this study was to explore and describe the experiences of disabled women, attending the state-provided reproductive health services, regarding the quality of care rendered by health professionals in the Eastern Cape. The study was conducted on disabled women at Flagstaff and Lusikisiki self-help group project sites. A qualitative exploratory and descriptive research design was used. A non-probability sample of 16 disabled women was chosen at Flagstaff and Lusikisiki. Individual tape-recorded interviews were conducted. Field notes were taken to capture non-verbal behaviours. Data were then analysed

The findings showed that most disabled women had negative experiences whilst few disabled women had positive experiences. Of the negative experiences the following can be mentioned; verbal insults, physical assaults, direct and indirect humiliation, accusations and discrimination.

The following themes were identified:

Attack on self-worth

Bargaining for self-protection

Self-resignation

Rights claimed

Being valued

The conclusion was that the rights of disabled women were violated in the reproductive health services. The following recommendations were made:

Provision should be made for disabled women in their capacity as community members, to be actively involved in the processes that influence the provision of health care and related matters. The slogan "Nothing about us without us" remains true in the case of the disabled women particularly in reproductive health care. Such provision can be facilitated by participation as members of the clinic committees, hospital boards and rehabilitation forums.

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## **CHAPTER 1**

### **1.1. INTRODUCTION**

This study was conducted to explore and describe the experiences of the disabled women attending the state-provided reproductive health care services in the Eastern Cape, regarding the quality of care rendered by health care professionals.

### **1.2. BACKGROUND TO THE PROBLEM**

According to the South African Constitution, Act 108 of 1996, Section 27(1)(a) everyone has a right to have access to health care services including reproductive health care. (Republic of South Africa 1996: 13)

In South Africa, society is predominantly patriarchal and this patriarchal order results in women generally being viewed as second-class citizens who are subservient to men. (Office of the Deputy President 1997: 4) Women in general are at the bottom of the ladder and their counterparts, disabled women are further down. (Mda; Schneider & Lagadien in Goosen & Klugman 1996: 176)

According to the White Paper on an Integrated National Disability Strategy, disabled people in South Africa have been the most disadvantaged group of the population. The majority has been excluded from the basic services. Generally they have been marginalized from receiving attention or access to the services that are normally easily available to the rest of the public. (Office of the Deputy President 1997: 2)

Because of their impairments, most disabled people are struggling to access education, employment, health care and many other basic services. They are often denied the right to express their sexuality and have children. (Stone 1999: 1)

The situation is even more disturbing when it comes to the disabled women. This situation is confirmed in a statement by Mda et al in Goosen and Klugman (1996:178), which says that disabled women are more exploited, marginalized and discriminated and this is due to the fact that they are not seen as worthy of being mothers. People often assume that women with impairments cannot achieve status of being mothers, wives or homemakers. This way of thinking results in the violation of disabled women's rights to reproductive health care.

Disabled women have the right to attend any reproductive health clinic and to be served like all other citizens. It is critical to note that in general reproductive health needs constitute a very sensitive care issue even to able-bodied women. Pregnancy is a disabling condition for many able-bodied women, and it therefore becomes more of an issue to a woman with impairment. (Jo Deegan & Brooks 1985: 135)

Out of 1 173 932 disabled women in South Africa, 199 038 are in the Eastern Cape. (Disabled People South Africa [DPSA] Statistical Record) In this region it is a cultural expectation that a woman should bear children irrespective of the marital status. A woman gains respect because of the children she has. Being childless takes away this respect.

The need for children is based on the belief that these children will look after their parents when they are old. They act as protectors especially to their mothers. If and when the father dies, it is the responsibility of the children to look after their mother. Most households are female-headed and with the support and protection from children, the female head gains considerable respect from members of society. Therefore childbearing in this culture is an investment that is essential to womanhood.

### **1.3 STATEMENT OF THE PROBLEM**

It was alleged that disabled women endure negative behaviour from health care professionals during their visits to the reproductive health services such as family planning, antenatal, delivery and postnatal clinics. Several complaints have also been received from disabled women attending these clinics.

It was alleged that some health care professionals have denied the disabled women the use of contraceptives, their reason being that because of their impairments, disabled women should not engage in romantic relationships. There was also a view that disabled women are not supposed to be pregnant as there is no reason why they should engage in sexual intercourse.

Several studies dealing with experiences of disabled women in the health care have been undertaken in urban settings both in South Africa and other countries. However no such study has been conducted in the Eastern Cape province of South Africa, to document the

experiences of disabled women. Because of the complaints of disabled women about the quality of reproductive health services generally, the researcher found it necessary to conduct a study in the rural area of the Eastern Cape.

#### **1.4. RESEARCH QUESTION**

What are the experiences of the disabled women attending the state-provided reproductive health care services in the Eastern Cape, regarding the quality of care rendered by health care professionals?

#### **1.5. PURPOSE OF THE STUDY**

The aim of the study was to explore and describe the lived experiences of disabled women attending the state-provided reproductive health care services in the Eastern Cape, regarding the quality of care rendered by health care professionals.

#### **1.6. SIGNIFICANCE OF THE STUDY**

It is the South African Government's vision to ensure that care given to the disabled people is equal to that of other citizens. This is embedded in the Constitution of South Africa, which provides for the rights of all people, for example, a right not to be discriminated on the grounds of disability and gender. (Republic of South Africa 1996: 7) Based on this understanding, the study may assist in the recognition of these rights, thereby benefit the disabled women attending reproductive health care services.

Disabled women themselves will be motivated to sensitise society on their rights as women. Through this the Department of Health may see the need to develop policies around reproductive health care to disabled women. Such policies may influence curriculum development in various areas of health care. The professionals thus produced will influence care delivery in ways that recognize the rights of disabled women.

## **1.7. DEFINITION OF TERMS**

### **1.7.1. Disabled women**

Parks (2001: 4) defines a disabled community as, "that community that shares the same kinds of problems with access and opportunity that is more commonly found among those peoples who have physical, cognitive, sensory or mental impairments." Disabled women are therefore broadly defined as women who share the same problems with access and opportunities because of physical, cognitive, sensory or mental impairments. In the context of this study the term, disabled women will be used to refer to women with physical or visual disabilities.

### **1.7.2. Reproductive health care services**

These are health services rendered and include essential components such as prenatal care, services for delivery, postnatal care, fertility, abortion and family planning. (De Haan 1996:186)

### **1.7.3. Health care professional**

According to Urdang (1983) a health care professional is any person who has completed a course of study in a health-related field. For the purpose of this study a health professional will be defined as any person who has completed a course of study in a health-related field and is currently practising in the field.

### **1.7.4. Self-help group**

In the context of this study a self-help group is a collection of disabled people (men and/or women) who meet and work together to achieve a common goal, in this particular case to generate income for them. They have a chairperson who is the manager of the group and also a consultant who may or may not be a disabled person. They usually meet at the project site daily excluding Sundays, to do project work.

## **1.8. CONCLUSION**

This chapter dealt with research title, background to the problem, research question, the purpose of the study, significance of the study. Lastly terms used in this study were defined. The next chapter will deal with literature reviewed during this research study.

## **CHAPTER 2.**

### **LITERATURE REVIEW**

#### **2.1. Introduction**

Although limited, the available literature points out to the discrimination disabled women are subjected to when they present themselves for health services particularly the reproductive health services.

#### **2.2. Literature review**

##### **Disrespect of individual's autonomy**

In a study undertaken by Lonsdale in London in 1990, a woman with muscular dystrophy narrated her experience about attitudes of health care professionals during pregnancy and delivery of her 8-year-old daughter. Every health care professional at the antenatal clinic was overly concerned about her pregnancy. The doctor asked her if she did not want to terminate her pregnancy. The woman refused. She further refused the advice to let the doctor deliver her at six or seven months of pregnancy. Despite all concerns by the health care professionals, about her impairment the woman continued to normal term and delivered normally without any assistance. (Lonsdale 1990: 76-77)

This author points out that although it is legitimate for health care professionals to be concerned about problems the disabled women might encounter during pregnancy, the concern should not lead to decisions being forced on the women. He cautions that such attempts may drive the woman away from the health care system thus exposing them to greater risks.

Jo Deegan and Brooks (1985: 135) undertook a pilot study in 1985 in Seattle where ten women with disabilities like spinal injury; multiple sclerosis, post polio and spinal bifida were interviewed. The aim of the study was to investigate the concerns of these women about health care professional's behaviour. In this study one woman with quadriplegia went to an obstetrician, to discuss with him the possibility of becoming pregnant. It is reported that the nurse who received her said with amazement, "... I was surprised you were here for a pregnancy test" This shows that the nurse never expected this woman to become pregnant and visit the obstetrician like other women.

Mda, Schneider and Lagadien in Goosen and Klugman (1996 185-186) also cite an incident, where health care professionals insisted that a 15-year-old disabled woman with paraplegia be sterilized. They further cite an incident where a woman with kyphosis went to deliver her baby in one hospital, and nurses burst into tears after she had delivered. They made such statements as, "amadoda anamanyala" (men have low morals). This comment implies that according to the nurses this woman had no right to be involved in a sexual relationship and that the man who made her pregnant had done something morally unacceptable. Comments like these do not only violate these women's rights but also humiliate them and traumatize them emotionally. Labelling a person who is in love with a disabled woman as having low morals has negative repercussions on the image of the disabled woman.

Because a disabled woman has a right to choose whether or not to have children, suggestions that she must not have children are a violation of her human rights. Nobody

should decide for her. Boylan also stresses that disabled women have a right to love, right to marriage and a right to motherhood. (Boylan 1991: 52) They [disabled women] have a right to choose their love or marriage partners and whether to have children or not.

### **Value placed on childbearing**

Women generally irrespective of culture place a lot of importance on bearing children. Those who do not have children yearn for them. This desire to have children was made evident by the disabled women of SACLA Rehabilitation Project in Khayelitsha, Cape Town who were engaged in participatory action research with the Division of Occupational Therapy at the University of Cape Town. The purpose of the research was to explore the disabled women's experiences of social and economic development and to assist them in building capacity for self-reflection and to develop the disabled women and community based rehabilitation workers. (Lorenzo & Saunders 2002: 5)

During the study women shared their experiences of joy and pains, laughter and tears of their journeys in life. This process assisted in creating awareness on the strengths and abilities of disabled people and the contribution they are capable of making in the realization of the vision of "society for all" that is defined in the Integrated National Disability Strategy. (Lorenzo & Saunders 2002: 6; Office of the Deputy President 1997: 18)

These disabled women showed that they wanted to have children and the fact that some of them were childless was worrying them. One woman is cited as saying: "I am waiting for happiness, for hope that God will add more years to my life. I'm also waiting to have

a child. I'm waiting for good things that are up there that I cannot get. My disability is bothering me because I do not have children." (Lorenzo & Saunders 2002: 38)

Another woman had children and she appreciated the support she was getting from her children. She revealed this when she said, "I'm so thankful that my children support me... most of the time in my house I don't cook. Even tea is made for me. They know even now that I am here and when I come home I don't even need to ask them, they make tea for me." This shows the value disabled women place on childbearing. You bear children that will assist you in household chores. Other people's children cannot afford to do what your own children are doing for you. Even if you are married and the husband leaves you, if you have children you have a shoulder to cry on. You have people to take care of you. A third woman had this to say, "my husband left me alone with my children... I trust God in that maybe one of my children will take care of me." (Lorenzo & Saunders 2002: 10) These experiences show that disabled women want to have children and they place a very important value on childbearing.

### **Right to love and to marry**

The disabled women in the above study voiced it strongly that their rights as disabled women to fall in love, to marry or to have children are violated and they need to fight against this. To register this objection one woman said, "They [people] do not expect us to fall in love. They do not expect us to marry and have children." Another further urged the disabled women to pull up their socks, and fight for their rights. (Lorenzo & Saunders 2002: 24)

### **2.3. Conclusion**

This chapter dealt with views of different authors in the literature regarding violation of disabled women's rights. It showed the disrespect of disabled women's autonomy. It showed the value these women place on childbearing and the support they get from their children. They also sent some messages that they have a right to love and marry and they are not happy when these rights are not respected. The next chapter will deal with methodology, i.e. research design, target population, sampling, sampling plan, data collection and trustworthiness of the study.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1. INTRODUCTION**

This chapter deals with research design; target population; sampling method; sampling plan i.e. recruitment, criteria for inclusion and exclusion, ethical considerations; data collection; and trustworthiness of the study.

#### **3.2. RESEARCH DESIGN**

The research design employed in this study was qualitative, exploratory and descriptive design. This method was chosen to enable the researcher to have deeper insight to the personal experiences of disabled women who had attended reproductive health services in the Qaukeni Health District with regards to the quality of care rendered by health professionals. The study was aimed at an in-depth exploration of the experiences of disabled women. The researcher wanted to have more insight into the problem.

De Vos (1998) indicates that a qualitative researcher seeks out groups and settings that are more conducive to the question to be answered. In this study the researcher identified self-help group project sites as the suitable place to be used, because her prospective informants (disabled women) were found in these.

#### **3.3. TARGET POPULATION**

The target population consisted of disabled women in the self-help groups who had visited state-owned reproductive health care services in the Qaukeni Health District

Services in the Eastern Cape. A self-help group is a collection of disabled people (men and/or women) who meet regularly and work together to achieve a common goal, in this particular case to generate income for them. They have a chairperson who is the manager of the group and also a consultant who may or may not be a disabled person. They usually meet at the project site daily excluding Sundays, to do project work.

#### 3.4. SAMPLING

The sample consisted of sixteen (16) Xhosa speaking disabled women, fifteen (15) physically disabled women and one (1) partially visually impaired woman who agreed to participate and who fitted the criteria outlined below. A non-probability convenient sampling method was used to obtain study participants. This method was chosen because of the small number of disabled women available at the self-help group sites. Criteria of inclusion of those women who have attended reproductive health care services also made the researcher to choose a convenient sample. The self-help project sites provided a meeting place where these women could be accessed without undue inconvenience to themselves and to the researcher.

#### 3.5. SAMPLING PLAN

##### 3.5.1. Recruitment

Qaukeni Health District has three Health Sub Districts, namely Lusikisiki, Flagstaff and Bizana and each have its self-help group. Recruitment of informants took place at the Lusikisiki and Flagstaff self-help group project sites. Bizana, the third Health Sub-district of Qaukeni Health District was excluded due to distance and financial constraints.

The researcher herself a disabled woman, obtained permission from the Mayor of Qaukeni Municipality (Annexure 4) to visit the various self-help group project sites for the purpose of recruitment of informants.

Permission was then obtained from the Chairpersons of Flagstaff and Lusikisiki Self-help group project sites. (Annexure 6 & 8) The chairperson of each group was then requested to arrange a meeting between the researcher and the disabled women at the self-help group project sites. Attendance at the meeting was voluntary. At the meeting the researcher explained to the disabled women the purpose of the study, the inclusion and exclusion criteria and asked their voluntary participation in the study. An arrangement for an interview was made with the disabled women who indicated their willingness to participate in the study. The date and times were arranged to suit each informant in each project site. As a reminder each prospective informant was given a piece of paper with the date and time of appointment.

During recruitment the researcher first visited Flagstaff and then Lusikisiki project site. In both project sites, the researcher did not select informants, but those who were willing to participate and met the criteria, volunteered to participate. There was no chance of the researcher showing her preference in selecting one informant over another. The researcher was also Xhosa speaking like informants, so there were no language preferences as well. All these prevented any influence that might have produced distortion in the results of the study. According to Brink (1996: 134) the main sources of

bias can be the language used and also when the researcher shows preference in selecting one participant over another.

### 3.5.2. Criteria

#### **Inclusion criteria**

The following were admitted to the study:

- Disabled women with physical disabilities or partial visual disabilities that do not affect verbal communication and had attended any of the state-owned reproductive health services in the Qaukeni Health District. Attendance was confirmed by asking each disabled woman whether she attended any of these services. If the reply was positive and a person was willing to participate, she was then included in the sample.

#### **Exclusion criteria**

- Disabled women with mental, cognitive, total blindness, hearing and speech impairments were excluded. The reason was that the researcher had no access to a sign language interpreter or Braille services. Mental and cognitive impaired were excluded because of the anticipated difficulties with communication and reliability of responses.

### 3.5.3. Ethical Considerations

The research was subjected to Code of ethics, for the protection of human subjects. Before this study was conducted, a proposal was presented to the University of Cape Town Health Science Faculty Research Ethics Committee, for approval (Annexure 2). The researcher wrote a letter to the Mayor of Qaukeni Local Municipality (Annexure 3).

seeking permission to undertake a study at Flagstaff and Lusikisiki Health Sub- Districts. The purpose of the study was explained. Other letters were written to the chairpersons of Flagstaff and Lusikisiki self-help groups in the two Health Sub-Districts where the study was conducted. (Annexure 5 and Annexure 7). This was done to protect the informants from exploitation.

After being granted permission, the informants were contacted through the meetings held in their respective project sites. The purpose of the study was explained to them. It was also explained that there would be no direct benefits to the informants from the study. They were informed that they had a right to decline to participate in the study. They also had a right to withdraw anytime during the study if they so wished. They were assured of confidentiality and anonymity. Their permission was also sought for interviews to be recorded. A tape-recorder was used during the interviews to record informants' responses and they were assured that whatever information they feel private will not be shared and will not be linked to their names. Anonymity was then assured by assigning each informant a number. According to Brink (1996:45) providing each informant with a number or code ensures anonymity. The researcher also used informant numbers when analysing and discussing data. Brink (1996:45) also indicates that this is another mechanism of ensuring anonymity. Although the researcher was with the informants during interviews, the use of informant numbers ensured anonymity. This means that she could not link the information with informant's names. The tapes were kept in a safe place and will be destroyed on completion of the study.

There were no obvious risks inherent in this study. The times of interview were discussed with and agreed upon by the informants, since they were engaged in their projects and busy. A single interview lasted from 20 - 40 minutes. A commitment was undertaken that the findings of the study would be communicated to the relevant authorities and themselves, should they be interested. This would be done to influence improvement of the reproductive health services and to create awareness of the rights of disabled women.

### 3.6. DATA COLLECTION

The researcher conducted individual interviews in the project office at both Lusikisiki and Flagstaff project sites. The researcher posed the following open-ended question to each informant, "What was your experience regarding the quality of care you received from the health care professionals, when you attended state-provided reproductive health care services?"

Before asking the question the informants were put at ease by reassuring them of their rights. Interviews were conducted in Xhosa as all women interviewed spoke Xhosa as their first language. This was done to prevent any language barriers between the informants and the researcher and to allow informants to express themselves freely. All informants were asked the same question. Probing questions were asked where necessary. This was done to assist in eliciting further information regarding their experiences. The interviews were tape-recorded. The researcher was also taking field notes simultaneously to capture unspoken language from informants. According to Field and Morse (1985: 80)

it is necessary to take field notes in tape-recorded interviews, as the latter don't portray the non-verbal communication. Field notes therefore supplement the taped interviews. Data collection went on until saturation of data occurred. Saturation of data means that there was no new information that was forthcoming.

### 3.7. TRUSTWORTHINESS OF THE STUDY

Trustworthiness refers to the quality value of the results and conclusions reached in a qualitative study. In this study trustworthiness was measured according to Lincoln & Guba's model (1985). Lincoln & Guba (1985: 301) propose four (4) strategies to ensure trustworthiness. These strategies are credibility, transferability, dependability and confirmability. These strategies are used to ensure that there are no biases in the results of qualitative analysis.

#### 3.7.1. Credibility

Credibility refers to authenticity of data collected or the confidence that the researcher has in the data. Lincoln & Guba (1985: 301) indicate that credibility comprises activities that will make it more probable to believe that the findings and interpretations of the study are really credible. To ensure credibility in this study the researcher put into place the following measures:

##### **Prolonged engagement with the group being studied**

Lincoln & Guba (1985) say that the fact that the researcher is being 'a stranger in a strange land' draws undue attention to the informants. It is therefore important for the

researcher to be involved with the group sufficiently long enough to detect and take account of any distortions that might creep into the data.

At the time of the study the researcher was working as Assistant Director for Rehabilitation Health Services of Qaukeni Health District for 3 months. She was appointed to manage and render rehabilitation health services to disabled people of Flagstaff, Lusikisiki and Bizana. This gave her adequate time to familiarize herself with the issues of disabled women before data collection. The researcher managed to build trust and gained the group's confidence. She also had an in-depth understanding of the group and their setting.

Prolonged engagement is important in research because it makes informants to feel at ease. Lincoln & Guba (1985: 302) say that it is imperative that the researcher becomes an accepted member of the group being studied. The fact that the researcher was a disabled woman and also Xhosa speaking added to the trust that the participants had developed over this period.

### **Triangulation**

**Method triangulation** was also used. This is the use of more than one method in data collection. (Polit & Hungler 1997: 305) Interviews were conducted and at the same time field notes were taken to assist in capturing non-verbal behaviours like crying and lowering of voice. Combination of these two methods was done to ensure that both verbal and non-verbal responses are captured.

**Investigator triangulation** was also used. This means the use of other individuals during analysis or interpretation of data. (Polit & Hungler 1997: 305) An independent translator was requested to translate a sample of six (6) interviews from Xhosa to English. The researcher's translated notes were compared with the independent translator's notes for consistency. This was done to ensure that the responses were translated accurately into English language.

### 3.7.2. Transferability

According to Lincoln & Guba (1985), transferability refers to the generalizability of the data or the extent to which the findings from the data can be transferred from one group to the other. The researcher should provide sufficient descriptive data in the research report so that the consumers or readers can be able to evaluate whether the data can be applicable to other contexts. The researcher should provide a description that will enable someone who has interest to make a transfer to reach a conclusion whether a transfer can be considered a possibility. Thick description that is a thorough description of the research setting and processes observed during the inquiry, determine whether transferability is feasible. (Lincoln & Guba 1985: 316)

Transferability can be possible in this study as the population studied was clearly defined. For example the findings of this study can be transferred to disabled women who have attended the reproductive health services in any district health of Xhosa speaking people and still preserve the meaning, interpretations and inferences. The detailed description of

the methodology will enable anyone who wishes to apply the research findings in a similar context or setting, or to replicate the study to be able to do so.

### 3.7.3. Dependability

Dependability of qualitative data means the stability of data over time and over conditions. (Polit & Hungler 1997: 306) Like in credibility, triangulation can be used to ensure dependability and Lincoln & Guba (1985) indicate that there can be no credibility without dependability. Dependability was addressed because an independent translator was requested to assist in translating interview transcripts from Xhosa to English. This was done to check whether the researcher's translations were accurate.

### 3.7.4. Confirmability

Confirmability means the objectivity of the data. (Polit & Hungler 1997: 307) The thick description of data in this study is one of the factors that contributed to confirmability. The findings, conclusions and recommendations were supported by sufficient descriptive data on the topic under study. The literature control also contributed to confirmability.

## **CHAPTER 4**

### **4.1. INTRODUCTION**

This chapter will deal with data analysis, discussions, conclusions recommendations and limitations of the study.

### **4.2. DATA ANALYSIS**

Data analysis was done following principles of Field and Morse. According to Field and Morse (1985: 99) after transcription of the interviews and field notes the researcher looks carefully at the transcripts and identifies some statements that are significant to the research topic. The researcher then identifies significant concepts or quotes within these statements. From those concepts or quotes, the researcher checks for recurrences that might indicate patterns and assign categories to these patterns. Major themes are then developed.

On completion of the interviews, the researcher transcribed the audiotapes word for word. Each interview was transcribed on its separate sheets of paper. Short pauses were indicated by means of dashes, e.g. "Maybe God is still going to give me another one." --- (Pause) and long pauses by means of dots, e.g. "This means that I was not blessed to get this baby"... (Long Pause) The tapes were replayed to check if everything had been captured accurately. Field notes that were simultaneously taken during interviews to capture non-verbal behaviours were examined to identify associated significant behaviours like crying, lowering of tone of the voice etc.

Each batch was coded with interview number and informant number, e.g. Interview No: 15 (representing the chronological order of the interview), Informant No. 24 (representing the code of that particular informant). Even numbers, the first of which was 2, were used for the Informants No, starting from 2. This numbering and coding was done following Field and Morse (1985) coding principles, which require that all pages should be numbered sequentially and each page of data should be coded with the interview number and the informant number. The researcher first translated all 16-interview scripts from the Xhosa language to English. An independent translator, who spoke Xhosa as first language and had experience as a translator from Disabled People South Africa (Organization of disabled people), was engaged to translate a sample of six (6) interviews, which were randomly selected.

To select the sample the interview numbers were written individually on identical pieces of paper. Each of these papers was folded twice and placed in a wide-mouth glass jar. A passer-by was requested to draw randomly six of these folded pieces of paper. The number on each of the drawn pieces of paper was used to pick six interview scripts with matching numbers. The independent translator then translated the Xhosa responses on the latter into English. The six interview scripts constituted 37, 5% of the total interviews and regarded as adequate for assessing consistency between the researcher and the independent translator. The matching sets of translations were then compared and found to be consistent.

The following steps were then followed.

### Step 1

#### Identification of significant statements

All translated transcriptions were repeatedly read and looked at carefully with a view to identifying significant content. The researcher went back and forth to the Xhosa responses, checking the English meaning and comparing with the independent translator's English scripts. While reading through the data, the researcher identified, underlined and wrote down on separate sheets of paper, statements that were relevant to the research question. All statements that addressed the disabled women's experiences were extracted verbatim so as not to lose their original meaning and cultural context.

The following are example of statements made by the respondents:

Interview No. 2: Informant No. 6

"When I go for contraception, firstly there is a question when you go for family planning that says, 'why are you using contraceptives being a disabled person?' It becomes difficult for this question to be answered, because it is difficult to say why you are using contraceptives. I think I am supposed to practice contraception as a woman, even if I am disabled. When I go for delivery... when you arrive at the hospital, even in the community not in the hospital only, there is a question that says, 'why are you bearing children being disabled?' I don't know whether I am not supposed to bear children as a disabled person, because I need to have a family although I am disabled. Secondly even if you are married, there is a question that says, 'you are married being disabled, why?' I

don't know whether I don't have a right to marry. I want to have a husband. I want to have a family like others, because there are times when I will need to have my own children and send them. I am not going to send other people's children because there is a say that, 'nobody bears children for others'”

Interview No.8; Informant No. 16

“I was a laughing stock to nurses. They were saying, what links me to a man being disabled. Insulting me saying, ‘Moving from side to side, wobbling as you are what links you to a man?’ They were taking turns talking and laughing.”

Interview No. 10; Informant No. 22

“The nurses said, ‘no what we are not going to do is to attend to somebody who comes with a dead baby’ because I delivered the baby already dead. They [nurses] said, ‘we don't eat dead bodies, we are not vultures.’”

Interview No. 7; Informant No. 14

“After delivery, nurses told me that I must not deliver again as somebody like me is not supposed to bear children and the person who impregnated me, must be arrested.”

## Step 2

### **Identification of significant concepts**

Significant concepts were then extracted from the statements.

Interview No. 8; Informant No. 16

“I was a laughing stock to nurses. This made me feel bad because I have feelings and I am healthy. They [nurses] were laughing at disability. Insulting me saying, ‘Moving from side to side, and wobbling as you are what link you to a man?’ They were taking turns talking and laughing.”

Interview No. 10; Informant No. 22

“We [nurses] don’t eat dead bodies, we are not vultures.”

Interview No. 7; Informant No. 14

“Somebody like you are not supposed to bear children and the person who impregnated me must be arrested.”

Interview No. 6; Informant No. 4

“Is there a man that can love somebody who is crippling?”

Interview No. 1; Informant No. 2

“Old as you are, you don’t know labour pains?” This is the first thing I did not like to be told like that”

“The nurse that delivered me treated me badly by way of beating me. The nurse was forcefully bending it [the leg] and beating me.”

Interview No. 11; Informant No. 20

“There are indirect comments like, ‘you like men but you don’t want to be pregnant.’”

Interview No. 16; Informant No. 32

“I was told that as they [nurses] are taking me to theatre for delivery, I would be sterilized. As I am like this, I will not get children again because I am not the type of person to get children.”

### **Step 3**

#### **Identification of patterns**

The researcher looked out for recurrences in the identified concepts that might indicate patterns. These were categorized into clusters according to the meaning they conveyed and each category was given a label.

Category 1: Verbal insults

These women experienced a state of being verbally insulted.

Wobbling as you are

You like men but you don’t want to be pregnant

We [the nurses] don’t eat dead bodies

### Category 2: Physical Assault

There were also physical assaults.

The nurse treated me badly by way of beating me. The nurse was forcefully bending it [the leg] and beating me.

### Category 3: Humiliation

Some disabled women were being humiliated.

#### Direct humiliation

Is there a man that can love somebody who is a cripple?

Old as you are, you don't know labour pains?

Somebody like me is not supposed to bear children and the person who impregnated me, is supposed to be arrested.

You are supposed to keep yourself because you have no right to be in love.

As I am like this I will not get children again because I am not the type of person to get children.

#### Indirect humiliation

They were taking turns talking and laughing.

### Category 4: Discrimination

Before we got inside we were told to go and do exercises. Since I am a disabled person I told the nurse there that I could not manage to do exercises. She told me that she would not attend to me unless I do exercises. I stayed. I was not given antenatal care.

#### Category 5: Being told

Some women were not given the right to self-determination and were just told what to do.

I was told to sign

I was told that as they [nurses] are taking me to theatre I will be sterilized.

Nurses told me that I must not deliver again as somebody like me is not supposed to bear children.

#### Category 6: Being accused

Why are you using contraceptives being a disabled person?

Why are you bearing children being disabled?

You are married being disabled, why?

Why are you pregnant?

#### Category 7: Bargaining

The following patterns were identified and categorized under Bargaining.

On arrival at home I said [to myself], instead of getting such treatment when delivering, it is better for me to go for family planning, for me not to get another child.

As I did not want any mistake to occur, because of the way I was treated, I felt I must use depo.

#### Category 8: Self-resignation

The following concepts were found to indicate a state of being self-resigned.

But you bear with that because you are the person who needs to be helped.

Because you often have to accept the manner a person treats you in hospital, no matter how it is.

#### Category 9: Rights claimed

The following shows that this woman is claiming her rights.

I think I am supposed to practice contraception as a woman, even if I am disabled.

I don't know whether I am not supposed to bear children as a disabled person.

I need to have a family although I am disabled.

I don't know whether I don't have a right to marry.

I want to have a husband.

I want to have a family like others.

#### Category 10: Being valued

This category was labelled as "being valued"

I was asked which contraceptives I think will be best for me.

They asked me what I want for contraception.

Nurses were so caring

Even now when I am going to the clinic, I am treated well.

Nurses were so kind.

They [nurses] delivered me well. I was treated well.

#### Step 4

##### Major Themes

On further interrogation of the above categories the following major themes emerged:

##### Attack on self-worth

The following categories in the previous step reflected an attack on the self-worth of the participants: verbal insults, physical assault, humiliation, discrimination, accusations, being told

### Bargaining for self-protection

From the statements made it appeared that the participants entered into a state of compliance as a form of bargaining in order to protect themselves from negative situations that would occur as a result of non-compliance. The responses that indicate bargaining are shown in category 7 in step 3 above.

### Self-resignation

Disabled women also had to bear with some situations they came across, as these situations were beyond their control. This is illustrated by responses in category 8 in step 3 above.

### Rights claimed

One woman was claiming her right to love, right to marry, right to have children and right to have a family. This is shown by the responses in category 9 in step 3 above.

### Being valued

Some women appreciated the good care and kindness they got from health care professionals. They also appreciated the freedom of choice they were given. This is seen in the responses in category 9 in step 3 above.

The above themes are further clarified in the discussions that will follow below.

### Summary

The aim of this study was to explore and describe the experiences of disabled women attending the state-provided reproductive health care services regarding the quality of care rendered by health care professionals. The findings showed that the experiences of the disabled women who participated in this study varied. Some women had negative experiences and some had positive experiences. The negative experience they [disabled women] revealed was the 'Attack on self-worth', which is shown as follows: verbal insult, physical assault, humiliation, discrimination and accusations. They [disabled women] also bargained for self-protection. Because of the situations they were in which was beyond their control, they developed a state of being resigned. Some disabled women appreciated being valued by health care professionals in the reproductive health care services.

### 4.3. DISCUSSIONS

The discussions that follow are based on the responses of disabled women, which showed their experiences. Although the purpose of this study was to explore and describe experiences of disabled women regarding quality of care rendered by health care professionals, it was noticed from the findings that the women had experiences regarding care received from nurses only. Responses from informants showed experiences of attack on self-worth; bargaining for self-protection; self-resignation. Some responses showed that at some point disabled women claimed their rights. Some responses showed that disabled women appreciated being valued in the reproductive health care services. These responses will then be discussed.

#### **Attack on self-worth**

Disabled women revealed in their responses the experiences of being verbally insulted, physically assaulted, humiliated and discriminated by nurses. Some nurses adopted an accusatory approach.

One woman was literally laughed at by nurses and they also insulted her verbally. This woman's voice was lowering down as she was narrating her story and you could hear that she is deeply hurt as she is talking. (See Annexure 1 Response No 1-3) She even said, "This made me feel bad because I have feelings and I am healthy." The latter part shows this woman's self-ego. It shows that she does not know why they [nurses] were laughing

at her like that as she knows that she is healthy and there is absolutely nothing wrong with her.

One woman delivered a dead baby and had Retained Products of Conception (the placenta and the membranes) that needed to be removed in hospital. She was in hospital the day before (Friday) and was told to go home because her doctor was in theatre and she should come on Monday. She then delivered this dead baby Friday night and went to hospital early hours on Saturday. This woman was so hurt when narrating this story, in so much that she broke into tears. Crying showed the pain she experienced and its effect on her. Although this happened four (4) years ago it still comes to the fore from her subconscious mind. (See Annexure 1 Response No: 8) Although this woman tried to use internalised oppression to resist these painful memories, they continue to hurt her inside that is why she is still crying after four years of the incident.

Nurses physically assaulted one woman. Beating clients is totally unacceptable in any public service. Each public servant in South Africa needs to render services in an acceptable and agreed standard as laid down by the Department of Public Service.

Some women were told what to do by nurses. Such instructional authoritative approach is not in line with the Batho Pele principle of Consultation. This principle indicates that people should be consulted about the level and quality of the services they receive and wherever possible, should be given a choice about the services that are offered. (Department of Public Service and Administration 1997). These disabled women were to

be consulted for whatever service that was going to be rendered to them not to be told what to do. This is also against the slogan of their organization, Disabled People South Africa, which says, "Nothing about us without us." This slogan says that nobody is expected to do whatever for a disabled person without consulting her/him. Consultation is so important for disabled person. The Batho Pele Principle of service standards was also not observed by these nurses. This principle indicates that people should be informed about the level and quality of services they will receive so that they are aware of what to expect. People should get full and accurate information about what they are entitled to receive. (Department of Public Service and Administration 1997).

The participants were subjected to accusations.

Nurses also adopted an accusatory approach in responses like;

"Why are you using contraceptives being a disabled person?"

"Why are you bearing children being disabled?"

"You are married being disabled, why?"

"Why are you using contraceptives, there is no man that can love you."

"Why are you pregnant again?"

This accusatory approach indicates that nurses do not consider disabled women as women. Mda et al in Goosen & Klugman (1996) also indicates that disabled women are not seen as worthy of being mothers. The Integrated National Disability Strategy (INDS) indicates that disabled women should be seen as women first, and then as disabled. (Office of the Deputy President 1997: 4) All the health care professionals should consider this when dealing with disabled women, as it is very important.

Boylan (1991: 52) says that, "In some societies it is considered somehow shocking that a disabled woman should marry..." It looks like this society where the study was conducted belongs to those, hence the question by the nurses, "you are married being disabled, why?"

It is also the culture of the society where the study was undertaken that women are expected to perform most of the household chores. The members of society often think that if someone has a physical impairment, she cannot marry because she is not capable of performing these household chores. Boylan (1991: 55) agrees with this when she says, "In developing countries... disabled women... have difficulties finding a spouse because much physical labour is expected from wives..." This means to them [members of society] that if you are physically impaired you are not capable of performing physical labour and as such not capable to be a wife.

### **Bargaining for self-protection**

Some women chose to attend family planning because of the negative experiences during their visits to the reproductive health care services. One woman indicated that she was told that depo is stronger than nuroisterate and she chose depo because she did not want to be pregnant again, because of the manner she was treated. (See Annexure I Responses 11)

One woman decided not to have a child and go to family planning because of the treatment she got during delivery. (See Annexure I Response 22)

**Self-resignation**

Some women showed a state of being self-resigned, because they found themselves in situations that were beyond their control (See Annexure 1 Responses 6 & 7). They felt that since there is absolutely nothing they can do about these situations they have to accept.

**Rights valued**

One of the responses showed that the rights are being claimed. This woman could not see why she should not get her right to marry, right to have children and the right to have a family. (See Annexure 1 Response 4) Disabled women are often denied their rights as women. Boylan (1991) agrees with this statement when she says, " ... disabled women are systematically denied the most human rights- the right to love, the right to marriage, the right to motherhood, the right to personal fulfilment." She further indicates that disabled men are more likely to love and marry than disabled women.

**Being valued**

Some disabled women's responses showed appreciation of being valued by nurses in the reproductive health care services. Disabled women appreciated the respect they got from nurses. Their statements showed that they were given freedom of choice (See Annexure 1 Response 16), which restored their self-worth as disabled women. In the White Paper on an Integrated National Disability Strategy it is indicated that disabled women should be seen as women first. (Office of the Deputy President 1997: 4) They should get whatever

respect other women are being given, as they are also women. These women also appreciated the good treatment they got from nurses. (See Annexure 1 Responses 17, 18, & 19) The good treatment they got is in line with the Batho Pele Principle of Courtesy. This principle indicates that people should be treated with courtesy and consideration. (Department of Public Service and Administration 1997)

#### **4.4. CONCLUSIONS AND RECOMMENDATIONS**

##### **4.4.1. Conclusions**

The vision of the Integrated National Disability Strategy (INDS) is a “society for all.” This concept of a “society for all,” means that all citizens, (disabled people inclusive) form part of societal activities. (Office of the Deputy President 1997: 18) It also means that the general systems and institutions of society are accessible to all people. It also means that the rights of all people should be respected.

In this study the conclusion is that the rights of most disabled women to be respected citizens of this country were not considered. According to the South African Constitution, Act 108 of 1996, Section 27(1) (a) everyone has the right to have access to health care services including reproductive health care. (Republic of South Africa 1996: 13) The rights of these disabled women as women who should access these health care services were violated.

Mda et al in Goosen & Klugman (1996) says that disabled women are more exploited, marginalized and discriminated and this is due to the fact that disabled women are not

regarded as worthy of being mothers. People often assume that disabled women cannot achieve the status of being mothers or wives. It is concluded that these assumptions are the cause of this attack on self-worth of disabled women. The assumptions are also the cause of violation of disabled women's rights in the reproductive health care services.

The United Nations issued a document called the Standard Rules for Equalization of Opportunities for persons with disabilities. This document calls for accommodation of diverse needs of disabled people in society. It also indicates that appropriate, accessible health services at all levels are essential for equalization of opportunities for people with disabilities. (United Nations 1994:6) It is then concluded that this equalization of opportunities in the health sector is not happening because these experiences of disabled women show that they are not seen as equal with their counterparts, non-disabled women. They are not seen as capable of being in love, bearing children or marrying.

The Integrated National Disability Strategy also calls for elimination of discrimination against women with disabilities. It calls for development and implementation of measures to identify and reduced discrimination on the basis of disability in the health sector. (Office of the Deputy President 1997: 26). Government departments and state bodies should ensure that measures are taken to ensure that disabled people are able to access the same fundamental rights and responsibilities as any other citizen in South Africa. It is concluded that disabled women don't access the same fundamental rights as other citizens. When trying to do so they meet obstacles.

#### 4.4.2. Recommendations

It is recommended that an environment that leads to full participation of disabled women at all levels of society should be created. The disabled women are responsible for creating this environment themselves. From this study it was also evident that if disabled women are given chance to express their views, they can live better lives. Some of them were capable of arguing in whatever was happening to them. For example one woman was told to sterilize, but she said, "I am not sterilizing with one child."

Disabled women should stand up and fight for their rights at all levels of society. Disabled People South Africa (Organization for disabled people) has a women's wing. This wing has national, provincial, regional and local structures. The aim of this wing is mainly to ensure that the issue of rights of disabled women is addressed. It was discovered that these women experience the same oppression as non-disabled women, but the former are denied the right to be mothers or wives. They [disabled women] experience more discrimination than other women. This wing is empowering disabled women to be at the forefront in human rights and development issues of disabled women. They [disabled women] should not wait for somebody else to do that for them. (Office of the Deputy President 1997: 4) Nowadays disability is regarded as a human rights and development issue. This understanding leads to recognition of the fact that disabled people are equal citizens and should enjoy equal rights and opportunities. (Office of the Deputy President 1997: 10) Since Flagstaff and Lusikisiki disabled women are affiliates of Disabled People South Africa and also of this women's wing, it is recommended that

they should take a lead in fighting for humiliation, discrimination and all the negative experiences discussed above.

Disabled women should participate equally in society like other members. Since the study assisted in the identification of violation of disabled women's rights, it is recommended that disabled women should be included in the health care governing structures. These include clinic committees, hospital boards and rehabilitation health forums. This violation of disabled women's rights should be discussed and solved in these structures. Involvement of disabled women will ensure that their needs and concerns are fully catered for. This will assist in raising awareness on disability issues and to prevent violation of disabled women's rights in the health sector. Disabled women will then be active participants in health matters.

Further research study is recommended to check this self-representation and its impact on health care delivery to disabled women. In the Disability Rights Charter, self-representation is one of the rights and also the disabled people have a slogan, "Nothing about us without us," to reinforce this self-representation.

#### **4.5. LIMITATION OF THE STUDY**

The first limitation is that disabled women with hearing, mental, cognitive and speech impairments were excluded and as such the study cannot be generalised to these women. Another limitation is that the study was undertaken in a rural area and cannot be generalized to an urban setting.

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## ANNEXURE I

### RESPONSES OF DISABLED WOMEN

1. "But in the second born when going to the clinic, I discovered that there is something laughable about disability. As if I am not suppose to have a child. I don't know how to explain this. I was a laughing stock to nurses. This made me feel bad (Tone of voice lowering) because I have feelings and I am healthy. I don't see any unhealthy thing in me. What happened nurses did not tend to me, until I delivered on my own"--- (Pause)

2. "When I was pregnant another child, prepared to go and be sterilized, I was chased away from the hospital, which I was telling myself it is ours. I was told to go back to the clinic. Those things upset me, because I know my condition. I go [to hospital] because I don't feel healthy otherwise I would not go to hospital for delivery. I don't feel healthy." (Voice becoming softer)--- (Pause)

3. "They [nurses] were laughing at disability. They were saying, what links me to a man being disabled --- (Pause) Insulting me saying, 'Moving from side to side, wobbling as you are what links you to a man. We cannot tend to you because you like men, disabled people.' They were taking turns talking and laughing."

4. "E--e-- When I go for contraception, firstly there is a question when you go for family planning that says, 'why are you using contraceptives being a disabled person?' ... It becomes difficult for this question to be answered, because it is difficult to say why you

are using contraceptives, I think I am supposed to practice contraception as a woman, even if I am disabled. When I go for delivery... when you arrive at the hospital, even in the community not in the hospital only, there is a question that says, 'why are you bearing children being disabled?' I don't know whether I am not supposed to bear children as a disabled person, because I need to have a family although I am disabled. Secondly even if you are married, there is a question that says, 'you are married being disabled, why? I don't know whether I don't have a right to marry, I want to have a husband, I want to have a family like others, because there are times when I will need to have my own children and send them, I am not going to send other people's children because there is a say that, "nobody bears children for others"'

5. "All this is said at the clinic, although I have not been treated well. But we bear with that although it is like that." (Tone of voice becoming lower)

6. "Where I got ill treatment, I got it in my third born, in one hospital I am not going to mention by name. When coming from theatre, after operation, the nurse who came to me in the morning did not treat me well.... But in hospital you often have to accept the manner you are treated, no matter how it is. ... The result of that caused me to bleed a lot. I got pale whilst in hospital, after delivery. Another nurse came and saw that I am pale... she asked me what happened. I told her that the nurse, who came in the morning, as I arrived during the night from theatre, came and said I must get out of bed in a manner that is not good and instructed me to go and wash.... When I was getting out I was dizzy, I fell painfully and the urinary bag I was holding came out."

7. "When I go for family planning, I get scared even before arriving at the nurses. This is a problem for people with disabilities. When going for family planning things are said, like, 'what are you using contraceptives for, being a cripple? What are you going to do? Is there a man that can love somebody who is a cripple?' So you fear being asked such questions. But you bear with that because you are the person who needs to be helped and not to have a large family. But they ask, why are you using contraceptives, there is no man that can love you being disabled."

8. "There is a problem maybe when you go for antenatal... you are asked how many children do you have as a disabled person? It is said, 'why are you pregnant? Why are you pregnant again?' Your answer may be that, 'I am pregnant because I want two children.' ... I don't know whether a person is not allowed to have two children. You start to be angry... I had a problem when pregnant the second child. I was sick... I was admitted... I was then discharged... the doctor told me to come the following week. On arrival [the following week] I was told doctor is ... in theatre, I was not going to get him/her. I was told to go home and come on Monday. That ... Friday night... it happened that I delivered... I went back to hospital... I explained to nurses that I came and I could not get the doctor... the nurses said, 'no, what we are not going to do is to attend to somebody who comes with a dead baby.' because I delivered the baby already dead. They [nurses] said, 'we don't eat dead bodies, we are not vultures.' ... Nurses reprimanded me... I was telling the nurses that I never felt labour pains. They said I am lying. I say we get abused so much. They also have a tendency to say if you are disabled,

sterilize before time. They also said so to me, I must sterilize. I said, I am not going to be sterilized, having one child. I am still saying that I am not sterilizing having one child.

Night nurses reprimanded me. I got help at 08h00. Nurses managed to remove after births that remained that time [of delivery] I was telling the nurses that I didn't feel any labour pains. They [nurses] said I am lying--- (Pause) (started crying) I am saying we are abused so much. The fact that you are pregnant amazes them. I don't know what is wrong with nurses."

9. "I can say this regarding women's health services, m-- m-- I can make an example by the time I was pregnant, attending antenatal clinic. I did not have any problems. I was getting the services well. I only got problems when going for delivery. I went to wait at the hospital before delivery time. As a person who was pregnant for the first time, I did not know the signs of onset of labour. As a waiting mother in female ward, I had to go to labour ward [when labour starts]. On arrival in labour ward I will tell the nurses that something is eating me in my tummy, and I could not clearly say that I have labour pains. It looked like the way I was saying this is not clear. They said to me, 'don't you know labour pains? Are you not in labour? Old as you are, you don't know labour pains? We want a person who is in labour here, not a sick one.' This is the first thing I did not like to be told like that, 'we don't want somebody who is eaten by something but we want somebody who is in labour. Go back because you are not in labour.'"

10. "The nurse that delivered me treated me badly, by way of beating me. As a disabled person, my leg was stiff and could not bend when I want it to.... My disability was new, I

was not even using crutches but my leg could not bend. The nurse was forcefully bending it [the leg] and beating me."

11. "My experience with family planning, I discovered that they let you chose from two things. Depo and nuristerate are being used. You are told how they work. That nuristerate is not stronger than depo. As I did not want any mistake to occur, because of the way I was treated, I felt I must use depo."

12. "When I was in labour I was told to sign and I was told that as they [nurses] are taking me to theatre for delivery, I would be sterilized. As I am like this, I will not get children again because I am not the type of person to get children."

13 "After delivery, nurses told me that I must not deliver again as somebody like me is not supposed to bear children and the person who impregnated me, must be arrested."

14. "When I arrived at the clinic on the first day for family planning, one nurse asked me, 'why are you using contraceptives?' I said I am using contraceptives because I don't want to get a child.... She said, 'you are supposed to keep yourself because you have no right to be in love.'"

15. "Before we got inside we were told to go and do exercises. Since I am a disabled person I told the nurse there that I could not manage to do exercises. She told me that she would not attend to me unless I do exercises. I stayed. I was not given antenatal care."

16. "I went to antenatal clinic. I was treated well. In so much that when other women were picking dolls, I was told not to pick because I am a disabled person. I was just looking at them [other pregnant women] picking. I was told at nine months to come and wait at the hospital... Nurses were so caring. When I was in labour, nurses delivered me well. I was treated well until the day for me to be discharged. I started family planning. Even then I was treated well. Even now when I go to the clinic, I am treated well. I started family planning in 1996. Even then I was treated well. I was asked which contraceptives I think will be best for me. Even now when I go to the clinic, I am treated well."

17. "I will talk about antenatal service. I was treated well. Nurses were so kind... I was treated well. I delivered with an operation. I also attended antenatal care well with my second born. Nurses treated me well."

18. "Only one child I delivered at the clinic. Nurses delivered me well."

19. "By the time I went for family planning at the clinic, I was treated well. And also during pregnancy I was not ill treated at the antenatal clinic. The time where I was not treated well is the time I went to hospital for delivery. I got ill treatment. ... I had labour pains and about to deliver, and I was told I am not in labour. I must go and stay in the waiting area. I was in labour.

20. "The third time was at least well. But the clinic we have does not have people with human element. I went there being in labour already and nobody cared for me. I stayed until I delivered on my own being alone in the room. That made me not to know what I am here in the clinic to do. In so much that I ended up not knowing what the clinic is for. Even now I don't know what the help of the clinic is.

21. "Whilst in the ward I was awakened and told to go and wash, still unable to walk. Delivered by an operation. I was unable to walk and I was still weak. I tried by all means to go and wash. I stayed in hospital, feeling a lot of pains and my blood pressure was high. I stayed in hospital for 8 days. I went home. "On arrival at home I said that, instead of getting such treatment when delivering, it is better for me to go for family planning, for me not to get another child."

22. "In 1993 I saw that okay because my child is old now I am still going to go my old ways. I went to family planning. This time when I arrived at the clinic on the first day, one nurse asked me, 'why are you using contraceptives?' I said I am using contraceptives because I don't want to get a child. She [the nurse] said, 'you are supposed to keep yourself because you have no right to be in love.' I said, 'why, because I have feelings, why am I not supposed to be in love?'"

23. "There are indirect comments like, 'you like men but you don't want to be pregnant.'"

24. "They [nurses] say, 'why are you giving birth?'"--- (Pause)

25. "My first day, m--m-- You are looked at when walking to the clinic for family planning. Then you will be asked your problem. You say, 'I am coming for family planning.' It is said, 'what are you using contraceptives for being a cripple?' It is not easy to answer. But you say, 'I don't want a child.' You don't want to have children. 'Are you in love being a cripple? Is there a man that can love you? At the end they help you, you don't go out without being helped"--- (Pause)

26. "I've already said that they have a tendency of passing remarks when you go for family planning. I stopped using contraceptives. I had a fear that it is going to be worse now that I come being pregnant, in what they said before [during family planning]. They [nurses] asked, 'is there someone who damages a government person, by way of ending up impregnating her? Why were you not using contraceptives?' I told them that I was afraid to come to the clinic because I was asked this and that, asked also why am I using contraceptives. But at last they helped me. You don't go out without getting help"--- (Pause)

27. "I already had experiences from the first child. The nurses repeated the question that says, 'why are you giving birth being disabled?' My reply was that we are preparing for us [disabled women] so that we can have people to assist us at the end when we are old. As the time goes on you need somebody to assist you especially with disability that is why we give birth".... (Long Pause)

**ANNEXURE 2. COPY OF ETHICS APPROVAL FROM UNIVERSITY OF  
CAPE TOWN**

University of Cape Town

UNIVERSITY OF CAPE TOWN

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Research Ethics Committee  
E53 Room 44.1, Old Main Building Groot  
Schoor Hospital, Observatory, 7925  
Queries : Xolile Fula  
Tel : (021) 406-6492 Fax: 406-6411  
E-mail : Xfula@curie.uct.ac.za

20 August 2004

REC REF: 300/2004

Ms V Nokwanele Mgwili  
c/o Prof NJ Mekwa  
Health & Rehabilitation Sciences

Dear Ms Nokwanele Mgwili

EXPERIENCES OF THE DISABLED WOMEN ATTENDING THE STATE PROVIDED REPRODUCTIVE  
HEALTH CARE SERVICES REGARDING THE QUALITY OF CARE RENDERED BY HEALTH CARE  
PROFESSIONALS IN THE EASTERN CAPE

*Thank you for submitting your study to the Research Ethics Committee for  
review.*

*It is a pleasure to inform you that the Ethics Committee has formally approved  
the above-mentioned on the 18<sup>th</sup> August 2004.*

Please quote the REC. REF in all your correspondence

Yours sincerely

  
PROF. T. ZABOW  
CHAIRPERSON

**ANNEXURE 3: COPY OF THE LETTER TO THE MAYOR OF QAUKENI  
MUNICIPALITY**

University of Cape Town

P.O.BOX 465  
LUSIKISIKI  
4820  
20:07:2004

The Mayor  
Qaukeni Municipality  
Flagstaff  
4810

Dear Sir/Madam

**Permission to conduct a study: Myself**

I am a student registered for the Masters of Philosophy Degree in Disability Studies at the University of Cape Town. I would like to request for your permission to conduct a research study at Flagstaff & Lusikisiki. The title of the study is "Experiences of the disabled women attending the state-provided reproductive health care services regarding the quality of care rendered by health care professionals in the Eastern Cape.

The purpose of the study is to explore and describe the experiences of the disabled women attending reproductive health services in the Qaukeni Health District. It is hoped that the findings from this study will help in improving the quality of care received by women with disabilities who visit the clinics in the state-provided services.

To obtain the necessary information each of the participating women will be interviewed. All information received will be treated with utmost confidentiality and no names of respondents will be revealed. Permission will also be obtained from each woman individually and only those who give their consent will participate in the study. The findings of the study will be communicated to authorized stakeholders and also published in professional media sources.

Kindly forward your response to the above-mentioned address. Should further information be requested on this matter please let me know.

Yours sincerely

.....  
V.N.Mgwili (Student No: MGWVIC003)

**ANNEXURE 4: COPY OF THE REPLY LETTER FROM MAYOR OF  
QAUKENTI MUNICIPALITY**

University of Cape Town

**QAUKENI LOCAL MUNICIPALITY**  
Province Of The Eastern Cape

135 Main Street  
P.O. Box 14  
Flagstaff  
4810



Tel: 039 252 0037/58/78/89/90  
039 252 0131/61  
Fax: 039 252 0699

23<sup>rd</sup> August 2004

Miss V.N Mzwili  
P.O.Box 465  
Lusikisiki  
4820

Dear Madam

RE – PERMISSION TO CONDUCT A RESEARCH STUDY ON DISABLED WOMEN WITHIN QAUKENI LOCAL MUNICIPAL AREA.

Your letter dated 20<sup>th</sup> July 2004 refers.

Permission is hereby granted to you to conduct a research study on disabled women within the area of jurisdiction of Qaukeni Local Municipality which comprises Flagstaff and Lusikisiki towns.

Findings of such research study might assist Qaukeni Local Municipal Council to formulate policies which could facilitate service delivery to all disabled people in the area.

I wish you good luck in your studies.

Yours Faithfully

A handwritten signature in black ink, appearing to be 'L.V. Ntsubane', written over a horizontal line.

His Worship- The Mayor  
L.V. Ntsubane

**L.V. NTSUBANE - MAYOR**

**ANNEXURE 5: COPY OF THE LETTER TO THE CHAIRPERSON OF  
FLAGSTAFF SELF-HELP GROUP PROJECT SITE**

University of Cape Town

P.O.BOX 465  
LUSIKISIKI  
4820  
20:07:2004

The Chairperson  
Masimanyane Centre  
Flagstaff  
4810

Dear Sir/Madam

**Permission to conduct a study: Myself**

I am a student registered for the Masters of Philosophy Degree in Disability Studies at the University of Cape Town. I would like to request for your permission to conduct a research study at Masimanyane Centre. The title of the study is "Experiences of the disabled women attending the state-provided reproductive health care services regarding the quality of care rendered by health care professionals in the Eastern Cape.

The purpose of the study is to explore and describe the experiences of the disabled women attending reproductive health services in the Qaukeni Health District. It is hoped that the findings from this study will help in improving the quality of care received by women with disabilities who visit the clinics in the state-provided services.

To obtain the necessary information each of the participating women will be interviewed. All information received will be treated with utmost confidentiality and no names of respondents will be revealed. Permission will also be obtained from each woman individually and only those who give their consent will participate in the study. The findings of the study will be communicated to authorized stakeholders and also published in professional media sources.

Kindly forward your response to the above-mentioned address. Should further information be requested on this matter please let me know.

Yours sincerely

.....  
V.N.Mgwili (Student No: MGWVIC003)

**ANNEXURE 6: COPY OF REPLY LETTER FROM THE CHAIRPERSON  
OF FLAGSTAFF SELF-HELP PROJECT SITE**

University of Cape Town

MASIMANYANE ARTS & CRAFT BUSINESS CENTRE  
P.O. BOX 8  
HOLY CROSS  
FLAGSTAFF  
4810  
25 AUGUST 2004

Miss V.N. Mgwili  
P.O. Box 465  
Lusikisiki  
4820

Dear Madam

As this group, we agree that you can conduct your study to the disabled women. We hope we will work together with you in your study.

Yours faithfully

MASIMANYANE ARTS & CRAFTS  
BUSINESS CENTRE  
P.O. BOX 8 HOLY CROSS 4811



N. Mxinzelwa

2004 -08- 25

SIGNATURE: .....

**ANNEXURE 7: COPY OF THE LETTER TO THE CHAIRPERSON OF  
LUSIKISIKI SELF-HELP GROUP SITE**

University of Cape Town

P.O.BOX 465  
LUSIKISIKI  
4820  
20:07:2004

The Chairperson  
Ziphilise Craft Centre  
Lusikisiki  
4820

Dear Sir/Madam

**Permission to conduct a study: Myself**

I am a student registered for the Masters of Philosophy Degree in Disability Studies at the University of Cape Town. I would like to request for your permission to conduct a research study at Ziphilise Craft Centre. The title of the study is "Experiences of the disabled women attending the state-provided reproductive health care services regarding the quality of care rendered by health care professionals in the Eastern Cape.

The purpose of the study is to explore and describe the experiences of the disabled women attending reproductive health services in the Qaukeni Health District. It is hoped that the findings from this study will help in improving the quality of care received by women with disabilities who visit the clinics in the state-provided services.

To obtain the necessary information each of the participating women will be interviewed. All information received will be treated with utmost confidentiality and no names of respondents will be revealed. Permission will also be obtained from each woman individually and only those who give their consent will participate in the study. The findings of the study will be communicated to authorized stakeholders and also published in professional media sources.

Kindly forward your response to the above-mentioned address. Should further information be requested on this matter please let me know.

Yours sincerely

.....  
V.N.Mgwili (Student No: MGWVIC003)

**ANNEXURE 8: COPY OF THE REPLY LETTER FROM THE  
CHAIRPERSON OF LUSIKISIKI SELF-HELP GROUP SITE**

University of Cape Town

Ziphilise Craft Centre

Lusikisiki

4820

24:08:2004

Miss V.N.Mgwili

P.O.Box 465

Lusikisiki

4820

Dear Sir/Madam

Re: Permission to conduct a Research Study at Ziphilise Craft Centre

We acknowledge receipt of your letter dated 20:07:2004. We hereby grant you permission to conduct the study and promise you our full support and co-operation.

Thank you

Yours faithfully



Z. Ngoma (Secretary)

**ZIPHILISE CRAFT CENTRE**

LUSIKISIKI 4820

EASTERN CAPE

PHONE: 083 532 5752

**ANNEXURE 9: COPY OF CONSENT FOR INFORMANTS**

University of Cape Town

**CONSENT FOR PARTICIPATION IN A RESEARCH STUDY**

My Name is Victoria Nokwanele Mgwili and I am a student registered for the Masters of Philosophy Degree in Disability Studies at the University of Cape Town. I am conducting a research study. The title of the study is, "Experiences of the disabled women attending the state-provided reproductive health care services, regarding the quality of care rendered by health care professionals in the Eastern Cape." The purpose of the study is to explore and describe the experiences of the experiences of the disabled women attending reproductive health services in the Qaukeni Health District.

You are kindly requested to participate in this study. Although the study will not benefit you directly, it is hoped that the findings from this study will help in improving the quality of care received by women with disabilities who visit the clinics in the state-provided services. You will not be exposed to any obvious risks during the study.

Your participation will mean that you will meet with me once for an audiotaped interview, which will last for an hour. As a researcher I will also be taking some field notes during the interview. I will keep a record of the participants in the study and I will also keep the tapes of the interviews together with a transcription, so the data will not be linked with your name. The data will be stored in a safe place and the tapes will be erased on completion of the study.

Your participation in the study is totally voluntary. You have a right to agree or disagree to participate or to withdraw your participation anytime during the course of the study, should you wish. A commitment will be undertaken to inform you about the study in your own language, so that you may understand and use it in your struggle for recognition of your human rights.

*Declaration by the researcher*

I have discussed the above points with the respondent. In my opinion the respondent understands the risks, benefits and obligations of participating in this study.

.....  
Researcher's signature

.....  
Date

*Consent by the respondent*

I understand that my participation in this study is voluntary and that I may refuse to participate or withdraw my consent and stop my participation anytime.

I hereby freely consent to participate in this study.

.....  
Signature of respondent

.....  
Date

.....  
Signature of witness

.....  
Date