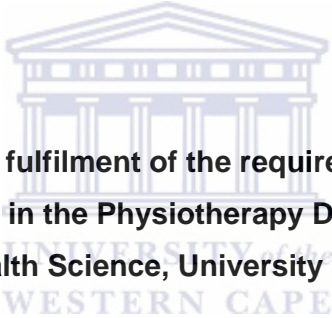


**PARADOX OF RISK: SEXUALITY AND HIV/AIDS  
AMONG YOUNG PEOPLE WITH PHYSICAL  
DISABILITIES IN NYANGA, SOUTH AFRICA.**

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**Thesis Submitted in the fulfilment of the requirements for the degree of  
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Community and Health Science, University of the Western Cape**

The logo of the University of the Western Cape, featuring a classical building with columns and a pediment, with the text 'UNIVERSITY of the WESTERN CAPE' below it.

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## ABBREVIATIONS

WHO	World Health Organisation
UWC	University of the Western Cape
DPSA	Disabled People South Africa
DFID	Department for International Development
HIV	Human Immuno-deficiency Virus
AIDS	Acquired Immuno-deficiency Syndrome
HSRC	Human Sciences Research Council
CASE	Community Agency for Social Inquiry
JEP	Joint Enrichment Project
CBR	Community Based Rehabilitation
ABC	Abstain, Be faithful, Condom use
ICF	International Classification of Functioning, Disability and Health
DRCSA	Disability Rights Charter of South Africa
VICE	Visualisation, Integration, Serendipity, Exploration
UNAIDS	United Nations and AIDS
UN	United Nation
UNICEF	United Nations Children Education Fund
AMREF	African Medical and Research Foundation
INDSP	Integrated National Disability Strategy Paper
PET	Postgraduate Enrolment and Throughput Project

## DEFINITION OF TERMS

**Physical disability:** Physical disability refers to damage to muscles, nerves, skin, or bones that lead to difficulties in moving about, in performing activities of daily living, such as dressing, eating, and cleaning. Examples of physical disabilities include Cerebral Palsy, Quadriplegia, Paraplegia, Hemiplegia, and post-Polio paralysis (DPSA, 2001: 19). [Detailed definition in Chapter 1].

**Paradox:** A paradox is a statement that sounds absurd or seems to contradict itself, but may in fact be true. It can also be a person or thing that combines contradictory qualities (Soanes, 2002: 607)

**Risk:** Risk is a systematic way of dealing with hazards and insecurities induced and introduced by modernisation itself (Beck, 1992: 21).

**Sexuality:** Sexuality is a capacity for sexual feelings. It can also be defined as a person's sexual preference (Soanes, 2002: 767). [Detailed definition in Chapter 1].

**Social construction:** Social construction refers to the socially created nature of social life. More specifically, the idea that society is actively and creatively produced by human beings (Marshall, 1994: 609).

## KEY WORDS

Physically disabled young people, sexuality, HIV/AIDS, contextual factors, discrimination, fluctuating identity, fatalistic attitudes, community-based and inclusive HIV/AIDS services, Nyanga, South Africa

## ABSTRACT

The current study aimed to describe the paradox of risk through an exploration of the experiences and perceptions of sexuality and HIV/AIDS among physically disabled young people in Nyanga, South Africa. This is against the background that AIDS has become a national and global crisis, which requires all people to participate in efforts to contain the pandemic. Yet literature indicates that young people with disabilities are not participating in such efforts. There is also an assumption, that physically disabled young people do not experience challenges in expressing their sexuality and accessing HIV/AIDS prevention services, to the same extent as other disability groups such as the blind and those with intellectual disabilities. Hence there was a need to explore disabled young people's own understanding of risk and the factors that hinder or support their participation in existing sexuality education and HIV/AIDS prevention programmes. It was also important for this group to suggest ways in which they may participate in such programmes.

A qualitative case study design was chosen as the appropriate means for achieving the aim of the current study. This design allowed me to study disabled young people without separating them from their context. In this way, a comprehensive understanding of this group was realised. Multiple methods of data collection from multiple data sources were employed, a feature that helped to discuss the 'case of disabled young people' in-depth and breadth.

Policy and programme documents and relevant literature were reviewed for relevant information on sexuality education and HIV/AIDS prevention services for disabled young people. Fifteen disabled young people between the ages of 15 and 24 participated in individual in-depth interviews and in focus group discussions. Pertinent issues that arose from individual interviews were discussed with 15 parents, 15 senior citizens, five sangomas and five counsellors in focus group discussions of 4-10 members each. Similar issues from focus group discussions were taken up with eight key informants in more individual in-depth interviews for confirmation and clarity.

Textual and contextual features of the Atlas.ti computer programme for analysing qualitative data were used to organize and analyse data. The textual features were used to code data and write memos, while the contextual features were used to link the codes and to form networks from which categories and themes were generated. Themes and sub themes were used to answer the research questions and meet the objectives of the study.

The study has revealed a complex interplay of contextual and individual factors that combine to create situations of risk for disabled young people. These factors affect disabled young people's experiences of growing up and participation in existing sexuality education and HIV/AIDS prevention programmes. Contextual factors include cultural beliefs and poverty, while individual factors include sexual behaviour and attitude towards HIV risk. I found that disabled young people have limited access to education and other social amenities, which in turn affect their experiences of life in general and sexuality and HIV/AIDS.

The study has revealed that the paradox of risk lies in the contradictory scripts and attitude towards the pandemic at contextual and individual levels. The belief that disabled young people are asexual is common in Nyanga, yet society targets this group for sexual exploitation and rape. In the face of an epidemic that has crippled the fabric of society, and in spite of the widespread availability of HIV/AIDS awareness programmes, most disabled young people still do not have accurate factual knowledge about HIV/AIDS. Yet accurate information is one of the prerequisites for making informed decisions about HIV/AIDS prevention.

Furthermore, gender differences make the experiences described above more serious for disabled young women who suffer discrimination and sexual abuse even from fellow disabled young men. Although most disabled young people indicated that they are aware of the gravity of the pandemic and that they personally feel threatened, they are not taking preventive measures against contracting the infection; they have adopted a fatalistic response to risk.

Participants argue that in the same way they are not able to protect themselves from going hungry, or living in shacks, they also cannot prevent getting infected with HIV, which they equate to any accident over which they have no control.

Disabled young people expressed the need to participate in mainstream education systems, sexuality education and HIV/AIDS prevention programmes. They also pointed out that there will always be disabled young people who require separate programmes because of special disability circumstances such as inability to travel to clinics/centres.

In order to meet disabled young people's expressed wishes, I have recommended in this thesis, a community-based sexuality education and HIV/AIDS prevention programme that focuses on the whole community instead of individuals only so as to deal with contextual and individual factors of risk. Such a programme encourages dialogue and participation as opposed to the information giving approaches from experts. A guideline that existing HIV/AIDS intervention programmes can use to include disabled young people's special circumstances, has been presented.

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# CHAPTER 1

## SETTING THE SCENE

### 1. INTRODUCTION

The problem of HIV/AIDS has been extensively described in literature as it affects the general population and not as it affects young people with disabilities<sup>1</sup>. There is growing concern about the vulnerability of this population to HIV infection in South Africa and the whole sub-Saharan region. While all young people are vulnerable to HIV/AIDS (Shisana and Simbayi, 2002), the special circumstances surrounding young people with disabilities make their situation more desperate and in need of immediate attention (Kelly, Ntlabati, Oyosi, van der Riet, and Parker, 2002a). Although Kelly *et al* (2002a) and Groce (2003) describe all disabled young people as a particular key group that is overlooked in global and national efforts to stop the spread of HIV/AIDS; this study only focuses on physically disabled young people.

A search of literature on disability and HIV/AIDS reveals a few studies on the subject as it affects intellectually disabled young people (Blanchett, 2000; Brown and Jemmot, 2000), blind young people (Kelly *et al*, 2002a), and disabled people in general (Groce, 2003), but little on physically disabled young people. Besides, many of my physiotherapy colleagues have questioned the relevance of the current study in the field of rehabilitation. While indeed HIV/AIDS is primarily a medical problem, contextual factors surrounding the disease, create complex situations that require multidisciplinary approaches to the problem. Most of such approaches are necessarily beyond medical interventions and some of those will be explored in the current study.

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<sup>1</sup>In this thesis the phrases 'young people with physical disabilities' and 'disabled young people' are used interchangeably: The disability rights movement of South Africa accepts both terms as opposed to terms like 'the disabled, the sufferers or the victim', which cast disability as a negative (DPSA, 2001: 16).

## **Definitions**

For the purposes of the present study, physical disability is defined as a limitation in one or more activities of daily living such as moving around, eating and dressing (Schneider, Classens, Kimmie, Morgan, Naicker, Roberts, McLaren, 1999). In addition, the Department for International Development (DIFID) (2000: 2) defines 'physical disability' as the outcome of complex interactions arising from a person's physical condition and their social and physical environment. This implies that, like other disabilities, physical disability has multiple dimensions and is far more than an individual health and medical problem.

Similarly, sexuality is defined as the integration of the physical, emotional, intellectual and social aspects of an individual's personality and it expresses maleness or femaleness (Daniels, Chipouras, Cornelius, and Makas, 1979). An important distinction to remember is that male and female are essentially words that describe a biological reality. But sexuality encompasses a great deal more than the physical aspects of reproductive functioning. Masculinity and femininity, therefore, as the social and cultural expression of biological sex, are not only expressed in the bedroom; rather they are part of all the activities which people engage in, like work, socialisation, decoration of one's home, telephone conversations, political discussions, expressions of affection, arguments, eating a meal, child rearing, walking down the street, watching a movie. Sexuality, then, is a central aspect of being human, an expression of the person one is, and it is evident in everyday interactions (Kupper, Ambler, and Valdivieso, 1992; Izugbara, 2005).

Although HIV/AIDS can be transmitted from mother to child and through unsterile needles, it is primarily a sexually-transmitted disease. The Acquired Immune Deficiency Syndrome (AIDS) was first documented in 1981. Five years later, after much debate and controversy, the Human Immunodeficiency Virus (HIV) was identified as the causative agent for AIDS (Kanabus, Fredriksson-Bass and Noble, 2007). Since then, the pandemic has spread throughout the world. It is estimated that HIV/AIDS has claimed over 14 million people in sub-Saharan Africa, and so it has been labelled the greatest

health crisis facing the world today (Kanabus *et al*, 2007). In view of the complex nature of the stated definitions of disability and sexuality, it is of little surprise that the relationship between the two phenomena is difficult to understand, especially as it relates to disabled young people's experiences and perceptions of HIV/AIDS risk.

### **1.1. THE PARADOX OF RISK**

The relationship between disability, being young, sexuality and HIV/AIDS is surrounded by complex similarities and contradictions. The social construction of disability is the umbrella factor that determines the stated complexities. Shildrick (2002) suggests that all people have a common human difficulty to admit to vulnerabilities in our bodies, which leads to our creating 'outcast' social groups. Although the grouping of high vulnerability and secondary status in this thesis is that of disabled young people in Nyanga, others are disabled and non-disabled women, the HIV-infected, homosexuals, the witches, the disfigured, and to an extent latterly, the old. These are groups of which none of us wants to see ourselves or be seen by others as 'one of them'. The logical shortcomings of such cultural misperceptions, all contribute to a contradictory tangle of paradoxical behaviour. There is a web of complex influences to be unwoven which includes cultural traditions, perspectives of the able-bodied, economic circumstances, family pressures, social sexual constructs, and social power structures. Examining the stated complex factors, which make up these contradictions and influences, is to explore that paradox of risk.

### **1.2. BACKGROUND OF THE STUDY**

In order to appreciate the extent to which the HIV/AIDS risk is a threat to disabled young people, it is important to describe some contextual factors that have driven the course of the pandemic to date. Parker (2004) suggests that a combination of historical, socio-cultural and economic factors collectively have created the scale of the problem that currently affects South Africa.

A national survey, which was commissioned by the Nelson Mandela Foundation and conducted by South Africa's Human Sciences Research Council (HSRC), found that HIV/AIDS affects all race groups in South Africa and that young people between the ages of 15-24 are affected the most (Shisana and Simbayi, 2002). Meanwhile, the UNAIDS (2006a) estimates that there were five and a half million South Africans living with HIV by the end of 2005, suggesting that South Africa had more people living with HIV/AIDS than any other country in the world. For this reason, UNAIDS has called for all strata of the South African society to be involved in the fight against the pandemic. Yet disabled young people appear to be missing from this drive.

While the effects of HIV/AIDS on special interest groups like prostitutes, truck drivers and young people in general have been described; little is known about the effects of HIV/AIDS on disabled young people (Groce, 2003). Groce (1999) describes adolescents and young adults with disabilities as an invisible population who are historically left out of all social networks and services. She notes that the said population is rarely included in social programmes intended for non-disabled young people. Consequently, there is a paucity of literature on the said population. For this reason and for the purposes of the present study, extrapolation is made based on the experiences of the disabled population in general and non-disabled young people in particular.

Further more, the social construction of disability is fraught with misperceptions and stereotypes, just as that of sexuality is fraught with cultural taboos<sup>2</sup>. In turn, sexuality taboos are equally applied to HIV/AIDS because most HIV infection in Africa is said to occur through unprotected sex (Van Dyk, 2001). Similarly, the discrimination meted out to people with disabilities is likened to that meted out to people living with HIV/AIDS. It follows that people with disabilities who become infected with HIV claim a double burden as they suffer discrimination on the basis of being disabled as well as being HIV positive (Yousafzi and Edwards, 2004; Sweeney, 2004).

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<sup>2</sup>Details about cultural taboos surrounding sexuality are discussed in Section 3.1 while disability misperceptions and stereotypes are discussed in detail in Chapter 2.



Within the said population, women with disabilities claim a triple burden because of the discrimination they suffer on the grounds of being disabled, being HIV positive and being female (African Network of Women with Disabilities, 2002).

Active sexual groups, as classified by Shildrick (2002), include prostitutes, truckers and young people, who are at serious risk of contracting HIV infection because of their sexual behaviour. Yet, there is also another risk that when the promiscuity of the said groups is restricted by cultural or religious scripts, they are likely to spread their sexual activity to 'invisible groups'. These include disabled people, older women, widows, and younger children. Since such groups are so often perceived as not sexually active, sexually invisible, they are seen as not being a risk to perpetrators, nor at risk themselves in sexual activities, be they consensual or forced. This has the potential for increasing the HIV risk to disabled people because of the greater invisibility of what is perpetrated upon them.

Thus the needs of physically disabled young people for sexuality education, HIV prevention and support services are no less than those of their non-disabled peers. There is therefore, a real need to examine the socio-cultural constructions and assumptions that contribute to this element of risk in this population group, and some of the political and economic power structures, which sustain the almost complete invisibility of the said population.

### **1.2.1. The Legacy of 'Townships'<sup>3</sup>**

In order to understand the state of AIDS in South Africa as it affects black disabled young people, it is important to review the history of townships in which this population lives. Racial inequalities, which were prevalent in the apartheid era, have significantly shaped the social profile as well as the health and health care provision in South Africa (Gilbert and Walker, 2001). Apartheid policies together with agricultural policies favouring large-scale

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<sup>3</sup> The word 'township' was used during apartheid to indicate a Group area for Africans, but in this study, it is not used as a derogatory term, rather a reality of where most black people continue to live.

agriculture, pushed millions of Africans off their land into impoverished reserves, homelands and townships. Thus the development of townships throughout South Africa reflects the impact of the racist policies of segregation that have existed since the earliest days of colonisation. Consequences of the said policies are poor access to quality education, employment, housing and social services for African people in general (Gilbert and Walker, 2001).

According to Legassick (2004), African people living in Cape Town had always been marginalised and excluded. Family life was forbidden initially, women were treated harshly, forcing many to opt out of Cape Town altogether. The aim was to turn many of the African population into single migrant workers – by attacking family relationships. At the end of apartheid, wives and children moved back to Cape Town and to this day, some continue to live in the hostels that were designed for single men, which offer inadequate living conditions. Others share a bathroom and a small kitchen. However, most of them moved out of the hostels seeking privacy. They built themselves shacks in nearby ‘squatter camps’ or informal settlements, one of which is called Nyanga<sup>4</sup>.



### **1.2.2. Nyanga**

Nyanga (see Map, Appendix H) is situated 26 kilometres from the centre of Cape Town city along the N2 highway, close to the international airport. Owing to the history (see section 4.5.1) of its creation, Nyanga is a community characterised by a social environment that offers few resources and little support for disabled young people (Dreyer, 2002). This township has poor makeshift housing known as shacks, where movement between the shacks is impossible for wheelchair users, a factor that contributes to disabled young people’s confinement to home. Shacks make up to 60% of Nyanga dwellings and do not provide privacy or adequate security, especially for disabled young people.

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<sup>4</sup> <http://www.labormilitantvoice.com/feaSA.htm> [Accessed 07.06.05].

Nyanga has one community centre that offers limited social services to disabled young people, such as access to social workers and rehabilitation workers. However, the township shares one clinic and one special school for physically disabled children with the neighbouring Guguletu, where access is impractical for those with movement problems. The clinic operates simply on the basis of offering limited treatment to those who come through the door, without any outreach capacity, nor particular target groups to aim at.

The overcrowded living conditions where residents seek comfort from one another are some of the factors leading to increased incidence of HIV/AIDS in South African townships (Dreyer, 2002). The other reality is the high crime rate in Nyanga, which forces vulnerable groups such as disabled people and the elderly to live in fear as well as being confined to homes. Nyanga is also characterised by a high unemployment rate, estimated at 56% (Statistics South Africa, 2001). Many people are involved in informal businesses or low-paid menial jobs. Most young people with physical disabilities get no opportunities for tertiary education, skills training or gainful employment. According to Statistics South Africa (2001), the disabled population of Nyanga is estimated at approximately 1600 people, out of a fluctuating population of some 60,000. There are 373 people with sight disability; 167, hearing disability; 64, communication disability; 481, physical disability; 165, intellectual disability; 241, emotional disability; and 90 with multiple disabilities. However, there is no breakdown available of how many were born disabled or who have become so through illness or accident since birth.

Although apartheid has technically been dismantled in South Africa, its legacy has permeated all levels of society, negatively affecting social organisations, access to health, and the quality of life and values of all South Africans (Chopra and Sanders, 2006). The National survey of South African Youth carried out by the Community Agency for Social Enquiry (CASE) on behalf of the Joint Enrichment Project (JEP) captures this state of affairs by indicating that young people in South Africa have been alternately stereotyped as the “lost generation” or as entirely unproblematic (Everrate and Orkin, 1993:3). Yet many find themselves alienated from their families, jobs, schools and

recreation; some have been victims of abuse and violence, which leads to poor self-image. There is an element of double bind for disabled people in that those around them frequently deny the reality of the problem of disability and, at the same time, see disabled people as potentially exploitable and usable.

The CASE survey also indicated that all informal settlements are under-resourced as to all amenities, from running water to sewerage, to electricity and telephones. This situation directly affects the life-chances of millions of African young people who cannot study, for example, because of lack of electricity. In contrast, nearly all white, Asian and coloured young people were said to live in houses or flats, while the majority of African young people live in shacks in the cities or huts in the rural areas. In addition, African young people were said to have been systematically and deliberately under-educated, as part of apartheid's grand plan, at the same time, women were discriminated against in the education system much more than their male peers (Everrate and Orkin, 1993).

The above situation equally captures the reality of the conditions under which disabled young people in Nyanga continue to live, 13 years into democracy. For these reasons, I describe Nyanga as a risky environment, since it does not provide adequate social services for the development of disabled young people, including the development and expression of their sexuality, or how they access information on sexuality education and HIV/AIDS support services.

In discussing the relationship between modernisation and risk creation, Beck (1992) argues that the social production of wealth is systematically accompanied by the social production of risk. In the context of the current study, it can be argued that the development of the modern city of Cape Town was systematically accompanied by the creation of the so called "Black Townships". As such, township risks of unemployment, crime, and HIV/AIDS, exist alongside high technological development of a modern city; as well as the new political dispensation that is trying to address the past inequalities.

### **1.3. RESEARCH PROBLEM**

Despite repeated calls for national and international recognition of the precarious situation of people with disabilities in the face of HIV/AIDS, most governments have not included disabled citizens on their list of vulnerable groups (Girois, 2005). In that sense, disabled people remain 'invisible'. According to Girois (2005), disabled young people are still left out of HIV/AIDS programmes in spite of evidence of their vulnerability to infection. Hence there is a need to examine the reasons for such omissions. Well-informed, consideration needs to be given to the social, economic and cultural factors – beliefs, customs, and assumptions – which contribute to the vulnerability of disabled young people to HIV infection.

There is also a need for both national and global awareness and commitment to examine existing sexuality and HIV/AIDS services, then develop strategies that address barriers to HIV prevention services for disabled young people. More importantly, the experiences, perceptions and responses of disabled young people to HIV risk need to be included in the formulation of intervention strategies, hence the need for a study of the current nature. In that way, services would be informed by disabled young people's own voices based on their experiences and perceptions of the pandemic.

### **1.4. RESEARCH AIM**

The general aim of the present study was to describe the paradox of risk through an exploration of experiences, perceptions and responses of physically disabled young people to sexuality and HIV/AIDS in the context of Nyanga.

## 1.5. RESEARCH QUESTIONS

The current study was guided by the following research questions:

1. What are disabled young people's experiences of growing up with a disability?
2. What are the contextual and individual factors in Nyanga that impact on physically disabled young people's experience of disability, sexuality and HIV/AIDS?
3. What are disabled young people's responses to the threat of HIV/AIDS?
4. What is the level of disabled young people's participation in existing sexuality education and HIV/AIDS prevention and support services?

## 1.6. OBJECTIVES

In order to answer the research questions and to achieve the broad aim of the present study, specific objectives were generated and used as a checklist for activities that I undertook to realise the stated goal, as listed below:

1. To describe disabled young people's experiences of growing up with a physical disability.
2. To identify specific contextual and individual factors that increase their vulnerability to HIV/AIDS with regard to:
  - i. Cultural beliefs<sup>5</sup> or scripts regarding sexuality and HIV/AIDS in the context of disability
  - ii. The spectrum of risk and protection factors, including family influences, political, economic and individual factors
3. To describe disabled young people's response to the HIV/AIDS pandemic and the threat of HIV/AIDS risk through an exploration of:

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<sup>5</sup> Byron Good has, with some real justification, criticized 'belief' as a concept. The word has a tendency to make Africans look superstitious, as opposed to Westerners being rational. He proposes the solution of speaking about cultural 'scripts' or 'schemes' (Good, 1994). Where this dissertation continues with the word 'belief', it is essentially an expression of the participants' vocabulary and perspective.

- i. Their knowledge levels about sexuality and HIV/AIDS, including sources of information on sexuality education and on HIV/AIDS prevention
  - ii. The availability and accessibility of formal or informal health services including sexuality, reproductive health and HIV/AIDS services at community or national level
  - iii. Their perceptions about the threat of HIV/AIDS risk
4. To recommend intervention strategies that would be inclusive of disabled young people's needs.

### **1.7. RATIONALE FOR THE STUDY**

It is widely acknowledged that the problem of HIV/AIDS requires everyone to be involved and included in prevention efforts (Yousafzi and Edwards, 2004; UNAIDS, 2006b). However, there are a number of factors that negate the involvement of disabled young people in existing HIV/AIDS prevention efforts. Firstly, AIDS service organisations claim that they do not know how to include the needs of disabled young people in their programmes (Banda, 2002) and so they exclude this group. Secondly, governments and the private sector seem unaware of the needs of this group; they see no urgent need to implement new or modify existing policies and programmes to meet the sexuality-education and HIV/AIDS prevention needs of disabled young people.

Consequently, and as stated above, little is known about disabled young people's experiences, needs and challenges regarding the subject under review. For this reason, there is a need for more research of this nature, which would reveal the obstacles to disabled young people's participation in HIV/AIDS prevention efforts. Research findings should serve to inform policy makers and custodians of culture to examine existing policies or cultural barriers to disabled young people's participation in mainstream activities for HIV/AIDS. Families and communities also need to be sensitised to the sexuality-education and HIV prevention needs of this group. Furthermore, professionals, especially therapists, who are constantly in touch with

physically disabled people at their most vulnerable times, need to be informed about their own role in the stated exercise. Thus the present study was undertaken to generate knowledge and to provide insight into ways of integrating disabled young people into mainstream HIV activities.

## **1.8. RESEARCH METHODOLOGY**

The research methodology is premised on the assumption that disabled young people are not participating in existing HIV prevention and support services. Besides, this group does not have the same opportunities to express their sexuality as their non-disabled peers because of the assumption that they are asexual. Such assumptions need to be explored using appropriate research methods as described below.

### **1.8.1. Research Design**

In keeping with the basic philosophy of capturing participants' own voices, a qualitative case-study design was used to explore the experiences and perceptions of risk among disabled young people. The choice of this research design was governed by the fact that qualitative research allows the researcher to "describe and understand how people make sense of their lives through an exploration of their perspectives and everyday realities" Hammell, Carpenter and Dyck (2000: 5). In addition, Hammell *et al* (2000) state that qualitative research gives credibility to people's beliefs, value systems and the meaning with which they make sense of their lives and experiences.

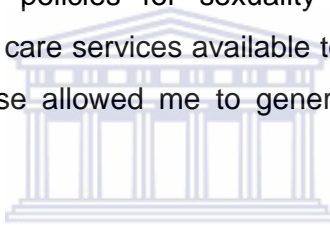
Qualitative researchers operate on the premise that people are inseparable from their contexts or environments, which might be social, physical, economic, political, legal or historical. Furthermore, qualitative research allows the researcher to be reflexively involved in the research process. This implies that the researcher is simultaneously aware of events which form part of the research process as well as of feelings, reactions, insights and interpretations during the interview sessions (Miles and Huberman, 1994). The researcher is centralised in the research process, in a reflexive capacity, which is crucial in qualitative research. The process of reflexivity allowed me to think about



myself, including my experiences and my research. A reflexive stance thus became a resource to guide data gathering and for understanding my own interpretations and behaviour in the research.

### **1.8.2. Research Strategy**

Another great attribute of qualitative research is that it allows for participation and conceptualisation of issues by the respondents. In that way, a wide selection of relevant literature, including the following documents were reviewed: The South African White Paper on Integrated National Disability Strategy (ODP, 1997), the Pocket Guide on Disability Equity (DPSA, 2001) and the United Nations Standard Rules on the Equalisation of Opportunities for People with Disabilities (United Nations, 1994) for information regarding the available rights and policies for sexuality education and HIV/AIDS prevention, treatment and care services available to disabled young people in South Africa. This exercise allowed me to generate relevant questions for interview sessions.



The next exercise involved in-depth interviews with 15 disabled young people. Pertinent issues raised by this group were explored with disabled young people themselves, 15 parents, 15 elderly men and women, four counsellors and five traditional healers in focused group discussions. A further exploration of the main issues raised in focus group discussions was taken up with 8 key informants who participated in individual in-depth interviews.

The rationale for triangulating with different methods of data collection is the recognition that there are various ways of understanding the world and hence different ways of constructing knowledge (Henning, Van Ransburg and Smit, 2004). For this reason, the different viewpoints from individual interviews, focus group discussions and document reviews helped to verify and strengthen the findings of the study. Furthermore, exploratory studies like the present one call for relatively less structured question and discussion guides that specify the broad topics participants are to discuss, but not the order in which topics are introduced (Henning *et al*, 2004).

I used a semi-structured interview schedule or a question guide (Appendix A) to channel the interviews and discussions towards accomplishing the research objectives. In that way, experiences and perceptions of physically disabled young people in Nyanga were drawn out as well as those of other members of the community. This process helped me to identify not only the contextual factors increasing disabled young people's vulnerability to HIV/AIDS, but also their response to the threat of the pandemic and the extent to which they access prevention and support services.

### **1.9. MOTIVATION OF THE STUDY**

The focus of the present study has arisen from my own professional experience as a physiotherapist working with disabled people of all age groups in both rural and urban settings of Zambia and Malawi. My particular experience in HIV/AIDS dates back to the period between 1985 and 1991, while managing a Community-Based Rehabilitation (CBR) programme at the Salvation Army rural Hospital in Mazabuka, Zambia. All health professionals working at that hospital then were required by management to train as HIV/AIDS counsellors because it was predicted that such skills would be relevant for every health worker. Initially, I was sceptical about this training, as it was hard to see a clear relationship between physiotherapy and HIV/AIDS, but the training made this relationship apparent. Consequently, the delivery of physiotherapy care to disabled people often involved HIV/AIDS counselling skills as well. Since then, I have worked as a therapist, advocate and HIV/AIDS counsellor for people with disabilities.

The present study is motivated by both my professional and personal experiences, which I consider learning and healing processes respectively. For many years HIV/AIDS remained a disease that only happened to my patients/clients until, in July 2004, while developing a proposal for the present study; two of my sisters died in one week from HIV/AIDS. Suddenly, I felt that my status had changed from that of an HIV/AIDS counsellor to that of an HIV/AIDS statistic; a concept that I continue to grapple with because of the

implications both at a personal as well as a professional level. However, two things became very clear to me, the first was that the socio-cultural/economic circumstances surrounding my sisters worsened the consequences of the HIV infection; secondly, I observed that the discrimination meted out to people with disabilities and those living with HIV/AIDS is very similar. Consequently, people with disabilities who become HIV positive understandably feel doubly disadvantaged. Hence I undertook this journey to bring out the voices of the voiceless who continue to be infected and not accessing the treatment and care they should have.

#### **1.10. STRUCTURE OF THE THESIS**

In **Chapter 1**, the context, aim and specific objectives of the study are highlighted. The background to the study focuses on the impact of the legacy of apartheid on the lives of African people and disabled young people in particular. This is in regard to poor living conditions, which make this population vulnerable to many social and health problems including exposure to infectious diseases like HIV/AIDS. Focus is placed on the fact that contextual and individual factors increase the vulnerability of disabled young people to HIV infection and the same factors prevent this population from accessing sexuality education, HIV/AIDS information and support services.

In **Chapter 2**, a brief introduction of the literature chapters, two and three is provided, followed by a description of the social construction of disability. I show the various ways in which disability is understood and explained by society. Brief outlines of the state of disabled young people in South Africa, social perceptions and cultural beliefs about disability are presented. In this chapter, I conclude with a description of different disability models and how these have been used to respond to specific challenges facing disabled people at different times in history, pointing out that none of the models have focused on the sexuality of people with disabilities as a problem.

**Chapter 3:** As stated above, chapter three is a continuation of literature review and is presented in two sections, 3.1 and 3.2 as follows:

In Section 3.1, I explore a paradox of risk as it is manifested in the social construction of sexuality and how this influences the common misperceptions about the sexuality of disabled people. Then perceptions of sexuality within disability movements and among professionals and families are explored, including the availability of sexuality information and education for this population. I conclude this section with an outline of the international sexuality rights and responsibilities for people with disabilities.

In Section 3.2, I deal briefly with the problem of HIV/AIDS among young people in South Africa - the risk factors for HIV/AIDS among disabled young people focusing on stigma and discrimination associated with disability and HIV/AIDS. Contextual factors such as economic constraints, literacy levels, sexual violence and how these impact on disabled young people's experiences of HIV/AIDS are outlined. I conclude the section with an argument that HIV/AIDS prevention programmes that only focus on raising awareness ignore the importance of contextual factors that are fuelling the HIV pandemic.

In concluding chapter 3, sections 3.1 and 3.2 are brought together to show the close relationship between sexuality and HIV/AIDS in the context of disability.

In **Chapter 4**, the rationale for choosing a qualitative case study for this thesis is highlighted. Qualitative research is presented as an umbrella concept, which enabled me to report on multiple realities of the 'case', including my own perceptions. An account of the study design including the process involved in identifying a study site and recruiting participants is presented. The procedure involved in the triangulation of three types of data collection methods, namely, document reviews, in-depth interviews, and focus group discussions is outlined. Ethical considerations that guided the study are outlined. The chapter concludes with a presentation a thematic analysis of data using a computer software package known as Atlas.ti is described.

**Chapters 5 and 6:** Owing to the extensive nature of the current study, findings are presented in chapters five and six, firstly, covering disabled young people's experiences of disability and secondly, their experiences of sexuality and HIV/AIDS as outlined below:

In **Chapter 5**, I present participants' expressions about disabled young people and their experiences and perceptions of growing up in Nyanga. Focus is placed on the way in which the social construction of disability underpins and affects disabled young people's experience of life in general, including the socio-economic factors that influence such experiences.

In **Chapter 6**, disabled young people's experiences and perceptions of sexuality and HIV/AIDS risk are presented, highlighting cultural beliefs about sexuality and how these contribute to increasing this population's vulnerability to HIV risk. The paradox of risk as it unfolds, revealing contradictions between societal perceptions and the reality as experienced by disabled young people as well as this group's response to the threat of HIV risk, is explored. The effect of socio-economic, political and cultural circumstances and individual behaviour on disabled young people's vulnerability and response to HIV risk is revealed. Lastly, the manner in which the same factors prevent this group from accessing information and support services is explored.

In **Chapter 7**, key findings of the current study are discussed, focusing on three main areas. The first is the impact of the environment and socio-economic circumstances of Nyanga, the second is the impact of culture and the third deals with existing HIV intervention strategies and the response of disabled young people to HIV risk. A convoluted interplay between contextual and individual factors results in complex situations of risk, which increase disabled young people's vulnerability to HIV/AIDS risk.

In **Chapter 8**, my conclusions are guided by the main research questions of the current thesis. This is followed by a presentation of the limitations of the study and the recommendations arising from the study. Most notably, a community-based intervention strategy for HIV/AIDS that targets whole

communities instead of individuals only, has been proposed, with guidelines for the inclusion of disabled young people in current strategies and programmes.

### **1.11. CONCLUSION**

In the first chapter, I have presented the problem of HIV/AIDS in South Africa, specifically as it affects young people in general, because little is known about the pandemic as it affects physically disabled young people. The nature of society's perceptions of disabled young people and the HIV risks they face is clearly paradoxical in that society's actions contradict the common beliefs held about this group's sexuality. I have pointed out findings from national and international researchers that indicate that most government and AIDS service organisations exclude disabled young people in the provision of sexuality-education and HIV prevention services. Such are the gaps that I set out to investigate through the experiences of physically disabled young people in Nyanga. Thus, I have set the scene for a detailed search of the voice of disabled young people in answer to the specific questions formulated to meet the core objectives of the current study.

Literature is reviewed extensively in chapters two and three, showing a close and yet complex relationship between disability, young people, sexuality and HIV/AIDS.

## CHAPTER 2

### THE SOCIAL CONSTRUCTION OF DISABILITY

#### 2. INTRODUCTION

Owing to the broad nature of the current study as well as the complexities, contradictions and the fundamental paradox involved in the issues of sexuality and HIV/AIDS in the context of disability, literature has been reviewed broadly in two separate chapters, for clarity and depth. In Chapter 2, I present an overview of the social construction of disability, which underpins the way disabled young people are treated and how they, in turn, experience and respond to life challenges in general. In Chapter 3, I build on the social construction of disability, demonstrating how this affects the social construction of 'disabled sexuality' and the experience of HIV risk. For this reason, chapter three is presented in two sections, where section 3.1 deals with issues of sexuality in the context of disability and section 3.2 deals with issues of HIV/AIDS in the context of disability.

As stated above, in Chapter 2, I am concerned with understanding the historical and cultural meaning ascribed to the concept of disability. The object is to illustrate that the presence of a physical disability is what makes the experiences of physically disabled young people unique and different from those of their non-disabled peers. Literature is thus reviewed under three main headings namely, (1) the state of young people with disabilities (2) Social perceptions of disability (3) and the various disability models, including the International Classification of Functioning, Disability and Health (ICF). Focus is placed on the importance of the meaning of disability, which has evolved over time and how such meaning is important in understanding the experiences of young people with disabilities.

## **2.1. THE STATE OF YOUNG PEOPLE WITH DISABILITIES**

Disabled young people between the ages of 10-24 are said to be among the poorest and most marginalised of the entire world's poor and the majority live in the developing world (United Nations, 1990). There appears to be no specific studies that have looked at the situation for disabled young people in South Africa. However, Evertime and Orkin (1993) found that, generally, more and more young people in South Africa are caught up in a poverty trap, because of socio-economic circumstances including high unemployment rates. At international level, Elwan (1999) found that subgroups such as disabled people in general and disabled women in particular are more affected by poverty. In addition, adolescents and young adults are equally disadvantaged because they are often bypassed both by the educational and recreational programmes and policies designed for disabled children and left out of advocacy initiatives, training and employment schemes targeted for adults with disabilities (UNICEF, 1999). In the same way, programmes designed for non-disabled young people overlook disabled young people's unique social, psychological, educational and economic needs. This is because adolescents and young adults are often grouped and discussed together by researchers and service providers because they share common characteristics (Groce, 2004a). It appears then, that the challenges that disabled young people face are not only similar to those of their non-disabled peers, but they are also a direct consequence of how society perceives the concept of disability, as is explored in the rest of this chapter.

### **2.1.1. Social Perceptions of Disability**

Perceptions of society towards disability are located within the meaning attached to disability at different levels of society (Ingstad, 1988). These meanings determine how disabled people are treated at family and community levels, what resources are provided for this population, and how disabled people in turn respond to their experiences of life. Thus the social construction of disability means that society or human beings actively and creatively produce the concept of disability in order to give it meaning (Ingstad, 1988). Based on this concept, disability can be an objective matter,



as factors such as gender, age, economic status and attitudes may affect the experience of disability. However, disability can also be a subjective matter, which is determined by the people experiencing disability and its consequences (Schneider *et al*, 1999).

The South African Government's official policy framework, contained in the Integrated National Disability Strategy (INDS), has adopted a socio-political approach to disability, which locates disability within the social environment (ODP, 1997). "The policy framework takes cognisance of the viewpoint that disability is a social construct and most of its effects are inflicted upon people with disabilities by their social environment" (Disabled People of South Africa, 2001: 6). For this reason, the document provides guidelines for ensuring equitable distribution of resources to people with disabilities.

In trying to understand the concept of disability in the context of Nyanga, reference is made to the impact of such an environment on the lives of growing disabled young people. Of particular note is the impact of apartheid with its deep roots in racism, inequity and injustice, which have had chronic negative economic and psychosocial consequences (ODP, 1997). The White Paper on Integrated National Disability Strategy points out that disabled young people, classified as black Africans during the apartheid era, live in these conditions and are still regarded as incapable, ill and a burden on society. Most of them live in inhospitable environments. Schneider *et al* (1999) describe different kinds of discrimination and marginalisation applied to people with disabilities, especially those whose disabilities are visible, like wheelchair users.

Society has created physical barriers and prejudiced attitudes that have been most effective in marginalising this population. Consistent with this view, Oliver (1996b) observes that disabled people, wherever they live, experience conditions of life far worse than their non-disabled counterparts. Such feelings arise firstly from the reality that disabled persons experience some impossibilities purely based on physical impairment as described by Lacan (1980). Secondly, at the level of imagination and symbolism in terms of law,

words and tests, society fails to decrease this physical problem or reality, and so creates other barriers for disabled people such as symbolic barriers, barriers of misconception and discrimination.

### **2.1.2. Cultural Beliefs about Disability**

In most African cultures, explanations related to divine displeasure, evil spirits and reincarnation have been advanced as causes of disability (Ingstad and Whyte, 1995). Regardless of age of onset, disability issues have historically been shrouded by stigma, prejudice, discriminatory and marginalising attitudes that have cumulatively disadvantaged all people with disabilities (Schoepf, 1997). While the concept of disability is universal, there is marked variation in how cultures interpret and understand it and how disabled people themselves experience it. According to Schoepf (1997), disability among Africans is closely linked to the concept of illness or misfortune where it is considered only one of the outcomes when one is struck by illness, accident or bad luck. It can thus be said that much of the discrimination experienced by people with disabilities in Africa is rooted in suspicion and fear of witchcraft.

Most suspicion often manifests after the birth of a disabled child. Fathers of disabled children will accuse their wives of promiscuity because of the belief that there is no way that men could have contributed towards the 'creation' of a disabled child (Nkabinde, 1994). Children with disabilities are considered a burden to the family and to the community. It is believed that such children are unnaturally conceived, bewitched and therefore, neither fully human nor productive members of the community (Kabzems and Chimedza, 2002). Such beliefs are reflected and reinforced by vocabulary employed to refer to individuals with disabilities.

Devlieger (1998) outlines how many Bantu languages use prefixes designated for noun classes referring to objects or animals when referring to individuals with disabilities, thus reminding disabled individuals of their place in society. For example Xhosa noun classes referring to people usually begin with prefix *um-* in the singular to refer to *umuntu*, meaning a person. Commonly used

nouns referring to people with disabilities use the prefix *is-* in the singular to refer to *isiqwala* and *isilema*, meaning handicapped and cripple respectively. These noun classes (*is-*) are normally used for objects and when used with humans are considered pejorative.

All societies have explanations as to why some individuals and not others are disabled, how individuals with disabilities are to be treated, and what roles are appropriate and inappropriate for such individuals. This includes decisions about rights and responsibilities individuals with disabilities are either entitled to or denied (Groce and Zola, 1993). Ingstad and Whyte (1995) and Whyte (1998) suggest that in some cultures, beliefs about the origins of disability are particularly useful and necessary when searching for therapy; while in other cultures the mere presence of a disability determines whether one is going to be accepted by society or not. When families in such societies are unable to cope with the care of a disabled relative it is as a result of poverty, lack of support and lack of knowledge about what can be done to improve the situation rather than a result of lack of love or negative attitudes towards a disabled person (Ingstad, 1997). It follows that individuals with disabilities are treated well or poorly, based on cultural beliefs about how and why they become disabled (Groce, 2004a).

## **2.2. SOCIO-ECONOMIC FACTORS WITH AN IMPACT ON DISABILITY**

Disabled young people's wider social needs continue to be neglected, which results in severe social isolation and poverty for them and their families (ODP, 1997). There exist at international and national level, policies, programmes and legislation, which are specifically supposed to address the poor conditions under which disabled people live. "Yet disabled people remain at the bottom of the pile all over the world" (Oliver, 1996a: 111). Similar contradictions abound in the lives of disabled young people in South Africa (ODP, 1997), and Nyanga in particular. The United Nations General Assembly, adopted the declaration on the Rights of Disabled Persons in 1975, recommending that all international organisations and agencies should

include provisions in their programmes to ensure the effective implementation of these rights and principles (United Nations, 1990). In spite of this declaration, the UN report states that disabled persons frequently live in deplorable conditions, owing to the presence of physical and social barriers, which prevent their integration and full participation in communities. As a result millions of disabled people throughout the world are segregated and deprived of virtually all their rights, and live a wretched, marginal life (Despouy, 1993: 1).

In spite of this declaration, it has been noted that people with disabilities continue to experience poor social status, disproportionate poverty and deprivation by virtue of being disabled (Elwan, 1999). To this effect, Elwan (1999) estimates that one in five of the world's poorest people are disabled. The material conditions under which this population lives throughout the world make disability an isolating experience (Oliver, 1996a). As poor people, they don't have enough to eat, they are kept in seclusion by the state or family, little of society's public spaces or wealth are accessible to them. For this reason, disabled people find it difficult to organise collectively in order to resist the discriminatory policies against them (Oliver, 1996a). It is also because disability can be an isolating experience that most disabled people experience their disability in individual terms rather than collectively. Such might be the reason they fail to stand up collectively to fight discrimination.

Poverty and disability are inextricably linked, disabled people are poorer as a group than the general population, and people living in poverty are more likely than others to be disabled (Elwan, 1999). Poor people live in underdeveloped areas like Nyanga, where there is lack of sanitation, water, health services, and job opportunities, educational and recreational facilities (United Nations, 1990). These factors collectively place disabled people at risk of contracting different types of infectious diseases including HIV/AIDS, getting no treatment or receiving poor quality treatment because they cannot afford the cost of decent services.

The 2001 South African Household Survey confirmed the above finding, pointing out that large numbers of people with disabilities live in areas where the infrastructure for the provision of basic services is very weak (Statistics South Africa, 2001). It follows that most previously disadvantaged young people continue to live in informal housing without basic amenities. Consequently, most of them are not reaching their full potential as healthy and happy individuals, because their concerns have been absent from economic and political theories of development (Mpofu, 2003). Thus, poverty is a key social factor responsible for cumulative disadvantage of people with disabilities (Elwan, 2003). Even in the poorest communities, people still differentiate between those in higher or lower brackets of poverty. By implication, disabled people run the risk of being treated as the lowest level within an entirely poor community as Nyanga.

In addition, Article 6 of the Disability Rights Charter of South Africa states that “Disabled people shall have the right to engage in sport and recreational activities and resources, such as sport facilities and financial assistance, as well as opportunities for participation shall be made available to support their initiatives in this regard” (Disability Rights Charter of South Africa, 2000). However, this aspect of disabled people’s lives is often forgotten or neglected by service providers. Most sports facilities are inaccessible to people with mobility problems.

Thomas (2004) argues that lack of activity for young people has been identified not only as a risk factor for chronic diseases of life, but also as a risk factor for abuse and engaging in risky sexual behaviour, which might lead to HIV infection. His point is that the provision of sport as a social activity could be a protective mechanism against social isolation of disabled young people. Social isolation contributes to making this group prone to sexual abuse. There is a need to make deliberate efforts to create an environment that encourages sport and recreation for disabled young people in South African townships to prevent idleness and risk-taking behaviour.

The review of literature above has provided some insight into some of the challenges that disabled people face and the risks they are exposed to, such as discrimination and poverty. However, this literature makes no reference to 'sexuality' as a big problem for this population. Thus, a review of international disability models seeks to establish how the sexuality of disabled people fits into these; because most existing intervention programmes for disabled people have been and continue to be informed by disability models.

### **2.3. MODELS OF DISABILITY**

At international level, attempts have been made throughout history to understand the concept of disability through various disability models. Through these, appropriate services for disabled people have been developed. The most prominent disability models are presented, highlighting their position on the sexuality of disabled people. These models are: the medical, social, human rights, and cultural models. Although it can be used to explain disability, the International Classification of Functioning, Disability and Health (ICF) was specifically developed to provide common disability language for all stakeholders.

#### **2.3.1. Medical Model**

Historically, the medical model has regarded disability as a health and social welfare issue. As such, professionals offer treatment or rehabilitation services to correct the disablement, while the State and faith-based organisations provide welfare support (ODP, 1997; Disabled People South Africa, 2001). Such interventions focus on individual assessment, describing the type of disability and how it can be corrected or minimised. A consequence of relegating disabled people to the 'sick role' is that they become passive recipients of charity. The 'sick role' also implies that this population may not be sexually active<sup>6</sup>. Thus in the medical model, ordinary social needs, such as sexuality and access to employment are not taken into account. Yet social needs play a pivotal role in the experience of disability (Barnes, 1992).

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<sup>6</sup> In Section 3.1, I have discussed in detail how different cultural scripts suggest that disabled people are asexual, because they are perceived as 'sick' and with no sexual feelings.

Another consequence of viewing disability through the lens of the medical model in the context of South Africa is the provision of a 'disability grant' instead of creating jobs for this population (ODP, 1997; Swartz and Schneider, 2006). While the grant is meant to solve the problem of unemployment among this population, it in fact has created dependency and has dis-empowered people with disabilities. The grant has reduced this population's capacity and confidence to interact on an equal level with other people in society (ODP, 1997). Critics of the medical model suggest that the model reinforces the devaluing and denial of disabled people's right to sexual expression because it views them as sexless beings (see section 3.1). Given these limitations inherent in the medical model, disability advocates proposed the social model of disability, which encouraged participation of disabled people in mainstream activities.

### **2.3.2. The Social Model**

The social model was inspired by an understanding that impairments are not the main cause of the problems facing people with disabilities, but that it is the way society responds to them as an oppressed minority (Shakespeare, 1996; Disabled People South Africa, 2001). Thus, the social model emerged as a new interpretation that generated a new approach to disability.

The social model was a way of getting people with disabilities to think about the things they have in common and the barriers they all face, while bearing in mind that some of these barriers are impairment-specific. Some of the strengths of the social model are, firstly, its recognition that disability is not the major barrier that stops people with disabilities from leading fulfilling social lives. Secondly, the social model advocates inclusion and integration of people with disabilities in mainstream activities (Disabled People South Africa, 2001). However, this model appears to have focused on all the problems that disabled people face with the crucial exception of their sexuality and sexual health needs (Bonnie, 2004).

Critics of the social model point to the importance of the subjective nature of disability, arguing that social services alone cannot meet the needs of this population (McConkey and O'Toole, 1995). The seeming neglect of the effect of physical impairment on the experience of disability might well imply that sexuality would be considered a private and personal matter and thereby justify the silence and neglect of the same. Although the social model had made remarkable gains in advocating services for people with disabilities (Disabled People South Africa, 2001), disability activists realised that this model was inadequate in driving political will for the creation of disability policies and legislation. This realisation ushered in the rights model of disability, which would enable the voice of disabled people to be heard at policy level, as well as ensuring equitable distribution of resources (Priestly, 2006).

### **2.3.3. Human Rights Model**

In the 1990s, the Rights and Independent Movements emerged as big ideas alongside the social model. The movement recognised that disabled people are not simply individuals, but an oppressed and disadvantage group in society (Priestly, 2006). The social model was no longer the factor that bound together disability movements in the way it had done in the 1980s. The disability rights movement in South Africa was shaped by the experiences of disabled people living under the apartheid system (Howell, Chalken and Thomas, 2006). Although all disabled people were discriminated against, the majority of black people struggled more to cope with segregation, poverty, deprivation and violence (Howell *et al*, 2006). Such oppression drove the leadership of the disability movement at international and national level to become involved in parliamentary campaigns to improve the rights of people with disabilities and push for services necessary for independent living.

Central to the disability rights movement is the assertion of disability as a human rights and development issue, which recognises and acknowledges that people with disabilities are equal citizens who should enjoy equal rights and responsibilities (ODP, 1997; DPSA, 2001). However, this position also



seems to have left out the sexuality, sexual and reproductive health needs of disabled people as human rights issues. Thus the human rights model has equally failed to address the problem of disabled people's sexuality.

The human rights model seems to have succeeded in helping the elite among the disabled population to rise and occupy political or parliamentary positions to fight for the rights of the rest of the disabled population. Yet, according to Nkoli (2007), the situation for the rest of disabled people has remained the same, especially that of disabled young people, who live in under-resourced areas like Nyanga. In recognition of the strengths and limitations of these disability models, the cultural model of disability emerged, which seeks a balanced view of understanding the phenomenon, as described below.

#### **2.3.4. Cultural Model**

The cultural model of disability explores the role of culture with respect to meanings, practices and discourses of disability (Devlieger, Rusch and Pfeiffer, 2003). In this model, Devlieger *et al* (2003) advance an inclusive view of disability, suggesting that people with disabilities are both the 'same' and 'different'. They point to many core disciplines that support the integration and normalisation of disabled people as principles of sameness, yet these principles are developed in response to the different ways in which disabled people are perceived by society. For example, the human rights perspective advocates equality on the premise of 'sameness' and 'difference'. The assumption is that disabled people are like every one else and so they should have equal access to rights and services. Be that as it may, such an assumption ignores the impact of impairment at a biological level. On the same note, Devlieger *et al* (2003) argue that disabled people are in fact not able to access similar services owing to attitude and environmental barriers, which suggests that they are perceived as being different because of their visible disability.

The cultural model of disability, which is referred to as the 'new era', calls for recognition, celebration and inclusion of a phenomenon that is an essential

part of human life (Devlieger *et al*, 2003). In other words, a cultural model seeks a balanced view of disability that places equal importance to the concept of 'sameness and difference'. In such a view, disability is no longer considered a category of certain populations; rather, it becomes a phenomenon that points to the knowledge that all human beings are potentially disabled people (Davis, 2002). According to Devlieger *et al* (2003), a cultural model is one that does not claim to supersede the other models, but rather it recognises and integrates the strengths that are present in each one of them. Like the other disability models, the cultural model does not address the problem of the sexuality and sexual expression of people with disabilities. Nevertheless, the paradoxes with respect to the said issues can be explicated through the cultural model framework.

Similarly, I have demonstrated so far, that literature on disability has not placed the sexuality of disabled people at the same level of importance as other social issues they face. Yet as stated by Finger (1992), disabled people consider sexuality as one of the most important problems they have to face. It is, therefore, important for researchers and disability advocates to start responding to the subject of sexuality with renewed vision. These findings have also been demonstrated among non-disabled young people in Ethiopia, where Tadele (2006) notes that sexuality issues of young people are clearly not addressed, which poses a serious problem in any effort to encourage responsible sexual behaviour and prevent HIV/AIDS.

### **2.3.5. The International Classification of Functioning, Disability and Health**

As stated in the introduction of this chapter, the International Classification of Functioning, Disability and Health (ICF), has been used to explain disability, but its overall aim is "to provide a unified and standard language and framework for the description of health and health-related states" (WHO, 2001:3). This aspect leans on the medical model with its strengths and limitations as discussed above. The ICF provides a description of a situation with regard to human functioning and its restrictions and serves as a

framework to organise this information as (a) components of functioning and (b) components of contextual factors (WHO, 2001).

Although contextual factors' of the ICF, which include 'Environmental and 'Personal Factors', are used to describe the impact of the environment on the experience of disability and its domains, these do not provide a clear explanation of 'disabled sexuality'. Only inferences can be made about the positive or negative influence of the environment on the sexuality of disabled people. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors are external to individuals and can have a positive or negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure (WHO, 2001).

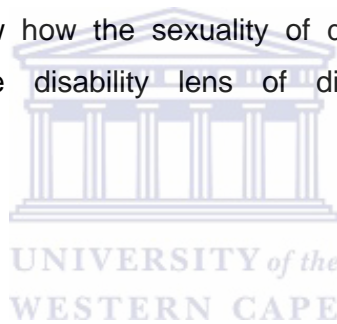
Thus the ICF, like the aforementioned models of disability, places challenges faced by people with disabilities beyond the effect of individual impairment, to relationships that this group has with micro- and macro-level structures. Micro-level factors may include issues such as engaging in risk-taking sexual behaviour, which increases disabled young people's vulnerability to HIV risk. Macro-level factors include elements such as poverty, cultural beliefs and lack of or inadequate policies, all of which play a role in increasing this population's vulnerability to HIV risk.

## **2.4. CONCLUSION**

In this chapter, I have clearly demonstrated that the situation for disabled young people worldwide is characterised by marginalisation and poverty, and they are overlooked in the provision of social services. Conversely, there is limited research that seeks to expose the situation for this population. As a result, they are bypassed by programmes that target children or those that target adults. I have argued that the social constructionist view of disability does not only provide meaning that varies from culture to culture, but such

meaning is constantly created and understood through social perceptions and cultural scripts.

South Africa has adopted a socio-political approach to disability, whose focus is on the influence of the environment, perhaps at the expense of disabled people's physical experiences at a biological level. In this case, the sexuality of disabled young people does not feature as a high priority on the agenda. In the same vein, the various disability models do not offer a comprehensive way of explaining or understanding disability and its complexities. It is thus clear that all the aforementioned ways of explaining disability are silent on the sexuality of disabled young people. Yet, as will be demonstrated in the next chapter, the meaning of disability influences the way disabled young people are allowed or prevented from expressing their sexuality. Furthermore, in the next chapter, I will show how the sexuality of disabled people has been understood through the disability lens of discrimination, deficit and exploitation.



## CHAPTER 3

### A PARADOX OF RISK: DISABILITY AND SEXUALITY– A CONCEPTUAL INTRODUCTORY STUDY

#### 3. INTRODUCTION

As stated at the beginning of Chapter 2, literature review in Chapter 3 builds on the social construction of disability, showing how such construction influences social perceptions about disabled young people's sexuality and their experience of HIV/AIDS. Chapter 3 is presented in two separate sections, 3.1 and 3.2 as stated below:

In Section 3.1, I deal with the social construction of sexuality in general, which reveals the different meanings that society gives to the subject. Literature is reviewed under the following major headings:

1. Social construction of sexuality
2. Common misperceptions about the sexuality of disabled people
3. Disability, gender and sexuality
4. Sexuality information/education
5. Sexual rights and responsibilities.

Using above headings, I provide a link between issues of disability, young people, sexuality and HIV/AIDS, which set the tone for section 3.2.

In Section 3.2, I then deal with the problem of HIV/AIDS in the context of disability and literature is reviewed under the following main headings:

1. Young people and HIV/AIDS in South Africa
2. Misperceptions about disabled asexuality and HIV/AIDS
3. Risk factors for HIV/AIDS among disabled young people
4. Disability, gender and HIV/AIDS
5. Intervention strategies.

In this section I demonstrate that issues of disability, young people, sexuality and HIV/AIDS are inextricably linked.

### 3.1. SOCIAL CONSTRUCTION OF SEXUALITY

Sexuality is defined comprehensively as a central aspect of being human, which encompasses much more than a sexual act. It “encompasses sex, gender, identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction, and is experienced and expressed in thoughts, fantasies, beliefs, attitudes, values, behaviour, roles and relationships” (Izugbara, 2004: 13). These sexual codes of conduct, or scripts, are constituted out of meaning, knowledge, beliefs and practice that structure sexuality and define a sexual culture in a given social context (Parker, 1991). Thus, sexuality is expressed within different cultural domains such as marriage, initiation rites and religion. Sexual behaviour is essentially the result of people’s attitudes towards sexuality and these attitudes in turn, are a result of how people have been brought up (Izugbara, 2004).

At a biological level, sex is a matter of being male or female. When it comes to sexual behaviour, however, clearly defined behaviour patterns are less easy to establish. The variations in culturally constructed sexuality involve more than basic physical structure or physical behaviour. There are, then, three levels of operation 1) sex, in the sense of gender, 2) sexual behaviour, as observable externally; and 3) sexuality, as a function of self-image and self-expression (Izugbara, 2004). There is even a fourth level of operation one might point to, 4) the social and cultural setting within which a person’s sexual behaviour and their identity in sexual terms are constructed and contained.

Sexual culture, then, is not only based on biological or physiological measures, but is also shaped by a broad range of social processes and pressures within any given culture. It is distinct from the individual expression of one’s sexuality. Sexual culture is an amalgam of society’s beliefs, values and understanding pertaining to sex and is therefore, an expression of that culture’s sexual behaviour that by some power structures is presented as the ‘ideal’ (Caldwell *et al*, 1989). For example, African sexuality is characterised by the importance of ancestry, descent and the maintenance of lineage (Caldwell *et al*, 1989; Ahlberg, 1994; Izugbara, 2004). To this effect, Caldwell

*et al* (1989) assert that there is a lot of mystery surrounding sexual matters in most African cultures because of the taboos and prohibitions surrounding sex.

Unlike biologically based theories that conceptualise sexuality as natural, in-built sexual essence impermeable to social impacts, social constructionist theories propose that sexuality is not an exclusive property of the body, nor a natural tendency, but is inextricably linked to society and social relationships (Bell, 1993). Social constructionists view sexuality as a social construction mediated by historical and cultural factors. As such, physically identical sexual expressions may have different social significance and meanings to different cultures at different points in history (Gagnon, 1977; Weeks, 1985; Schwartz and Rutter, 1998;).

Consistent with this view, Laubscher (1979) describes the difference between the expression of sexuality among rural, Xhosa-speaking young people and their urban counterparts. According to Laubscher (1979), urbanisation has eroded the control over the expression of sexuality that rural communities used to uphold. In that sense, urbanisation has strongly influenced the meaning and practice of sexuality among Xhosa-speaking young people in Nyanga, as will unfold in this thesis. The idea that sexuality is mediated by significant historical and cultural factors impinging upon different social contexts is reflected in the dissimilar ways in which the sexuality of physically disabled people has been perceived and responded to in different times and contexts as demonstrated by the following quotations:

I have known girls go out with me because they wanted to look after me. I'm their baby in a pram, they push me everywhere and they weren't open to the idea that I could get turned on (Shakespeare, 1996: 197).

I heard there was these two people in the supermarket and they were both wheelchair users, and they had a kiss. I don't know why they wanted to kiss in the supermarket, but they did. And somebody came up to them and said "do you mind", its bad enough that there are two of you (Shakespeare, 1996: 200).

These quotations reflect the dominance of existing able-bodied norms that negate and devalue the sexuality of people with disabilities. Morris (1993) and Peters (1996) have argued that entrenched devaluing discourses significantly hinder disabled people from expressing their sexuality meaningfully.

Two contrasting discourses become apparent in reviewing the social construction of the sexuality of people with disabilities. On the one hand, this population is viewed through the lenses of the medical and moral models of disability, that is, the “charity-welfare, alms-for-the-poor” construction that transforms them into sexless beings and in need of assistance (Mckown, 1986; Lonsdale, 1990). In this view, disabled people’s sexuality is ignored and suppressed. On the other hand, disability has been associated with what Hahn (1988a) terms ‘subversive sensualism’ which refers to a curiosity about and fascination with the disabled that is often infused with erotic impulses. In this view, people want to have sex with disabled people just to satisfy their curiosity. In the middle ages, physical disability was associated with heightened fertility, revelry and uninhibited sexuality (Hahn, 1988b). Disabled people were constructed in terms of extreme ends of the sexual potency continuum, as either asexual or sexually incompetent or conversely as sexually perverse. Such constructions evoked fear and revulsion in the non-disabled individuals with consequent avoidance and isolation of disabled people<sup>7</sup> (Cole, 1975; Livneh, 1980; Thurer, 1980).

As a result, disabled people were not expected to have a normal sexual life. Normal or sexually-acceptable behaviour appeared to be the sole privilege of the non-disabled population. It would appear that these contrasting views about disabled people’s sexuality are still prevalent today, as will be explored later in this thesis. Contradictions in the construction of disabled people’s sexuality place disabled people at risk of sexual suppression and sexual exploitation.

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<sup>7</sup> There is a clear parallel here with modern views of the history of female sexuality in Christendom, where the same split of perception – woman as the hypersexual being (prostitute) or as the sacred virgin, pre-sexual or asexual. There is an ongoing difficulty around the understanding of and acceptance of the sexuality of women, and of disabled people.



Disability activists see devaluation of the sexuality of disabled people as a by-product of the ideological construction of disability, which followed the advent of capitalism. They argue that during the nineteenth century, industrialisation and the rise of the factory saw large numbers of people with disabilities unable to cope with the demands of the production line. These were subsequently segregated from mainstream economic and social activity into a variety of specialist institutions (Oliver, 1990; 1993). Oliver (1993) suggests that the rise of these institutions coincided with the rise of the medical profession, which endorsed the categorisation of deserving and undeserving people and applied the sick label. The assumption is that people who are sick are not expected to show interest or to participate in sexual activities. In contrast to this view, disability activists assert that people with disabilities are not sick, as such, so there are a myriad ways through which these people may express their sexuality (Kroll and Klein, 1992; Bonnie, 2004). This population, therefore, should be allowed to be fully human.

Capitalism seems to have everlastingly changed the way that people with disabilities are perceived by society. The capitalist economy required that individuals sell their labour on the free market; it demanded a break from collectivist notions of work and created the ideological construction of the isolated, private individual<sup>8</sup>. People came to be seen in terms of 'bodies', which were:

“more or less utilisable, more or less amenable to profitable investment, those with greater or lesser prospects of survival, death, illness, and with more or less capacity for being usefully trained” (Foucault, 1980 in Oliver, 1990: 45).<sup>9</sup>

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<sup>8</sup> Jos van Ussel, the Dutch sexologist, shares this view. The rise of industrialisation and capitalism created an anti-sexual attitude in which the only valid reason for sex was procreation, requiring the suppression of anything that reminds us of non-procreative sex, economically useless and unproductive, said to be the work of the female or of the disabled body, Available at <http://www.google.co.za/search?hl=en&q=Jos+van+Ussel&btnG=Search&meta=> [Accessed 08.05.07]

<sup>9</sup> Foucault actually follows van Ussel's argument further back in time, asserting that repressive attitudes to sex go back to the dawn of recorded history and beyond, but seeing the same socio-economic, religious power politics as fundamental to negative interpretations of female, disabled, and sexuality.

Hence the construction and validation of the able-bodied for having the physical capacities for operating factory machines and for their willingness to surrender mind and body to the discipline and routines of the factory (Oliver, 1990). On the other side of the equation, this view created a socially-excluded, devalued category of individuals to whom the description “unfortunate, useless, different, oppressed and sick” could be applied (Hunt cited in Barnes and Mercer, 1996). This relegation to the category of social deviance or social minority was automatically accompanied by a general devaluation of the disabled person as ‘not quite human’ and, therefore, not entitled to the same human rights as their able-bodied counterparts. It would appear that, although the disability policy in South Africa upholds the human rights of people with disabilities, this population continues to be discriminated against (ODP, 1997) and their sexuality and sexual health needs ignored.

While social responses to disability may not be always uniform, it is argued that there has been a consistent negative bias associated with disability throughout history. Livneh (1980) highlights the fact that symbolic comparisons such as “as blind as a bat” ascribe animal characteristics to disability, suggesting at a hidden level that disabled people are less than human. The socially-constructed perception of physical disability as implying an inhuman condition (a blurring of the boundaries between human and animal) reinforces the notion of the sexuality of the physically disabled person as being dangerous, out of control and therefore, needing containment through exclusion from mainstream society.

Trieschman (1988) postulates that human beings display a natural tendency to perceive differences among people, categorise and assign different valuations, and tend to reject things that are different. Abuse and murder of disabled children at birth were once commonplace on the grounds of utilitarianism, social value systems (prizing strength, beauty and intelligence) and religious beliefs (divine retribution) (Waxman, 1991). These cultural meanings are linked to social constructions of the physically disabled as sexually primitive and dangerous. Examples have been cited of abandonment

of one partner by the other in the case of a disability, of infringements of or denial of the right to privacy, the prohibition of physical relationships in residential centres or special schools, and of compulsory contraception at puberty, to name but a few discriminatory practices (Shakespeare, 2000). Such practices form an integral part of the realities of disabled people's sexual lives. It would appear that society regards such practices as normal and unavoidable responses to the deficiencies and problems of people whom society assumes to be abnormal and not entitled to or capable of having a 'normal' sexuality.

Shildrick (2002) also presents the theme of the permissible ("seems allowed") expression of aggression of violence towards the deviant, the 'monster' that is the non-male, disabled, non-hetero, non-white, non-adult, non-Christian, non-western; so that, in other words, it is difficult to imagine disabled people as desiring or desirable – as sexual beings – and to normalise their sexuality. The above reality leads to stereotyping of the sexuality of disabled people, which is influenced by the stereotypes about the concept of disability.

### **3.1.1. Common Misperceptions about the Sexuality of Disabled People**

As indicated above, the primary assumption is that both disability and sexuality are socio-cultural constructions whose values and meanings vary historically and cross-culturally (Guldine, 2004). For this reason, the experiences of sexuality may vary from culture to culture and generation to generation. Disabled young people in Nyanga grow up in a socio-cultural environment where misconceptions concerning sexuality and disability are rife. These drastically and unnecessarily curtail the sexual expression of disabled young people by perpetuating the misconceptions about disabled asexuality (Saiti, 2001). Consequently, the problems with expressing one aspect of life, in this case sexuality, often have a negative impact on all the other areas of life such as self-concept, vocational performance and the motivation to live as independently as possible. Some common misconceptions about sexuality and disability are listed below:

1. Disabled people are asexual
2. Disabled people are over-sexed and have uncontrollable urges
3. Disabled people are dependent and child-like and thus need to be protected
4. Disability breeds disability
5. Disabled people should stay with and marry their own
6. Parents of disabled children do not want sex education for their children
7. If a disabled person has a sexual problem it is almost always the result of the disability
8. If a non-disabled person has a sexual relationship with a disabled person, it's because she/he cannot attract anyone else (Gordon, 1974: 2).
9. People with disabilities can't have sex, don't want sex or are not interested in sex (Shakespeare, Gillespie-Sells, and Davies 1996: 18)

The reactions of society to the sexual needs and concerns of disabled people may be directed by the presence or absence of fear, as well as by general ignorance of the subject. Based on social prejudice and stereotype, the sexuality of disabled young people is viewed in the following ways:

In the realm of sex and love, the generalised assumption that disability is a medical tragedy becomes dominant and inescapable. The potential and actual independent sexual activity is considered the essential element of full adult personhood; because disabled people are infantilised, so consequently their sexuality is undermined. The assumption of asexuality is a contributing factor towards the disregard of disabled people (Shakespeare *et al*, 1996:10)

People often react in disbelief, disgust, avoidance and indeed active suppression of disabled people's sexuality (Bonnie, 2004). Active suppression may be the most personally oppressive, but the most damage is done by avoidance, because of how widespread it is and the number of levels it can appear on. Bonnie (2004) notes that while society continues to perceive

disabled people as asexual, disabled people themselves consider sexuality as one of the most important aspects of their lives, and she asserts:

I would rather someone considered the thought of me being sexually active as distasteful rather than believing me to be asexual; at least with the former they are thinking of me as a sexual being (Bonnie, 2004: 125).

In addition, rule 9.2 of the United Nations Standard Rules for the Equalisation of opportunities for Persons with disabilities, which deal with family life and personal integrity, states:

Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood ... Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies. (United Nations, 1994: 9.2)

Disabled young people have been denied this basic human right to the extent that their sexuality and sexual expression have been oppressed in a number of ways. Society tends to segregate them and deny their right to participate fully in social, romantic and sexual relationships (Bonnie, 2004). Society's stereotypes stem from popular culture's narrow definition of sexuality, the physical aspect only, and about the widespread misperception that sexuality is connected with physical perfection (World Bank, 2004b). It has been observed that in most instances the way people are perceived often becomes the way they perceive themselves (Kroll and Klein, 1992). Consistent with this notion, McCabe, Cummins and Deeks (2000) demonstrated that people with physical disabilities experience low levels of sexual knowledge and experience and hold negative feelings about sexuality.

To this effect, Nosek *et al* (2001b) found that women with disabilities express stronger feelings of being asexual than women without disabilities, further confirming the above findings. Based on these findings, it might be argued that a disabled person considered as a sexual being has no representation or model of a positive way to sexual activity. Therefore, he/she may adopt an asexual role in the face of a consistently negative approach expressed as

anything from merely distaste to the violence of rape. In spite of such findings, Bonnie (2004) asserts that disabled people are sexual beings who have a potential capacity to express their sexuality in a myriad ways uniquely their own. This is because often the wish to be perceived as sexual, even in the face of expressed distaste in response, is preferable to being reduced, to the status of asexual beings. But the ways of achieving this can seem fragile, because disabled people subject themselves to society's stereotyping and mis-labelling that tell them that they cannot be sexual (CROWD, 2002). As a result of the conflict between natural inclination and socio-cultural repression, disabled people may lack confidence in their ability to express their sexuality; many of them can and do opt to ignore the issue of sexuality all together – denying themselves an expression of passion, caring and love (CROWD, 2002).

It follows that, if society were to believe in disabled young people as sexual beings, this population might well be free to believe the same about their own sexuality. This may be a long road, however, as the absence of a positive sexual self-image is not merely a physical and behavioural problem, it is also a psychological problem that needs more positive image building through education, social acceptance and action.

### **3.1.2. Perceptions of Sexuality within Disability Movements**

While disability movements have made remarkable gains in identifying disabling barriers that prevent disabled individuals from realising their full potential of an economic, political, social and cultural nature, “they have not given issues of sexuality the same recognition” (Barnes and Mercer, 2003: 10). The neglect of sexual politics within the disability movement and its absence within disability literature mirror the wider attitudes of society to disabled sexuality (Shakespeare *et al*, 1996). Even the South African White Paper on an Integrated National Disability Strategy (ODP, 1997), which is comprehensive in terms of legislation concerning human rights and disability, is silent on issues of the sexuality rights for people with disabilities. It is observed that all stereotypes against disabled people's sexuality are

damaging, but the stereotypes of disabled people themselves are the most debilitating (Finger, 1992). Furthermore, Finger (1992) posits that the Disability Rights Movement has not put sexual rights at the forefront of its agenda and she declares:

Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about and formulate strategies for changing discrimination in employment, education and housing than to talk about our exclusion from sexuality and reproduction (Finger, 1992: 9).

Consistent with the above view, Guillian Parker's study of marriage and disability, 'With this Body', argues that discussion of marriage is absent from work on disability (Parker, 1993) and yet the author herself discusses marriage and completely ignores issues of sex and love. Such is the extent to which the disability movement has succumbed to social perceptions of disabled asexuality, hence the deafening silence on the subject. Critical of the social model of disability, Crow (1996) suggests that this model gives too much space to structural factors and neglects the personal experience of disabled people. These include issues of the body, impairment, sexuality, relationships and family life. In line with Crow's view, it has been asserted that disability studies have "downplayed the personal and focused on the structural -- reproducing a wider split between the public lives of men and women, but next to nothing about their private and personal lives" Shakespeare *et al* (1996: 7). Foucault (1980) also helps us to understand how structures of power inequality and discrimination are interiorised and written in to the bodily experience of women, disabled people and other sub-groups such as homosexuals.

The prevailing attitude central to the prejudice faced by people with disabilities is that sex and disability are incompatible, hence the neglect and the silence on the subject (Shakespeare, 1996), which is also shared by family and professionals.

### **3.1.3. Perceptions of Professionals and Families**

Professionals who work with disabled people have been blamed for avoiding the subject of sexuality and for advancing excuses for such reluctance. Diamond (1984) suggests that “agencies avoid the subject because they are concerned with performance targets and worried about their image” (Diamond, 1984: 210). Shakespeare (1994) posits that professionals view sexual issues as of lower concern than other rehabilitation priorities. Most families ignore the issue of sex, although they recognize that sex and sexuality are valid issues. Families generally want to ignore the sexual concerns of their disabled children, they want them to sort of ‘go away’ (Shakespeare, 1994: 4). Milligan and Neufeldt (2001) argue that most families are ill-at-ease dealing with disabled children’s sexuality and really don’t know how to handle the issues. Such families are torn between accepting their disabled children’s sexuality as normal and causing difficulty or avoiding the subject altogether. In well-meaning efforts to protect disabled children from future rejection, vulnerability to sexual abuse or unwanted pregnancy, parents and professionals avoid the subject of sex, choosing to keep disabled children as children forever. As mentioned in Chapter 1, the very fact that such fundamental prejudices are so often unconscious makes them much more difficult to change. Systematic manifestations of this avoidance problem are presented below, based on the work done by Morgan (1971).

Parents, rehabilitation and medical professionals sometimes believe that sexuality will remain latent as long as the topic is not mentioned. Many medical and rehabilitation professionals claim that sexuality is not related to rehabilitation, therefore, not their job. Although much time is spent on strengthening muscles, providing ‘assistive’ devices/appliances, and providing vocational training, sexual needs and concerns are ignored (Morgan, 1971). This narrow view of rehabilitation promotes increased compartmentalisation, confusion and unnecessary suffering on the part of the disabled person. Other professionals avoid the subject because it is private. Cheausuwantavee (2002) argues that although sexual expression is private, the subject itself is



not private. Activities such as bladder control and dressing are also private, but are considered appropriate to discuss in a rehabilitation setting. The stated response by professionals reflects an unwillingness to discuss the subject of sexuality, a reluctance that might largely stem from the service provider's discomfort rather than concerns for a patient's privacy.

Rehabilitation professionals mask their negative attitudes toward the expression of sexuality by disabled people through resigned tolerance, claiming that there is nothing they can do about the subject (Cheausuwantavee, 2002). Although there are no active attempts to eliminate sexual behaviour, the underlying message is that sexual expression is not considered socially acceptable for disabled persons. Resigned tolerance, however, does allow sexual activity to some extent. While not a positive approach, it is at least not actively suppressive (Bonnie, 2004). Alternatively, this can be seen as highly questionable – negligence justified by embarrassment and formal job demarcation lines. It is a lot to expect that sexuality can unfold in a context of silence, without proper education and role models for disabled people.

In the views of Bidgood (1974: 1), it is time professionals stopped putting “all of our efforts toward the walking”, and began dealing with the real needs of disabled citizens. Bidgood (1974) further suggests that if professionals were sincere in helping disabled people to become all they are capable of becoming, to lead fulfilling lives and to enjoy all the aspects of their God given humanity, then professionals would not continue evading this issue of sexuality. “Instead they would invest their time, talents, knowledge and their energies in working for the acceptance of the fully human, fully sexual nature of people with disabilities, so that some day soon disabled people would not have to beg for acceptance, but would state proudly; we are like other people” (Bidgood, 1974: 1).

Furthermore, Cheausuwantavee (2002) suggests that it is important for a wide range of professionals such as doctors, nurses, psychologists, physiotherapists, occupational therapists and others to break down barriers to

enable people with disabilities to become comfortable about consulting professionals regarding sexual health problems. Apart from professional attitudes, gender inequalities also affect disabled people's sexuality differently as illustrated below.

#### **3.1.4. Disability, Gender and Sexuality**

Although all people with disabilities are marginalised and prevented from expressing their sexuality, disabled girls and women appear more disadvantaged because of discriminatory cultural and societal norms and prejudices. Disabled women are viewed as sexually undesirable by men and often by women themselves (Phillips, 1990). As a result, society expects them to be grateful for the attention of any man even if he is abusive and contributes nothing positive to the relationship (Phillips, 1990). The way in which family, friends and society respond to disability in general determines the patterns of daily behaviour of women with disabilities including their sexual behaviour (Howland and Rintala, 2001). Traditional social expectations for women with physical disabilities are that they should not engage in dating behaviour. According to Howland and Rintala (2001), parents who encourage their disabled teenage daughter to go out and meet people, who give her the expectations that she could marry some day if she wished, who equip her with the information and social skills she needs to attract dates, who make her feel valued and attractive, set the stage for her to have positive dating relationships. Howland and Rintala (2001) argue that laying a foundation for future adult relationships gives a young woman with a disability strength to deal with social prejudice against her dating as an adult. Conversely, parents who overprotect their disabled daughter, who tell her not to expect to date or get married, or who are neglectful or abusive, set the stage for unsuccessful attempts to establish dating relationships, repetitive exploitative relationships or unplanned pregnancy.

It is suggested that girls with disabilities have fewer opportunities to interact with their peers (Nosek *et al*, 2001a). The process of socialising and interacting with peers has been described as essential in enabling young

people to learn from each other and assert themselves as sexual beings. Conversely, overprotection and internalised social expectations make disabled women and girls more vulnerable to psychological pressure for sex and intimacy, yet they have limited access to opportunities that would teach them how to set boundaries for physical contact (Nosek *et al*, 2001c). This means that there is a need to create awareness of the specificities of disability while shaping opportunities at the same time for young people to develop as sexual beings within that disabled framework.

Most parents expect young women disabled at birth or early in childhood to be dependent all their lives and in need of protection from a cruel society (Howland and Rintala, 2001). Consistent with this assumption, Nosek *et al* (2001a) indicate that women who have been disabled since birth or during childhood often have the same desires as non-disabled girls to get married when they grow up. Their families, however, often tell them not to expect to get married, but to get an education instead. Some are told that they are incapable of being a housewife or taking care of a baby, so no-one would want to marry them. Those who live with their parents are particularly susceptible to being overprotected from involvement in dating or sexual relationships.

Gender discrimination exacerbates the problem of sexuality for disabled girls and women (Singh, Sansar, and Sharma, 2005). This problem persists because little has been written on the subject. Research on sexuality either involves few women or women are excluded purposely from some studies (Singh *et al*, 2005). A study of women after Spinal Cord Injury (SCI), found that a woman's ability to become pregnant, carry and deliver a child is largely unaffected following SCI, hence it is incorrect to assume that the sexuality of women after SCI is negatively affected (Singh *et al*, 2005). As a result, little attention is given to the sexuality of women with SCI because of these incorrect assumptions. As referred to earlier in this chapter, sexual attitudes and values from parents and others that "sex is dirty" and double standards of sexual behaviour for men and women perpetuate the avoidance of women's sexuality. Religious and cultural beliefs that sex is only for reproduction and

not for pleasure are additional socio-cultural factors that contribute to the negative impact on the sexuality of women with disabilities (Rao, 2002).

Although the establishment of romantic relationships ranks high in life's priorities for most women, and the importance of socialisation experiences in adolescence is generally acknowledged, most girls with disabilities have limited access to those experiences due to attitudinal and environmental barriers (Blackburn, 2002). These young people tend to be infantilised, perceived either as children with a child-like sexual innocence or, more problematically, as adults with sexual urges and desires which they are not equipped to handle (Tepper, 2000). Families, educators and service providers have not paid much attention to these issues. Potgieter and Khan (2005) state that dealing with a disability during adolescence postpones dating or ends it all together. Some girls may strive to date anyone they can get, regardless of how badly they are treated; this is an attempt to disprove fears that they would never again be worthy of love. Others may be overly agreeable to their partner in an attempt to hold on to the relationship at any cost, even the loss of their identity or safety.



The most troublesome problem for women with disabilities is attracting partners to date. They have low self-esteem, less education, and they suffer from communication impairment and social barriers to dating, such as a man being interested, but not asking a disabled woman out because of what others might say (Rintala, Howland, Nosek, Bennet, Young, Foley Rossi, Chanpong, 1997). Some women consider their impairment as a personal barrier to dating. Such women are always anxious to form relationships, and feel that no-one approaches them (Rintala *et al*, 1997). Having been raised to expect that they would never marry, most women and girls with disabilities are given little if any information on reproduction except that it should be avoided at all cost. Thus women with disabilities experience negative stereotyping and barriers to understanding and nurturing their womanhood.

Disability advocates are concerned about the lack of empowerment of disabled women (Department for International Development, 2000). There is

evidence of gender inequality, which suggests that females with disabilities may be more vulnerable to marginalisation and prevented from accessing education (UNICEF, 1999). Limited or lack of education increases the vulnerability of disabled women and girls to unemployment, which relegates them to poverty and social isolation. In turn, social isolation predisposes this population to risk of sexual abuse and contracting sexually-transmitted diseases, including HIV/AIDS.

### **3.1.5. Low Sexual and Self-esteem**

It has been postulated that self-esteem is a vital component of how all people face the challenges of life. “When basic self-respect is eroded, good relationships with others are hard to develop and maintain, inner peace remains elusive, and anger, depression and addictive behaviour become commonplace” (Kroll and Klein, 1992: 35). Sexual esteem has been defined as positive regard for and confidence in an individual’s capacity to experience his/her sexuality in a satisfying and enjoyable way (Snell, Fisher, Walters, 1993). According to Snell *et al* (1993), self-love, confidence and assertiveness are critical elements in a successful emotional, sexual and romantic life. Disabled people may not have these qualities and may suffer low self-esteem because they are routinely denied acceptance in every area of their lives from transportation and schooling to employment and social interactions, including sexual expression (Kroll and Klein, 1992).

In a traditional African culture, disabled women are viewed as liabilities (Smith, Murray, Yousafzi and Kaseba, 2004). They are perceived as incapable of performing household chores to the same extent as their non-disabled counterparts; hence, disabled women have less opportunity for marriage. Social norms of beauty, power and productivity present another challenge to people with disabilities, who may be perceived as unattractive. For this reason, this population needs to work harder at developing a positive, optimistic approach to their sexuality, more than non-disabled people. According to Nganwa *et al* (2002), disabled people do not quite fit the description of beauty in the African context, which is largely considered

functional and physical. Beauty of soul rarely comes into play when choosing a spouse. The perception of unattractiveness erodes self-confidence and increases low self-esteem.

Furthermore, most men abandon disabled women once conception has taken place for fear of being associated with a disabled woman and her child (Nganwa *et al*, 2002). On the one hand, disabled women are considered good enough to have sex with, but on the other hand they are considered too unattractive to be seen in public with their lovers. Such contradictions may often, indeed nearly always, send a message to people with disabilities that they are neither fully functional nor attractive. Owing to lack of privacy and overprotection by parents or caregivers, researchers indicate that disabled people become socially isolated, which reduces their opportunity for sexual expression (Bach and Bardach, 1978; Knight, 1983; and Taleporos and McCabe, 2001). Reduced mobility interferes with disabled people's sexual expression, while dependence on others for care restricts this population's opportunity to freely express their sexuality. The impact of these contextual barriers is low sexual and self-esteem in all people with disabilities, but more so in women with physical disabilities. More often women with low self-esteem may also lack skills to defend themselves, report or escape violence and sexual abuse.

### **3.1.6. Violence and Sexual Abuse**

Sexual abuse has been defined as being forced, threatened, or deceived into sexual activities. These activities range from looking or touching to intercourse or rape. Physical abuse is any form of violence against the body, such as being hit, kicked, restrained or deprived of food or water (Nosek *et al*, 2001b). People with disabilities are at risk for all the stated forms of abuse including financial exploitation, neglect, and exploitation for medical and treatment purposes. Although there is a wealth of literature on domestic violence and sexual assault against women, it almost never incorporates the element of disability (Kaufman, Silverberg and Odette, 2003). Literature on the disability arena appears to have focused mostly on abuse of intellectually disabled

children and only a few studies have looked at the whole spectrum of other disabilities (Nganwa *et al*, 2002; Groce, 1999; 2003).

It is reported that perpetrators of rape are targeting a growing number of disabled people, specifically because this population either cannot report the abuse or they will not be believed when such abuse is reported (Groce, 2003). Thus, disabled young people are at increased risk of physical and psychological abuse, domestic violence and rape. Other studies indicate that individuals with disabilities are three times more likely to be victims of domestic violence, violence in the community and rape than their non-disabled peers (Sobsey, 1991; Chenoweth, 1996; Kaufman *et al*, 2003). Moreover, these researchers allege that disabled young people are often not protected by law because police prosecutors are reluctant to take complaints from disabled people or allow them to give testimony in courts. As a result, violence against this population continues unimpeded.

Most disabled young people with cerebral palsy, paraplegia or quadriplegia relegate part or all of their care to attendants or family members. Apart from having their privacy compromised, they may also be exposed to sexual exploitation by their carers, which is a double tragedy. It has been suggested that overprotection and internalised social expectations make disabled women and girls more vulnerable to psychological pressure for sex and intimacy (Rintala *et al* 2001). Disabled young people have limited access to opportunities that teach them how to set boundaries for physical contact, hence their vulnerability to sexual abuse. They lack perception or sound judgement regarding safe or unsafe advances from sexual predators.

Furthermore, disabled young people suffer an equal or up to three times greater risk of stranger or acquaintance rape than their non-disabled peers (Saxton *et al*, 1988). A study done in the Kibwezi Community Based Rehabilitation (CBR) programme in Kenya found that sexual abusers are usually family members (AMREF, 2000). This finding introduces a further and profound element of secrecy and repression – that of incest – which is a deep-seated taboo that makes disclosure of abuse even more difficult. In spite

of the finding that disabled and non-disabled children tend to be raped, the difference is that disabled children are less likely to report abuse than their non-disabled peers AMREF (2000). This is because most disabled children have been raised to believe that they are asexual and so they might not be believed should they report rape (World Bank, 2004b). Where incest is involved, disclosure, never mind redress, is even more problematical.

Although the incidents of abuse of disabled women are similar to those experienced by women in general (Nosek *et al*, 2001c), disabled women suffer a double risk because some types of abuse are specifically disability-related, such as withholding needed orthotic equipment (wheelchairs and braces), personal tasks such as dressing or getting out of bed. Other factors include higher rates of exposure to institutional facilities and the stereotype that this population is dependent, passive and easy prey (Nosek *et al*, 2001c; Groce 2004b). Abuse can take the form of fondling or forcing sexual activity in return for accepting help. Perpetrators may take advantage of physical weakness and inaccessible environments (such as upstairs apartment or shacks) to force sexual activities. Nosek *et al* (2001b) pointed out that certain disability-related settings create an environment of isolation and diminish the defences of disabled young people. Examples of these include special education classrooms, residential facilities, hospitals and clinics. Segregated schools for students with disabilities magnify the vulnerability of disabled young people who may not be able to communicate easily (Nosek *et al*, 2001b). It is further reported that women with disabilities tend to experience abuse for longer periods, reflecting the reduced number of escape options open to them due to more severe economic dependence, environmental barriers and social isolation (Rintala *et al*, 2001).



### 3.1.7. Sexuality Information

Parents may not realise that they have a responsibility to teach their children fundamentals of life through daily words and actions and through what they say or do not say (Kupper *et al*, 1992). Issues like love, human interaction, friendship, fear, laughter, assertiveness and so on are part of the lessons that children learn from their parents. In the process, parents become their children's primary educators about values, morals and sexuality (Kupper *et al*, 1992). However, based on cultural beliefs about sexuality that were outlined earlier in this chapter, most parents in an African setting may not be comfortable with this role.

For personal and social reasons, some parents find sexuality a difficult subject to teach. Whether children are disabled or non-disabled, the idea of discussing sexuality with them makes parents uncomfortable, regardless of their culture, educational background or religious affiliation, beliefs or life experiences (Kupper *et al*, 1992). Parents of disabled children are even more anxious about their disabled children's sexuality; the subject may arouse different strong emotions. On the one hand, sexuality represents goodness, joy, sense of family, warmth, pleasure and love. On the other hand, it represents fear due to sexually-transmitted diseases, exploitation and unwanted pregnancy (Kupper *et al*, 1992). Owing to this dilemma, disabled young people have a genuine need to learn about sexuality, its meaning in adolescence and adult life. Such information would enable this population to make informed decisions and would allay parents' fears. Physically disabled young people need information about values, morals and the subtleties of friendship, dating, love and intimacy. They also need to know how to protect themselves against unwanted pregnancy, sexually-transmitted diseases and sexual exploitation. To this effect, Shakespeare's (1996) observation is pertinent – *“Information is power and disabled people still don't have it.”*

Lack of access to sexuality information is one of the major challenges facing disabled people in general, and in particular, disabled young people (Fegan, Rausch and McCarthy, 1993). Fegan *et al* (1993) posit that disabled young

people often lack access to information specific to their individual circumstances, about appropriate expression of sexuality and effective sexual communication skills. Earle (1999) observes that since society views persons with disabilities as asexual, social structures do not feel compelled to let disabled people have access to sexuality information. Eventually, this becomes a barrier to safe sex education and leads to a gap in attitudes between persons with or without disabilities.

It is suggested that disabled people are sometimes deliberately misinformed about sexuality in order to discourage their interest (Hingsburger and Tough, 2002). Other beliefs have been advanced, which build on each other and systematically prevent disabled young people from accessing information on sexuality and sexual health (Kaufman *et al*, 2003). A study done by Rintala *et al* (2001) indicates that women learn very little about sexuality from their families and school. In the study above, those who had received sexuality information thought that because they had a disability, it did not apply to them. Those who received formal rehabilitation reported that sexuality classes were given too early during recovery when they had other more pressing issues to consider. It is worth noting that the above findings represent the experiences of a disabled population who have access to rehabilitation. It could be assumed that disabled people who live in poorer settings like Nyanga may have limited access to rehabilitation services, and so they may report different experiences. Low literacy levels among disabled young people may also be a barrier to their ability to read and understand sexuality issues.

### **3.1.8. Sexuality Education**

There is a distinction between providing sexuality information and sexuality education (Haffner, 1990). Sexuality education is not just about providing information in a broad sense on the basic facts of life, reproduction and sexual intercourse. "Comprehensive sexuality education addresses the biological, socio-cultural, psychological and spiritual dimensions of sexuality" (Haffner, 1990: 28). As such, it should address:

1. Facts, data, and information
2. Feelings, values, and attitudes
3. The skills to communicate effectively and make responsible decisions  
(Haffner, 1990: 28)

In this way, many facets of human sexuality would be addressed. According to Haffner (1990), the following should be the goals of comprehensive sexuality education:

**a) *Provide information:***

All people have the right to accurate information about human growth and development, human reproduction, anatomy, physiology, masturbation, family life, pregnancy, childbirth, parenthood, sexual response, sexual orientation, contraception, abortion, sexual abuse, HIV/AIDS, and other sexually-transmitted diseases.

**b) *Develop values:***

Sexuality education gives young people the opportunity to question, explore and assess attitudes, values, and insights about human sexuality. The goals of this exploration are to help young people understand family, religious and cultural values, develop their own values, increase their self-esteem, develop insights about relationships with members of both genders, and understand their responsibility to others.

**c) *Develop interpersonal skills:***

Sexuality education can help young people develop skills in communication, decision-making, assertiveness, peer refusal skills, and the ability to create satisfying relationships.

**d) *Develop responsibility:***

Providing sexuality education helps young people to develop their concept of responsibility and to exercise that responsibility in sexual relationships. This is achieved by providing information about helping young people to consider abstinence, resist pressure to become prematurely involved in sexual intercourse, properly use contraception and take other health measures to

prevent sexually-related medical problems such as teen pregnancy and sexually-transmitted diseases, and to resist sexual exploitation and abuse (Haffner, 1990: 4). It is clear from the above list that a great deal of information about sexuality, relationships and then self-esteem needs to be communicated to all children and young people, including those with disabilities. In addition, parents and professionals need to allow young people opportunities for discussion and observation, as well as for practicing decision-making skills, assertiveness and socialising (Blackburn, 2002). It follows that, sexuality education cannot be achieved in a series of lectures that take place when children are approaching or experiencing puberty. Sexual education should be a lifelong process and should begin as early in a disabled child's life as possible.

Providing sexuality education to children and young people with disabilities may be particularly challenging because of their unique circumstances. These individuals often have fewer opportunities to acquire information from their peers, have fewer chances to observe, develop and practice appropriate social and sexual behaviour, may have a reading level that limits their access to information, may require special material that explains sexuality in ways they can understand, and may need more time and repetition in order to understand the concepts presented to them (Kupper *et al*, 1992). Ultimately, learning about comprehensive sexuality would prepare disabled young people to assume the responsibilities of adulthood, living, working, and socialising in personally meaningful ways within the community (Kupper *et al*, 1992). It would also prepare them to be aware of sexual and reproductive health and when and how to seek such services.

### **3.1.9. Sexual and Reproductive Health Care**

As noted earlier, disabled young people may not feel comfortable talking about sexuality and sexual health matters with attendants or family members who attend to some of their personal needs like bathing and dressing. As a result, most disabled young people may not report any sexual health problems should they arise (Digiulio, 2003). Instead, they may become

confused, filled with guilt and remain silent over sexual and reproductive health matters. Even in an era of sexual enlightenment, “a code of silence continues to envelope the issue of sexuality and disability” (Kroll and Klein, 1992: 20), with consequent neglect of the sexual and reproductive health needs of disabled young people. Society is blinded to such needs for disabled young people.

Access to a wide range of information on sexuality and sexual health is “firstly, an essential component of an individual’s ability to avoid sexual health problems such as sexually-transmitted diseases, unwanted pregnancy, sexual exploitation and abuse. Secondly, sexuality and sexual health information enhances an individual’s health by improving his/her positive self-image and integration of sexuality into mutually satisfying relationships” Digiulio (2003: 61). Sexual health involves more than practicing safer sex to prevent sexually-transmitted diseases. It is about mental, emotional and physical health and safety. It is also about keeping free from sexual coercion and being damaged by the actions of others (Kaufman *et al*, 2003). Safer sex information often assumes that disabled people have the ability to be aware of their physical and mental state. On the contrary, a combination of lack of information, knowledge and lack of privacy actually prevents disabled people from self-monitoring their reproductive organs for any unusual symptoms (Szollos and McCabe, 1995).

Those with no feelings may have no sensation of pain or discomfort (Kaufman *et al*, 2003) and so may not be able to tell the difference should they contract a sexually-transmitted disease. Consistent with this finding, Rintala *et al* (2001) found that women with disabilities are less likely to complain of symptoms suggesting a sexually-transmitted disease. Mobility and sensory impairments prevent them from noticing a rash or vaginal discharge or from feeling pain and itching; therefore, sexually-transmitted diseases are less likely to be detected in time and treated in women with disabilities. Failure to be treated of sexually-transmitted diseases could place disabled women in jeopardy of getting pelvic inflammatory disease and increase their risk of

developing cervical cancer or infertility and contracting sexually-transmitted diseases including HIV/AIDS.

Health care providers often mistakenly assume that young people with severe or disfiguring disabilities are not sexually active, and may neglect to screen for sexually-transmitted diseases (STDs) (Saiti, 2001). Nosek *et al* (2001a) advise that health care workers should not wait until a woman brings up the subject; because some women may have been sheltered from getting sexuality related information or may have grown up believing that their bodies are so different from the able-bodied that they are not susceptible to getting the same disease. The results of nation-wide seminars with disabled people in all the provinces of South Africa indicated that health workers in some parts of the country ridicule disabled people who present with sexually-transmitted infections at health centers (Saiti, 2001). Such attitudes are a major deterrent to disabled people seeking intervention for sexual and reproductive health problems.

Furthermore, Tilley (1996) found that women with physical disabilities do not receive the same quality of gynaecological health care, such as pap smear testing for cervical cancer. While Anderson and Kitchin (2000) found that women with physical disabilities have limited access to family planning services compared to their able-bodied counterparts. In addition, it is difficult for disabled women to receive information about methods of birth control that would be safe and effective in the light of the special considerations related to their disability (Anderson and Kitchin, 2000). Besides, many disabled people who become infected with a sexually-transmitted infection cannot afford treatment and others do not know where to go for the same (Saiti, 2001).

In Lusaka, Smith *et al* (2004) reported that physically disabled women feel they attract negative attention when using reproductive health services. They report that some of the gestures from staff contribute to the idea that there is something unusual for disabled women using reproductive health care services. In the same vein, Welner (1999) observed that the high examination tables deter physically disabled women from going to obtain health screening

and contraceptive counselling. Thus the exclusion of disabled people from sexual and reproductive health services is seen to arise from a range of factors such as discriminatory attitudes in society, gender-related and architectural factors. Ignorance about sexual rights and responsibilities in disabled people and society at large contributes towards the deprivation of sexual health services for this population.

### **3.1.10. Sexual Rights and Responsibilities**

There follows a detailed description of the sexual rights and responsibilities that all human beings are entitled to (Daniels *et al*, 1979). These rights and responsibilities are quoted at some length in order to highlight what society should strive to achieve for young people with disabilities. In keeping with the United Nations Declaration of Human Rights (1948-1998), every citizen has the same basic rights as other citizens of the same country and age. No person should be denied a right because of a perceived difference, for example, race, sex, economic status, presence of a disability or political opinion (Daniels *et al*, 1979). It would appear that this basic concept is still not a reality for many disabled young people. All people including disabled people have the following sexual rights and responsibilities:

#### **a) The right to sexual expression**

Sexual behaviour among consenting adults, regardless of mental age and whether it is homosexuality or heterosexuality, should be nobody else's business, providing there is little risk of bringing an unwanted child into the world. No-one has the right to limit the sexual expression of another person unless coercion or the high probability of an unwanted child (unwanted by the individual, not by society) is involved. The right to sexual expression includes the opportunity to experiment and discover what is sexually satisfying - for example, masturbation, the use of sex aids and the use of various positions (Gordon, 1974).

## **b) The right to privacy**

All people need privacy in their daily lives, yet disabled individuals are not always accorded the same right that non-disabled people often take for granted. Privacy during activities such as going to the bathroom, undressing, having sex and simply being alone may be difficult to arrange. Disabled young people living in institutions, for example, may sleep in dormitories with no adequate partitions, use bathrooms or toilets that are in the open and socialise under the watchful eyes of the staff. Those living in shacks share insufficient space with other family members. In order to engage in sexual activities with some degree of privacy, disabled people living under such circumstances may find it necessary to resort to the bushes or broom closets. Lack of privacy can also be a problem outside the institutional environment. Overprotective parents of a disabled young person may not realise that, although their child is disabled, he/she is approaching adulthood and needs more privacy. The common tendency to treat a disabled child or young person like a dependent child limits the individual's opportunity for growth and sexuality development.

## **c) The right to be informed**

All people need the opportunity to talk and learn about matters related to sexuality. Accurate information is essential for the healthy development of one's sexuality; the opportunity to put this information into practice is also important. The lack of social skills - for example, how to start a conversation with another person - frequently creates difficulties for disabled young people and adults<sup>10</sup>. They know what to do *when* they get there, but they do not know *how* to get there. Some knowledge of social norms, in terms of what is generally considered socially acceptable, is also necessary to enhance sexual development. Although an individual may choose a sexual option, which is not culturally typical, they should at least be aware of the existing social norms.

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<sup>10</sup> Disabled young people's need for assistance, individually and at the social level in education is considerable, but disabled people are scarcely unique in this respect, of course, as so many of us who can remember our early teen years will confirm.



**d) Access to needed services**

Although special services may sometimes be appropriate, disabled people should also have access to services used by the general community whenever possible. This normalised approach to services may require modifications by the service providers such as building ramps or providing interpreters. Easy access to sexuality-related services is a right of all individuals. Examples of such services are:

1. Contraceptive counselling
2. Medical care (examination by a gynaecologist)
3. Legal aid (related to matters such as competence to handle own affairs and marriage laws).

**e) The right to choose marital status**

Arbitrary restriction of marriages involving disabled people is a violation of human rights. No-one has the right to decide for others whether or not they should be permitted to marry. Many non-disabled people lack the maturity and commitment to make a marriage work; these people, however, are not prevented from getting married. Yet some disabled people encounter resistance to their plans for marriage, strictly on the basis of their disability. Individuals with severe physical and mental disabilities most often experience this form of discrimination. Disabled people are generally the best judges of their own limitations and capabilities. Although some counselling and training may be necessary so that marital responsibilities are clearly understood, the final decision should rest with the couple. Disabled people also have the right not to marry. Children and young people should not be conditioned to believe that marriage is the only acceptable option available. Some people do not want to marry and should not be made to feel “abnormal”.

**f) The right to have or not have children**

The decision to have or not to have children is made by the potential parents. Disabled people are also entitled to this right. A realistic assessment of one’s limitations and capabilities is an essential component of making a responsible decision regarding parenthood. Modifications and supportive services may need to be considered, for example, an attendant to help a person with limited

use of their hands take care of a new born infant. Education and training should be available so that the decision whether or not to have a child is made on a realistic foundation. As with marriage, no person should be conditioned to believe that being a mother or father is equated with maturity and adulthood. If an individual does not wish to be a parent, that should be his/her choice.

**g) The right to make decisions which affect one's life**

Feelings of helplessness, resulting from lack of control of one's life, can have devastating effects on one's self-esteem, attitudes toward others and on one's behaviour. Overprotection, albeit with the best intentions, although it may be motivated by the best intentions, unnecessarily limits the disabled person's potential for achieving independence. Learning to cope with problems and make decisions involve an element of risk. Risk, however, is an integral part of life. To deprive the disabled person of choice and risk is to condemn him/her to permanent childhood. Making a mistake may cause temporary unhappiness; being treated as a dependent non-person often results in lifelong isolation, confusion, frustration and boredom. With appropriate education, training and experience, all disabled people can have at least some significant level of control over their own lives. This level is almost always higher than the evaluation made by non-disabled "carers". The right to make decisions implies the right to choose one's values concerning sexuality. No-one has the right to make these decisions for another adult.

**h) The right to develop one's fullest potential**

Growth and increased independence in one area of life affects other areas as well. By receiving education and encouragement aimed at enhancing their sexual potential, a disabled person achieves greater self-esteem, confidence and independence. These changes may then influence the individual's perception of and motivation for other aspects of life, such as work, recreation, and community involvement. Rehabilitation, if it is to be truly meaningful, should address *all* aspects of a disabled person's life. Attempts to compartmentalise these aspects into narrow slots only serves to undermine the rehabilitation process (Daniels *et al*, 1979).

Based on the foregoing literature, disabled people and society at large need to be educated on these rights, if the sexuality rights of disabled young people are to be respected. In the same way, governments and service organisations need to be informed by these rights in order to provide sexuality and sexual health services that are sensitive to the special circumstances of disabled young people. Having established the paradoxes and contradictions inherent in disabled young people's experiences and perceptions of sexuality in the context of disability, the next section deals with HIV/AIDS issues.

### **3.1.11. Summary**

In section 3.1, I have dealt with the social construction of sexuality, including issues of African sexuality, which are fraught with historical and cultural taboos and legends. These taboos are reinforced and complicated by the various ways in which disability is understood and explained. Environmental conditions of culture and poverty combine with individual factors to de-regularise this population's sexual expression through prejudice, suppression or over-control. These conditions double the risk of disabled people's vulnerability to low self-esteem, sexual exploitation and the risk of contracting sexually-transmitted diseases. The section concludes with an outline of the universal sexuality rights and responsibilities of people with disabilities.

## **3.2. HIV/AIDS RISK IN THE CONTEXT OF DISABILITY**

As indicated above, in this section I explore the HIV situation among young people in general, and among disabled young people in particular, focusing on this population's experiences of HIV/AIDS.

### **3.2.1. Young People and HIV/AIDS in South Africa**

According to WHO (2002), HIV/AIDS is one of the top causes of illness and death among young people all over the world, and, specifically in sub-Saharan Africa. The AIDS pandemic has had catastrophic consequences for the general well-being of young people and their communities. It was stated in the first chapter that young people in South Africa are considered central agents in the fight against HIV/AIDS because they are not only disproportionately affected by the pandemic, but the sustainable development of nations is dependent on healthy and productive young people (World Bank, 2003).

When young people who are infected with HIV become sick, they lose the ability to work and provide for themselves and for members of their families. This worsens the poverty situation in many households, which further increases the vulnerability to HIV infection of other family members in the household. Poor people may trade unprotected sex for food and monetary gifts. The Department of Education (2001a) states that large numbers of young people in South Africa are getting infected and affected by HIV/AIDS. This situation leads to psychological, social, economic and educational problems. Other studies by Venier and Ross (1997) and Abt Associates (2001) demonstrate that most HIV infections occur during adolescence. Likewise, a study done by Morris, Leslie, Ulmer and Chimnani (2003), which assessed the impact of education on young people's knowledge of HIV/AIDS, indicates that a half of all new infections with HIV occur in young people under the age of 25 years. In spite of the supposed high levels of knowledge about HIV infection, young people seem impervious to the need to change sexual behaviour in order to avoid contracting the infection (Galloway, 1999;

MacPhail and Campbell, 2001). Such findings point to limitations of HIV prevention efforts that are aimed at conscious levels of behaviour change, without taking into account the unconscious levels, cultural and social aspects of behaviour.

Other researchers have indicated that young people have limited knowledge about HIV/AIDS. For example, in a study about young men's sexuality in Ethiopia, Tadele (2006) argues that young men's sexual behaviour is in fact driven more by ignorance rather than adequate knowledge about HIV/AIDS. In another study among students in the Western Cape, Kuhn, Steinberg and Mathew (1994) found that relatively few believe that HIV/AIDS can affect them and so their attitudes toward prevention are largely negative. Close to half of these students believe that having one uninfected sexual partner helps prevent AIDS (Kuhn *et al*, 1994).

Furthermore, a survey done by Harvey (1997) indicates that Zulu-speaking, grade-10 students do not have enough information to provide a foundation for developing safer sexual behaviour. Although most students in the stated study acknowledge the severity of the disease, few report feeling personally susceptible and so deny the immediacy of the threat. The same study found that most young people are sexually active with a third having more than one sexual partner. Similarly, Hartel (2005) in his study about the sexual behaviour of adolescents found that although they are sexually active and have basic knowledge about HIV/AIDS, they do not know how the virus is transmitted. For this reason, Hartel (2005) proposes that young people in South Africa should be regarded as a high-risk group for HIV. The level of the risk is difficult to quantify, as not knowing how HIV is transmitted indicates a lack of even the basic knowledge that Hartel suggests these young people have.

It might be assumed that young people in South Africa constitute a homogeneous grouping, hence the one-size-fits-all research focus and HIV intervention programmes designed for this population. Such research and intervention programmes do not meet the special circumstances that create different needs for disabled young people (MacPhail and Campbell, 2001; Kelly *et al*, 2002a), for example, physically disabled young people with mobility problems require intervention programmes that are accessible. For this reason, there is a need for research about young people as well as HIV/AIDS programmes to take note of variations between disabled and non-disabled young people in the experience and interpretation of risk when planning intervention strategies.

### **3.2.2. Misperceptions about Disabled Asexuality and HIV/AIDS**

As explored in Chapter 2 above, disabled young people are perceived as passive and sexually inactive, lacking sexual interest and skills to explore their sexuality (Johnson, Johnson, and Jefferson-Arker, 2001). This perception is in contrast to the construction of the teen years that have been labelled a time of experimentation that is characterised by risk taking behaviour that leaves young people at increased risk for contracting HIV/AIDS (Morris *et al*, 2003).

The deceptive picture of disabled asexuality was dispelled by a survey conducted in Minnesota, U.S.A., which found that there are no differences between disabled and non-disabled adolescents' sexual activity rates; rather significantly high rates of sexual abuse among disabled adolescents were noted (Suris, Resnick, Cassuto, and Blum, 1996). This finding does not only demonstrate that this population is sexually active, but also that disabled young people are as likely to contract HIV infection from their engagement in sexual activity as from sexual abuse. Similarly, in another study, Cheng and Udry (2002) reported that although adolescents with disabilities are more socially isolated and slower in pubertal development than their non-disabled peers, they are nevertheless sexually experienced. This finding also dispels the falsehood about disabled asexuality and points to similar vulnerabilities to sexually-transmitted HIV infection. The World Bank survey (2004a) indicates

that because disabled people are as likely as their non-disabled counterparts to be sexually active, they are exposed to equal, even more, risk factors for HIV/AIDS as their non-disabled peers, hence the double risk that was pointed to earlier.

One of the key consequences of the false assumptions about disabled asexuality is that individuals with disabilities are excluded from HIV/AIDS prevention and AIDS outreach efforts (Nganwa, *et al* 2002; Groce, 2003; 2004). When strategies on HIV/AIDS are drafted, policies developed and budgets allocated, the needs of disabled young people are often ignored (Kelly *et al*, 2002a). This neglect could partly be because existing programmes are designed for young people in 'general'; therefore, specific needs of disabled young people as highlighted in the current study are neglected. In their attempt to avoid stigmatisation, Governments and AIDS service organisations provide general programmes, which in fact, fail to reach specific at-risk groups.

The other reason for the neglect of disabled young people's specific needs is the limited research targeting this population. Groce (2004a) and Potgieter and Khan (2005), in their separate studies about disabled young people, have confirmed a paucity of literature, due to limited research that has specifically focused on disabled young people as a key group. It is thus pointed out that young people with disabilities are nominally included in children and adult programmes alike. This is a matter that calls for new programmes to re-focus on the needs of disabled young people as a unique group (UNICEF, 1999). There is a need to prioritise this group's vulnerabilities to HIV risk and the prevention needs thereof.

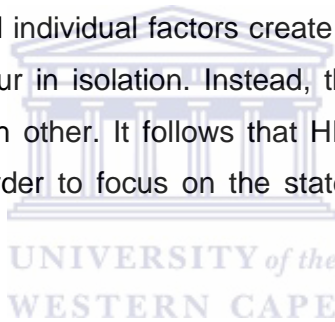
### **3.2.3. Risk Factors for HIV/AIDS among Disabled Young People**

It would appear that disabled young people face a double tragedy with regards to HIV/AIDS. On the one hand, they are exposed to the same risk factors as their non-disabled peers. On the other hand, they face risk factors that are disability-specific which complicate and double their risk. The

following issues have been broadly identified as some of the factors that place disabled young people at increased risk of HIV infection:

1. Community -level factors such as cultural beliefs about disability, peer and parental pressure
2. Individual perceptions about health and vulnerability such as sexual behaviour
3. Wider social influences including the social construction of male and female sexuality and gender discrimination and gendered power relations
4. Economic constraints such as limited access to gainful employment (MacPhail and Campbell, 2001).

The stated contextual and individual factors create complex conditions of risk because they do not occur in isolation. Instead, they are closely interlinked and they exacerbate each other. It follows that HIV intervention efforts also need to be doubled in order to focus on the stated complexities of risk for disabled young people.



#### **3.2.4. Cultural Issues**

Historical and cultural beliefs about the sexuality of people with disabilities discussed in Section 3.1 have implications for HIV/AIDS risk, as they are key to the effect the pandemic has had on this population. Some cultural beliefs about disability appear similar to those about HIV/AIDS. Consequently, people living with HIV/AIDS may experience the same discrimination as people with disabilities. Culture has been identified as a fundamental factor in how HIV/AIDS impacts on the African population (Van Dyk, 2001). To this effect, Van Dyk (2001) has indicated that the belief that HIV/AIDS is caused by witchcraft is widespread in South Africa, and the whole of sub-Saharan Africa. Such belief systems carry a connotation of blame, which leads “society to hold HIV positive individuals culpably responsible for their illness” (Desclaux, 2002:3). Similarly, the common belief in African cultures that disability is caused either by witchcraft, ancestor’s sorrow or anger, breaking a taboo or



God's will/natural causes (Schoepf, Nkera, Ntsomo, Engundu, and Schoepf, 1988), leads to blame, fear and neglect of disabled people.

The above beliefs towards HIV positive individuals and those with disabilities are based on the stated historical and cultural views, according to which disease is caused by breaking taboos, an act punishable by supernatural powers (Desclaux, 2002). HIV/AIDS, like disability, may be viewed as a consequence of failure to observe social norms. The affected are thus viewed as guilty persons who are being punished and have to bear the consequences of their reprehensible behaviour. In most societies, HIV/AIDS and disability lend themselves to this interpretation, legitimising rejection and condemnation of the people affected (Desclaux, 2002). Such cultural beliefs become a barrier to caring for a population that is presumed guilty and deserving of their circumstances.

Perceptions of fear and revulsion lead families and communities to shun people with disabilities and those living with HIV/AIDS, so as to avoid perceived contagion by direct or indirect contact with the affected individual (Desclaux, 2002). As a result, people living with HIV/AIDS suffer marginalisation and discrimination in their families and communities in the same way as people with disabilities. Similarly, the carers of those living with HIV/AIDS who are often women and mothers bear the burden of living in constant fear as they care for the sick, just as mothers of disabled children live in fear of ostracism. Such situations drive the HIV infected into self-isolation because this group does not dare assert that they are not contagious. In the same way, disabled people tend to go into self-isolation to escape being teased or ridiculed.

Discriminating against people on the basis of a disability or HIV/AIDS status confirms the argument that social attitudes and responses to impairments create vulnerabilities among disabled people (Nganwa *et al*, 2002). Such an argument further confirms that on the biological level, impairments do not make disabled people more vulnerable to HIV infection. Thus many decisions and outcomes of disabled young people's experiences of HIV/AIDS can be

attributed to the socio-cultural environment in which their disability is born and bred. For this reason, Airhihenbuwa, Makinwa and Obregon (2000) recommend that any new direction for HIV/AIDS prevention in Africa should make culture the central theme and allow it to direct efforts in HIV/AIDS prevention, care and support. Such programmes are likely to find ways of dispelling the false assumptions about disabled asexuality and facilitate the inclusion of disabled young people in mainstream HIV/AIDS activities. In the same vein, Desclaux (2002) has demonstrated that the social exclusion of people living with HIV/AIDS has some of its origins in cultural beliefs. This can be countered by making information available to the general population about ways through which HIV/AIDS is transmitted and the precautions needed for protection of self and others.

### **3.2.5. Stigma and Discrimination**

As detailed earlier, the 'right' not to be subjected to discrimination is enshrined in Article 2 of the Universal Declaration of Human Rights and in many international legal texts (United Nations, 1948-1998). Like people with disabilities, many people living with HIV/AIDS continue to be discriminated against. Stigma and discrimination have historical, cultural and social origins (Desclaux, 2002). In many societies, it is said that individuals who are born with or acquire a disability are stigmatised and discriminated against (Lang, 2000). When such individuals become HIV positive, they feel doubly stigmatised (Yousafzi and Edwards, 2004). Again, it follows that double stigma requires double effort for intervention.

In the context of the fight against HIV/AIDS, Desclaux (2002) suggests that discrimination should be regarded as a public health issue based on the premise that discrimination is an obstacle to the provision of HIV information to all populations. Discrimination depersonalises the risk of HIV as it generates mistrust and criticism, which reduces chances of negotiating preventive measures. Young people with or without disabilities may be less willing to learn about their serostatus for fear of criticism and rejection. Thus discrimination limits recourse to screening for HIV infection as disabled and

non-disabled individuals alike deny that they may be infected. Such denial makes HIV-infected individuals less likely to seek treatment.

In summary, it can be said that discrimination is a crosscutting phenomenon, which increases the social vulnerability of individuals living with HIV/AIDS and their families; it also increases disabled young people's vulnerability to HIV infection. The illustrations presented above show that the effects of discrimination on people with disabilities and on those living with HIV/AIDS are similar and mutually reinforcing. The UNAIDS (2001) has declared that no population group, including young people with disabilities, is completely free from the HIV/AIDS pandemic. For this reason, only a global approach based on mechanisms that strengthen social cohesion can reduce the spread and impact of the pandemic. Strong social cohesion implies that people are respected regardless of their background and lifestyle and of the group or social category to which they belong (UNAIDS, 2001). Based on this declaration, there needs to be an effort to fight discrimination against disabled people, and particularly disabled people living with HIV/AIDS.

### **3.2.6. Economic Constraints**

As covered in Chapter 1, urbanisation in South Africa is described as an important factor in determining the population's health and its disease patterns (Gilbert and Walker, 2001). According to Statistics South Africa (2001), 9% of the South African urban population live in shantytowns, with limited access to basic facilities such as safe water, sanitation, electricity and health services. Many disabled adults and young people of African origin live in these poorly resourced areas, like Nyanga, where such services are either limited or absent all together (ODP, 1997). This implies that disabled young people are likely to be vulnerable to all risk factors involved in living under the stated conditions of poverty, including HIV/AIDS.

Yousafzai and Edwards (2004), and Sweeney (2004) point out that HIV/AIDS is both a cause and a result of poverty. They allege that poverty fans the HIV pandemic and is also the fruit of the pandemic. Their point is that poverty

limits the choice for safe sex and safe partners among people with disabilities because people are driven more by their need for survival than maintaining a moral code. Thus, poverty drives disabled people to use sex as a means of meeting their economic needs. In the process, they place themselves at increased risk from HIV/AIDS. In the same vein, those who become sick from HIV/AIDS may lose their jobs and spend a lot of their resources on treatment and care. Chronic illness creates huge financial demands for ongoing medical care, time-out of productive working hours for both the sick person and his/her carers, thereby increasing poverty in the household (Yousafzi and Edwards, 2004). Thus the experience of HIV/AIDS reduces the ability of individuals to be economically productive. For this reason, the experience of disability and a positive HIV serostatus are repeatedly described in this thesis, as a double risk for disabled young people.

Other environmental factors, such as inaccessible public transport and buildings, may impact negatively on physically disabled young people's experience of HIV/AIDS. This population may not be able to access a health clinic or a Voluntary Counselling and Testing (VCT) centre because of these constraints (Saiti, 2001). As pointed out earlier, in some countries, disabled people have reported being turned away from HIV testing centres, because clinical staff assure them that disabled people cannot get AIDS (World Bank, 2004b). In this way, disabled people are systematically excluded from existing HIV prevention services. The World Bank (2004b) warns that exclusion of disabled people from HIV/AIDS services is short-sighted, given the size of the world population of people with disabilities (estimated at 10% of the world's citizens). Efforts to curb the pandemic cannot afford to have such a big population of the world's citizens not playing a role in HIV prevention efforts. Other barriers to accessing HIV prevention services have been attributed to low literacy levels among people with disabilities.

### **3.2.7. Literacy and HIV/AIDS**

Education has been described as a powerful weapon in the fight against HIV/AIDS infection in today's youth (Schinke, Botvin, Arlandi, Schilling and

Gordon, 1990). Yet, in most schools disabled children and adolescents are less likely to receive science and health education and are more likely to be excused from sexuality education courses (Oliver and Sapey, 2006). Families and societies often do not consider that children with disabilities need education (Neufeldt and Albright, 1998). For this reason, disabled children experience exclusion from education from a very young age. Lack of schooling may reflect, among other things, that such children are an embarrassment and should not regularly be seen in public. Landsdown (2003) states that disabled children are often excluded from statistics compiled to demonstrate achievement in enrolment in primary education. Low literacy levels have been identified as a risk factor for HIV/AIDS, because comprehension of HIV/AIDS prevention messages is difficult for those with limited or no education (World Bank, 2004a). The World Bank (2004a) notes that literacy is vital to understanding HIV/AIDS messages and translating them into individual behavioural change, and so it has expressed concern over low literacy levels among disabled young people. Poor literacy levels present unique challenges in the provision of HIV prevention messages, clinical care and reproductive health services to this population.

Considering that adolescents with disabilities might continue to be at risk of HIV infection if existing education and prevention programmes do not include this group; Johnson *et al* (2001) propose that it is imperative that materials and techniques that are employed to teach adolescents about HIV/AIDS prevention include adaptations for children and young people with special needs. While the challenge of lack of information on HIV/AIDS affects all disabled young people, disabled females are said to be more disadvantaged on account of being women as well as being disabled (Smith *et al*, 2004).

### **3.2.8. Disability, Gender and HIV/AIDS**

Low literacy levels among disabled girls and women are said to be another risk factor for HIV/AIDS, which prevents them from accessing prevention services (Chenoweth, 1996). Helander (1998) has pointed to low literacy levels among disabled women worldwide. According to Chenoweth (1996),

women with disabilities are more likely to be illiterate and less educated, unemployed or marginally employed, more overprotected, and to have a poorer quality of intimate relationships compared to non-disabled women and disabled men. Furthermore, disabled girls and women form part of the minority populations who are discriminated against on the basis of gender and economic status, which is another reason why this group is vulnerable to HIV/AIDS (Milligan and Neufeldt, 2001). Disabled women's safety in sexual relationships is compromised by gender norms, which insist that women should be submissive; a rule that impedes disabled women's ability to negotiate safe sex with their partners (Albertyn, 2003).

In South Africa, the particular vulnerability of young and adult women to HIV infection is linked to an apartheid past in which separate development and migrant labour policies damaged the social fabric of African families and communities (Albertyn, 2003). Social and economic policies of exclusion and dispossession created and reinforced racial poverty and inequality. Although Albertyn (2003) describes this situation for women in general, it should equally be applied to disabled women and girls in particular. Women's lack of power over their bodies and their sexual lives, reinforced by social and economic inequality, makes them more vulnerable to contracting HIV/AIDS.

Disabled women in Swaziland reported that men frequently approach them because they believed them to be free of HIV/AIDS. For the same reason, disabled women are targeted for rape (Smith *et al*, 2004), a point made in Section 3.1. The low social status of women with disabilities makes them less likely to find a spouse (Jackson and Scott, 1997). Difficulty in securing sexual partners forces some disabled young women to live in a series of unstable relationships where they lack the power of choice for safe sex and prevention of HIV/AIDS (Groce, 2003). Owing to the low social status of disabled women, they are also unlikely to demand an HIV test from a lover prior to sleeping together, lest they lose the man.

The importance of children in most African societies might be another risk factor for HIV/AIDS. The ability to have children increases a woman's acceptability, as children are considered a source of security for the future as well as an assurance of immortality (Van Dyke, 2001). After death, children are believed to keep the genealogical line and to keep the woman in a state of personal immortality for as long as her children will remember her. This belief has implications for disabled women who are prohibited from having children of their own. Such women are deprived of their cultural right to future 'security' through their children. The same belief has implications for HIV prevention messages that promote condom use, at the same time preventing conception. Conversely, disabled women may deliberately practice unsafe sex in order to have a child, particularly where having children is highly valued as stated above (Ruhweza, 2001; Smith *et al*, 2004).

Since young women with disabilities are not considered fit for either marriage or procreation, their need for sexual expression and the need for information on HIV/AIDS and reproductive health are ignored (Smith *et al*, 2004), yet no similar restrictions about having children are imposed on disabled men. The 'African Women with Disabilities' group issued a statement calling for recognition that women and children with disabilities are at high risk of contracting HIV/AIDS and are particularly vulnerable to abuse of their sexual and reproductive rights for the following reasons:

1. Exclusion and discrimination in terms of access to education, health services, family life and employment
2. Low self-esteem and confidence, which results from a life of discrimination and exclusion
3. Misconceptions, myths, prejudice and abuse (African Network of Women with Disabilities, 2002)

In addition to the above factors, women with disabilities bear the brunt of the HIV/AIDS pandemic because, in most instances, they are the main caregivers not only for themselves, but also for family members who fall sick or are living with HIV/AIDS (Banda, 2002).

### 3.2.9. Sexual Violence and Rape

It is pointed out in Section 3.1, that people with disabilities are more likely to be victims of violence, sexual exploitation and rape (McCabe *et al*, 2000). Yet disabled young people may be too afraid to report rape because of the fear that they may not be believed. Some perpetrators of rape may threaten disabled young people with violence against family members or the disabled young person themselves (Wazakili, Mpofo, Devlieger, 2006). Unless families and communities create an environment that enables the general population to realise that young people with disabilities need to be protected from rape and the risk of HIV infection, disabled young people may continue to suffer sexual abuse, which increases their vulnerability to HIV risk. Clearly, sexual abuse negates the idea of choice or behavioural change by disabled young people.

South African women continue to be subjected to indiscriminate violence, particularly of a sexual nature, which exposes them to the risk of contracting HIV/AIDS (Pereira, 1999). It is suggested that disabled women/young women are more likely to be victims of rape, sexual abuse and domestic violence compared with their non-disabled peers (Chenoweth, 1996). Disabled women/girls face unique challenges in preventing HIV/AIDS infection because of their heightened risk of gender-based violence, lack of access to reproductive health care services and low awareness of mother-to-child HIV transmission (Nganwa *et al*, 2002). Disabled young people are specifically targeted for sexual exploitation, rape and coercion into unwanted sex. This is because they are physically vulnerable and considered as easy targets since they are unable to escape abusive situations (Smith *et al*, 2004).

Disabled women who have financial limitations and need assistance with activities of daily living are at increased risk for emotional, physical and sexual abuse (Nosek, 1996), which increases their vulnerability to HIV risk. Cheng and Udry (2002) indicated that twice as many girls with disabilities have experienced forced sex compared with their non-disabled peers. What's more, the Global Survey on HIV/AIDS and disability describes the concept of "virgin



rape”, where individuals with disabilities are raped by men who believe themselves positive for HIV and hope to get cured by sleeping with disabled women whom they believe free from HIV infection (Groce, 2004b). Such practices increase disabled young people’s vulnerability to HIV infection. Cultural myths about mystical or supernatural powers associated with disability contribute to creating beliefs about HIV cure by sleeping with disabled women (Leclerc-Madlala, 2001; De Vries, 2004).

### **3.2.10. Intervention Strategies**

“Information about HIV/AIDS can mean the difference between living a long healthy life or living with a catastrophic condition” (Johnson *et al*, 2001: 28). Johnson *et al* (2001) postulate that young people will continue to be at risk of HIV infection unless education and prevention programmes are implemented for all young people, including those with disabilities.

The HIV/AIDS pandemic has created a worldwide response with a massive production of information in many languages. Yet this information has not reached many disabled people in sub-Saharan Africa (Brown and Brown, 2004). Although AIDS awareness and education seem entrenched in mainstream society and can be seen in newspapers, on radio, TV or billboards, disabled young people seem to be missing out (Brown and Brown, 2004). Tadele (2006) argues that ‘universal’ AIDS campaigns are too knowledge-oriented and too cognitive by design, they miss the culture sensitive, socio-moral perspective and the social inequalities that fuel the pandemic. For example, the idea that sleeping with a virgin will cure an infected person from HIV/AIDS; actually drives people to have more unprotected sex with those who are not able to defend themselves like disabled and non-disabled women and girls. The other problem is how such universal verbal messages can possibly reach the deaf, blind and those with learning difficulties without tailoring such messages to their special needs. Different disability groups, as stated above, have diverse challenges and may fail to access HIV/AIDS information for the following reasons:

1. Access to health information and services is reduced by lack of mobility aids and inaccessible buildings and structures (May-Teerink, 1999).
2. Inaccessibility of the information - the methods of conveying HIV/AIDS messages are not reaching disabled people because most of these messages can only be accessed through reading, hearing and seeing. As a result, people with disabilities who cannot read, hear and see are automatically excluded (Brown and Brown, 2004). Besides, awareness interventions that emphasise abstinence, fidelity and condom use overlook the importance of other contextual factors such as education, which are crucial in the comprehension of HIV messages. Disabled young people with little or no education need information to be simplified to their level (Johnson *et al*, 2001).
3. In addition, awareness-based interventions do not take into consideration the needs of people, including disabled people, who may contract HIV infection through rape or coercion; they have no choice about when and with whom to have sex (Haignere, 1999).
4. Individuals with disabilities are less likely to have access to condoms or other preventive measures because HIV services and education materials are non-inclusive and inaccessible (Brown and Brown, 2004). Furthermore, Leclerc-Madlala (2002), and Kelly, Parker, and Oyosi (2002b) point to a number of socio-cultural and economic barriers, which limit young people's access to HIV/AIDS prevention, treatment and care, like cultural beliefs and poverty.

For the past two decades, HIV/AIDS programmes have focused on prevention as the most reliable method of containing the pandemic (Parker and Aggleton, 2003). Even as antiretroviral therapy is now made available to some people living with HIV/AIDS, emphasis continues to be placed on prevention. To this end, an abundance of information about the contagion and spread of HIV/AIDS has been produced and widely disseminated through awareness campaigns. According to the Western Cape Department of Health (2000) the Abstain, Be Faithful, and *Condomise* [consistently use a condom] (ABC) message of HIV prevention is relatively simple and widely available in institutions of learning and in the media in South Africa. With such a simple

message and so many resources already allocated, it might seem that all who need to know about HIV/AIDS have access and that understanding the message also leads to sexual behaviour change. However, these interventions are not relevant to the needs of disabled young people who are raped or those who cannot access condoms due to inaccessible public buildings or clinics.

The efficacy of existing HIV/AIDS messages is now being questioned (James *et al*, 2004; Parker, 2004). This is because the incidence of HIV/AIDS among young people continues to rise (Parker, 2004). Since the beginning of the HIV/AIDS pandemic, the Abstain, Be faithful and Condomise (ABC) message has been the credo for the HIV prevention programmes. However, studies have shown that there is little evidence to suggest that this message is yielding the desired outcomes among young people (Kelly *et al*, 2002b, Shisana and Simbayi, 2002). This finding points to the limitations of individual-based intervention strategies for a pandemic that so widely permeates the fabric of society.

Young people in South Africa have received much of their knowledge of sexual health promotion from government mass media campaigns (MacPhail and Campbell, 2001). A study that tried to establish the nature of the strongest influence on young people's sexual activity indicated that young people express greater need to learn more about sexuality and contraceptives from their teachers and parents (Howland and Rintala, 2001). Yet most HIV/AIDS programmes have used participatory peer education approaches. MacPhail and Campbell (2001) state that there is little evidence that such approaches have had a significant impact on the pandemic. It may well be that young people need a combination of encouragement from peers and the confidence and authority that only parents and teachers can give. According to Leclerc-Madlala (2002), part of the problem is that much information about sexual health education tends to explain dangers and set out rules of conduct that aim to minimise risk. Only too seldom is this done in the setting of a real personal relationship or the cultural context in which real-life sexual activity takes place in people's lives. Thus, many existing sexual health programmes

appear to focus more on awareness-raising, emphasising individual behavioural change. Parker (2003) argues that this form of communication is ineffective because:

1. The traditional model of health education relies on a predominantly one-way transmission of information from health care providers to communities and patients in the form of public information campaigns, pamphlets and interpersonal delivery of information by health care workers.
2. Such a communication model often mistakenly assumes that people retain and act on information delivered in the form of texts, facts, figures, rules and writings. Caldwell *et al* (1989) and Parker (2003) note that although there are many public service announcements, public education campaigns, Non-Governmental Organisations (NGO) and community-based health clinics that employ more effective communication strategies, there are also many that do not – especially in the under-resourced areas of Southern Africa.

In recent years, there has been an increased interest in male circumcision as an additional intervention strategy for HIV. Such an interest is based on findings from epidemiological studies, which have established a significant association between male circumcision and reduced HIV infection rates (Mattson, Bailey, Muga, Poulessen, and Onyango, 2005). A study conducted in the Nyanza Province of Kenya revealed that although the lack of male circumcision is an identifying feature of Luo culture, participants perceived male circumcision as both preventive and curative (Bailey, Muga, Poulussen, and Abicht, 2002). Participants saw male circumcision as preventing STDs and HIV transmission through improved penile hygiene. Their argument is that dirt and germs remain under the intact foreskin where they are provided with a protective and warm environment. As such, participants were in favour of promoting male circumcision in the province in order to ensure hygiene and to reduce HIV transmission (Bailey *et al*, 2002). While the benefits of male circumcision are significant, my opinion is that promoting male circumcision as another HIV prevention strategy, is likely to yield the results that have been

seen with promoting HIV prevention through the ABC credo. Male circumcision alone without accompanying sexual behaviour change would not yield the desired results. Besides, in non-circumcising cultures, promoting circumcision would be re-medicalising the HIV/AIDS problem at a time when it is clear that the biggest challenge in the control of HIV is of a social rather than a medical nature.

### **3.3. CONCLUSION**

In Sections 3.1 and 3.2, I have demonstrated the inextricable links between issues of disability, young people, sexuality and HIV/AIDS, as they are each characterised by social and cultural prejudices and risk. Such prejudices account for the paradox and complexities of risk, because the relationships between the stated phenomena are also shrouded with contradictions. I have established that in general, disabled young people face a double risk to HIV because they are exposed to the same social circumstances and risk factors like all young people. Yet disability brings in added risk factors, such as disabled young people's increased risk to sexual abuse, hence the double risk they suffer, should they become HIV infected as well. It is evident that medical intervention strategies alone have not succeeded in addressing the social factors surrounding the disease, such as cultural influences and poverty. To this effect, I have pointed at the limitations of existing HIV/AIDS prevention strategies that focus on rules of conduct for individuals rather than the whole context in which risk is created and experienced.

In view of the complexity of the relationship between sexuality and HIV/AIDS in the context of disability, appropriate research methods were used to elicit the views of disabled young people and some members of the Nyanga community on the subject under study. The next chapter deals with such methods.

## CHAPTER 4

### RESEARCH METHODOLOGY AND RESEARCH DESIGN

#### 4. INTRODUCTION

In this chapter, the general qualitative research framework, within which a case-study design was used, is presented. An outline of a research design that utilised multiple data sources, using different data collection methods is also presented. Documents were reviewed to determine the policies and services that are available to disabled young people as well as to determine the gaps in the provision of services. Individual in-depth interviews were used to gain the views of disabled young people and key informants. Focus group discussions were used to gain views from disabled young people, parents and other community members. A detailed account of using the Atlas.ti computer package for analysing qualitative data is presented. The chapter is concluded with a table showing the main themes and sub themes that were generated in the current study.

The main aim of the present study was to describe the paradox of risk through an exploration of physically disabled young people's experiences, perceptions and responses to sexuality and HIV/AIDS risk in the context of the Nyanga. The study was guided by specific research objectives (Section 1.6), which will be presented in more detail in Chapters 5 and 6.

#### 4.1. QUALITATIVE RESEARCH

A qualitative research framework was employed to guide the case-study approach for the present study. Qualitative research has been described as an umbrella concept covering several forms of enquiry that help researchers understand the meaning of social phenomena with as little disruption of the natural setting as possible (Merriam, 1998). It is based on the view that individuals interacting with their social worlds construct reality. Qualitative researchers are interested in the meaning people have constructed – how they make sense of their world and the experience they have in the world.

Qualitative research therefore, “means a direct concern with experience as it is lived or felt or undergone” (Sherman and Webb, 1988: 7). Qualitative research can reveal how all the parts work together to form a whole. It is assumed that meaning is embedded in people’s experiences and that this meaning is mediated through the investigator’s own perception. Patton explains:

Qualitative research is an effort to understand situations in their uniqueness as part of a particular context and the interactions there. This understanding is an end in itself, so that it is not attempting to predict what may happen in the future necessarily, but to understand the nature of the setting – what it means for participants to be in that setting, what their lives are like, what’s going on for them, what their meanings are, what the world looks like in that particular setting – and in the analysis to be able to communicate that faithfully to others who are interested in that setting ... the analysis strives for depth of understanding (Patton, 1985: 1).

The key concern is to understand the phenomenon of interest from the participants’ perspectives, not that of the researcher. This is referred to as the ‘*emic*’ or insider’s perspective as opposed to the ‘*etic*’ or outsider’s view (Patton, 1985). Furthermore, in qualitative research, the researcher admits to the value-laden nature of the study, and reports on her/his values and biases as well as the value-laden nature of information gathered from the field. This is referred to as reflexivity, which Henning *et al* (2004) identified as the most distinctive feature of qualitative research. It captures the idea that researchers need to recognise and understand the processes and values by which they are making sense of the world through critical self-reflection.

A second characteristic of qualitative research is that the researcher is the primary instrument for data collection and analysis (Guba and Lincoln, 1981). Its third characteristic is that it usually involves fieldwork. The researcher physically goes to the people, setting or institution (field) in order to observe behaviour in its natural setting. A fourth characteristic is that qualitative research employs an inductive research strategy. That is, building abstractions, concepts, hypotheses or theories rather than testing existing ones (Henning *et al*, 2004).

Finally, qualitative research focuses on process, meaning, and understanding; the product of a qualitative study is richly descriptive. Words and pictures rather than numbers are used to convey what the researcher has learned about a phenomenon. In order to achieve the aim and objectives of the present study, all the characteristics described above were employed using a case-study design, as described below.

#### **4.2. A CASE-STUDY DESIGN**

The case-study design was chosen because I was interested in insight, discovery, and interpretation rather than hypothesis testing. Case study has been differentiated from other research designs by what Cronbach (1975: 123) calls “interpretation in context”. Yin (1994) states that case study is a design particularly suited to situations in which it is impossible to separate the phenomenon’s variables from their context. “By concentrating on a single phenomenon or entity (the case), the researcher aims to uncover the interaction of significant factors characteristic of the phenomenon” (Merriam, 1998: 29). A case study focuses on holistic description and explanation. Yin (1994) and Merriam (1998) advance definitions of the case study that are congruent with this discussion.

Becker (1968: 233) defines the purpose of a case study as twofold, that is, “to arrive at a comprehensive understanding of the group under study” and “to develop general theoretical statements about regularities in social structure and process”. Guba and Lincoln (1994) state that the purpose of a case study is to reveal the properties of a class to which the instance being studied belongs. Based on the above definitions, physically disabled young people living in Nyanga constitute ‘the case’ for the current study. The contextual conditions to the threat of HIV/AIDS risk among this population were not clearly evident at the beginning of the study. Therefore, I needed to collect data so as to describe disabled young people’s own experiences and perceptions on the subject with the view to informing and guiding policy regarding appropriate intervention strategies for this population. A case-study



design was perceived as the appropriate technique for addressing the research problem because of the following special features it has:

1. *Particularistic* means that case studies focus on a particular situation, event, programme or phenomenon. Shaw, (1978: 2) asserts that case studies “concentrate attention on the way particular groups of people confront specific problems, taking a holistic view of the situation. They are problem centred, small-scale, entrepreneurial endeavours”. The case is important for what it reveals and what it might represent. This specificity of focus makes it a good design for practical problems - for questions, situations or puzzling occurrences arising from everyday practice (Merriam, 1998).
2. *Descriptive* means that the end product of the case study is a rich, “in-depth” description of the phenomenon under study. Case studies have also been labelled holistic, grounded and exploratory. The descriptive nature of a case study can illuminate the complexities of a situation – the fact that not one but many factors contribute to it (Merriam, 1998).
3. *Heuristic* means that case studies illuminate the reader’s understanding of the phenomenon under study. They can bring about the discovery of new meaning, extend the reader’s experience or confirm what is known (Merriam, 1998). “Previously unknown relationships and variables can be expected to emerge from case studies leading to rethinking of the phenomenon being studied. Insight into how things get to be the way they are can be expected to result from case studies” (Stake, 1981: 47).

Thus, Merriam (1998) suggests that the uniqueness of a case study lies not so much in the methods employed (although these are important) as in the questions asked and their relationship to the end product. While Stake (1994) claims that knowledge learned from a case study is different from other research knowledge in that case-study knowledge is more concrete, it resonates with our own experience because it is more vivid and sensory than abstract. Furthermore, case study knowledge is more developed by reader interpretation, that is, readers bring to a case study their own experience and

understanding, which lead to generalisations when current data for the case are added to old data. Stake considers these generalisations to be part of the knowledge produced by case studies (Stake, 1995). The stated qualities of a case-study approach can be realised through multiple sources of data collection as stated below.

#### **4.2.1. Data Collection in Case Studies**

“The case study’s unique strength is its ability to deal with a full variety of evidence documents, artefacts, interviews and observations” (Yin, 1989: 20). Consistent with this notion, Merriam (1998) states that all data collection methods or techniques can be used in a case study depending on the researcher’s theoretical orientation, the problem and purpose of the study and the sample selection. “Understanding the case in its totality, as well as the intensive, *holistic* description and analysis characteristic of a case study, mandates both breadth and depth of data collection”, hence the need for flexibility in choosing data collection methods that would achieve the required depth (Merriam, 1998: 135).

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Marshall and Rossman (1995) have named the four primary methods of data collection in qualitative research as (i) participation in the setting (ii) direct observation (iii) in-depth interviewing, and (iv) document reviews. In addition, several supplementary methods can be incorporated like narratives, focus group discussions, life histories, historical analysis, film, video, and photography. Thus, qualitative researchers have a wide range from which to choose suitable combinations of data collection methods suitable for qualitative case studies. Each data collection method used in the current study is described first in terms of its strengths and limitations. This will be followed later by the application of such methods in the field, presented under ‘Data collection procedure’ (Section 4.6):

a) ***Document review***

The review of documents is said to be an unobtrusive method, one rich in portraying the values and beliefs of participants in the setting (Marshall and Rossman, 1995) because researchers gather and analyse documents produced in the course of every day events. These include policy documents, logs, letters and minutes of meetings, which are useful in developing an understanding of the group studied. Archival data are routinely gathered records of a society, community or organisation and may further supplement other qualitative methods.

The strengths of document reviews are that many documents are easily accessible; they are free and contain information that would take an investigator enormous time and effort to gather otherwise. Documents are also a good source of data as they are often used when it appears they will yield “better or more data than other tactics” (Merriam, 1998). The researcher determines where the greatest emphasis lies after the data have been gathered (Marshall and Rossman, 1995). However, the limitation is that most documents are not produced for research purposes; therefore, the information they offer may not be in a form that is useful or understandable to the investigator. Furthermore, such data may not fit present definitions of the concepts under scrutiny (Merriam, 1998).

b) ***In-depth interviewing***

Interviews are categorised into (i) “formal conversational interview (ii) general interview guide approach, and the (iii) standardised open-ended interview” (Patton, 1990: 280-290). Patton (1990) and Marshall and Rossman (1995), state that in-depth interviewing is a data collection method that is relied on extensively by qualitative researchers and in numerous studies it might be the only source of data. The main purpose of an interview is to find out what is in or on someone else’s mind. Patton (1985), and Rubin and Rubin (1995) have described in-depth interviewing as a conversation with a purpose. That is to say that qualitative in-depth interviews are much more like conversations than formal events with predetermined formal response categories (Marshall and Rossman, 1995).

Some of the strengths of interviews are that they are a useful way to get large amounts of data quickly. Immediate follow-up and clarification are possible; participants are treated as partners rather than objects of research as questions are asked that tap into the participants' experiences (Rubin and Rubin, 1995). In addition, Seidman (1998) explains that interviewing provides access to the context of people's behaviour and thereby provides a way for researchers to understand the meaning of that behaviour. Some of the limitations of interviewing lie in the fact that they involve personal interaction for which co-operation is essential, without which it would be difficult to conduct successful interviews.

Furthermore, participants may be unwilling or uncomfortable to share all that the researcher may hope to explore, or they may be unaware of recurring patterns in their lives (Marshall and Rossman, 1995). The researcher may not ask questions that evoke the desired responses either because of lack of expertise or familiarity with local language or because of lack of skill. By the same token, the interviewer may not properly comprehend responses to the questions or elements of the conversation. Besides, one-on-one interviews may be impoverished because the participant had not reflected on the topic and feels unprepared to respond (Marshall and Rossman, 1995: 84).

**c) *Focus group discussions***

Focus group discussions have been described as a tool for collecting qualitative data from a group of people who are unfamiliar to one another but who share common interests (Marshall and Rossman, 1994). Group discussions are semi-structured, person-to-person interviews that aim to explore a specific set of issues Kitzinger (1994). Such interviews involve six to twelve people in a 'focused' interview lasting one to two hours. The focus group technique is timesaving as it allows one to gather information from a range of people within the same timeframe it would take to interview one person (Kitzinger, 1994). The researcher follows a predetermined interview guide to facilitate discussions in a group with the purpose of collecting in-depth information about a group's perceptions, attitudes and experiences of the subject under study (Academy for Educational Development, 2004).

Some of the advantages of focus group interviews are that the technique is “socially oriented, studying participants in a natural, real life atmosphere; the format allows the facilitator the flexibility to explore unanticipated issues as they arise in the discussion; the findings appear believable. Furthermore, the technique is relatively low cost; it provides quick results and it can increase the sample size of qualitative studies by interviewing more people at one time” (Krueger, 1988: 44-46; 1998). Another strength of focus group technique is that it allows for group interaction so that participants are able to “build on each other’s ideas and comments to provide an in-depth view not attainable from individual questioning” (Marshall and Rossman, 1994: 84). A focus group technique can reveal consensus and diversity of participants’ needs, experiences, preferences and assumptions.

However, some of the limitations of focus groups are that “the interviewer has less control over a group interview than an individual one, which can result in lost time as dead-end or irrelevant issues are discussed, the data are difficult to analyse, as context is essential to understanding participants’ comments” (Marshall and Rossman, 1995: 85). In addition, focus groups can generate large amounts of data that are often difficult to analyse. More outspoken individuals can dominate the discussions, so that viewpoints of less assertive people would be difficult to assess (Academy for Educational Development, 2004).

#### **4.2.2. Data Analysis in Case Studies**

In qualitative research, data analysis is a process conducted simultaneously with data collection (Marshall and Rossman 1989; Creswell, 1994; Merriam, 1998; Patton, 1990), implying that the process is ongoing, emerging and non-linear. This is contrasted with surveys and experimental designs where the distinction between data collection and analysis is clear. In qualitative research, the fluid and emergent nature of a naturalistic inquiry makes the distinction far less absolute (Merriam, 1988; 1998). Merriam (1998) further states that at the outset of a qualitative study, the researcher knows what the problem is, but does not know what will be discovered, or what the final

analysis will be like. Merriam's point is that the final product is shaped by the data that are collected and the analysis that accompanies the entire process. She asserts that without ongoing analysis, the data can be unfocused, repetitious and overwhelming in the sheer volume of material that needs to be processed. Furthermore, qualitative data analysis is inductive, as Altheide (1987: 68) states, "that the process of data analysis involves the simultaneous coding of raw data and the construction of categories that capture relevant characteristics of the content in the data". This has been described as content analysis for themes and recurring patterns of meaning (Merriam, 1998). Literally, qualitative data analysis involves taking words, sentences and paragraphs apart in the research project in order to make sense of, interpret and theorise the data. This is done by organising, reducing and describing the data (Henning *et al*, 2004). Alasuutari (1995: 7) states that "data analysis in qualitative research does not rely on frequencies or the quantities with which something occurs as evidence, but rather meaning is elicited from the data in a systematic, comprehensive and rigorous manner".

### **4.3. MERITS AND LIMITATIONS OF A CASE-STUDY DESIGN**

All research designs can be described in terms of their relative strengths and limitations. The rationale for selecting a particular design is usually dependent on the merits of selecting it as the most appropriate plan for addressing the research problem. The merits and limitations of a case-study approach are presented below:

#### **4.3.1. Merits**

Case study is the best plan for answering the kind of research questions raised in this thesis; its strengths outweigh its limitations. Processes, problems and programmes can be examined to bring about understanding that in turn can affect and perhaps even improve practice.

The case study offers a means of investigating complex social units consisting of multiple variables of potential importance in understanding a phenomenon.

Anchored in real-life situations, the case study results in a rich and holistic account of a phenomenon (Merriam 1998: 41).

A case study also offers insights and illuminates meanings that expand its reader's experiences. These insights can be construed as tentative hypotheses that help structure future research; hence, a case study plays an important role in advancing a field's knowledge base.

#### **4.3.2. Limitations**

Although literature on the case-study approach has expanded in the last few years, Yin (1994) states that it still lags behind other types. In spite of this limitation, I was able to collect enough literature on the subject to support my choice of the case-study approach.

The rich in-depth descriptions of analysis that are possible in a case study are not always possible because of financial and time constraints. Where it is impossible to reduce these thick descriptions, the product may be too lengthy, too detailed or too involved for busy policy makers to read and use (Merriam 1998).

Another limitation is that "case studies can oversimplify or exaggerate a situation, leading the reader to erroneous conclusions about the actual state of affairs. Furthermore, case-study reports tend to masquerade as a whole when in fact they are but a part – a slice of life" (Guba and Lincoln, 1981: 377). In view of the above statement, the current study does not attempt to trivialise the experiences of disabled young people or claim that the results can be generalised for all young people with different types of disabilities (See limitations of the study in Chapter 8).

Lastly, qualitative case studies might be limited by the sensitivity and integrity of the researcher. As the researcher is considered the primary instrument for data collection and analysis, most researchers have not been trained in

observation and interviewing skills. The investigator is left to rely on his or her own instincts and abilities throughout most of the research efforts.

#### **4.4. TRUSTWORTHINESS OF THE DESIGN**

A research design is “an action plan for getting from here to there, where here may be defined as the initial set of questions to be answered, and there is some set of conclusions about these questions” (Yin, 1994:19). There are many steps between ‘here’ and ‘there’ including major steps of data collection and data analysis. Research design is a blueprint that deals with research questions to be formed; what data are relevant ; what data are to be collected; and how to analyse the data (Yin, 1994). However, researchers differ in their description of the criteria used to judge the quality of the research design.

Quantitative researchers espouse concepts of construct validity, internal validity, external validity and reliability (Kidder and Fine, 1981). While qualitative researchers argue that there is nothing wrong with the conventional criterion for rigour, it must, however, be applied to the conventional or scientific paradigm. As most qualitative research is carried out on a naturalistic paradigm, it requires a substitute paradigm to validate its credibility. Therefore, Lincoln and Guba (1985) proposed the concept of trustworthiness, which illuminates respect for truth in case-study research. Under these criteria, they have identified criteria of credibility, transferability, dependability and confirmability (Guba and Lincoln, 1981; Lincoln and Guba, 1985). These are outlined below.

##### **a) *Credibility***

Credibility involves establishing that the results of qualitative research are believable from the perspective of the participants in the research. In qualitative research, truth-value is obtained from the discovery of human experiences as they are lived and perceived by informants (Strydom, Fouche, Poggenpoel and Schrunk, 1998). Furthermore, a qualitative study can be considered credible when it presents such accurate descriptions or



interpretations of human experience that people who also share that experience would immediately recognise (Sandelowski, 1986).

**b) *Transferability***

Transferability refers to the degree to which the results of qualitative research can be generalised or transferred to other settings. The qualitative researcher can enhance transferability by doing a thorough job of describing the research context and the assumptions that were central to the research. The person who wishes to “transfer” the results to a different context is then responsible for making the judgement of how sensible the transfer is (Lincoln and Guba, 1985).

**c) *Dependability***

The idea of dependability emphasises the need for the researcher to account for ever-changing conditions to the phenomenon chosen for research as well as changes in the design created by increasingly refined understanding of the setting. In other words, the researcher is responsible for describing the changes that occur in the setting and how these changes affect the way the researcher approached the study (Lincoln and Guba, 1985).

**d) *Confirmability***

Qualitative research tends to assume that each researcher brings a unique perspective to the study. Thus, confirmability is focused on whether the results of the research could be confirmed by another and places the evaluation on the data themselves (Lincoln and Guba, 1985).

#### **4.5. RESEARCH PROCEDURE**

Specific steps based on the above precepts of a case-study approach guided the procedure for the current study. These include identifying a research setting, a study sample, data collection and analysis procedures as follows:

#### 4.5.1. Research Setting and Participants

An account of the legacy of apartheid, which led to the creation of townships in South Africa, was presented in Chapter 1. In this section, a little more detail about Nyanga is provided. As one of the oldest and biggest 'Black Townships' in the Western Cape Metropolitan area, Nyanga is predominantly inhabited by the Xhosa speaking people. In Xhosa language, the word Nyanga means 'the moon'. This township, was established as a result of the migrant labour system in the early 1950s when the so-called black migrants were forced to settle there as Langa [*the sun*], the first established black township, became too small.

Nyanga became fully established in 1955 with an increase in the number of people coming from the Eastern Cape. Later it served to accommodate African people removed from a residential area known as 'District Six' near Table Mountain. Nyanga is a manifestation of the gross social inequalities that exist along racial, class, and gender lines (Gilbert and Walker, 2001) and if I may add, disability status. Unemployment is rife and so most families have inadequate, food and limited access to other necessary services such as safe water, sanitation, electricity, education and health services.

Apart from the rehabilitation services offered by the UWC Community Rehabilitation Project, described below, there is no other community-based programme, which offers services to disabled people at their doorsteps in Nyanga. Thus almost all physically disabled young people in the current study have passed through the UWC Community Rehabilitation Project, either for therapy or to be referred for other social services, such as applying for a disability grant.

To gain access to work in a township, I obtained permission from the UWC Community Rehabilitation Project in Nyanga. This project primarily provides rehabilitation services to disabled people in Nyanga, and is also used as a community training facility for Occupational Therapy students from the University of the Western Cape. In addition, I contacted the umbrella

organisation of disabled people in South Africa known as Disabled People South Africa (DPSA) to point me to disabled young people I could work with. They provided me with a list of names of physically disabled young people from the main townships in the Western Cape, who had been trained the previous year as AIDS peer educators. Through DPSA, I identified Vuyo (pseudonym), who is physically disabled himself, lives in Nyanga and was willing to work as my intermediary. Besides, Vuyo knew most of the physically disabled young people living in Nyanga because he had interacted with them in 2004 when he worked as an HIV/AIDS peer educator. Nyanga's close proximity to UWC and its relative easy access by public transport made it a suitable site for the present study. As a non-South African in Nyanga, being associated with the UWC Community Rehabilitation Project and being seen together with Vuyo helped me to be readily welcomed and accepted in the community and in participants' own homes.

Initially, I had intended to work with physically disabled young people studying at UWC, but abandoned the idea when I realised that this population has better access to sexuality and HIV/AIDS information and services on campus compared to their peers in townships, special schools or rehabilitation centres.

For this reason, I attempted to work with special schools and rehabilitation centres. To this end, I visited special schools such as Bel Porto (school for learners with learning difficulties) and Athlone School for the Blind. I also visited residents of a Cheshire Home (presenting with a range of physical disabilities), Golden Girls (children with mainly cerebral palsy and learning difficulties) and a Protective Workshop in Athlone. During this time, I had been thinking of working with young people with all types of disabilities, but realised that my intention was not to do a comparative study across disability groups; which would have been a very big study untenable within the time-frame I had. Thus, I decided to work with physically disabled young people only from one township. Besides, I had also realised at this point, that there is a common misperception that physically disabled young people have no problems in the area of sexuality and HIV/AIDS compared to their blind and

intellectually disabled counterparts. I was thus compelled to verify such misperceptions, since my own experience as a physiotherapist working with physically disabled young people had taught me otherwise.

#### **4.5.2. Study Sample**

A purposeful sample of 20 physically disabled young people was identified and selected (Appendix B). Although all of them agreed to participate after the purpose of the study was explained, five disabled young women opted out along the course of the interview process because they were too shy to talk about sexuality matters. Thus a total of 15 disabled young people, 4 male and 11 female, whose physical disabilities included post-polio paralysis, spina bifida, cerebral palsy, spinal cord injury, hemiparesis and paraplegia participated in the study. The diversity in terms of type of physical disability served to highlight similar challenges this group faces in their experience of sexuality and HIV/AIDS.

Since I wanted to understand the 'experiences' of disabled young people, it was important to interview other people who contribute to such experiences. For this reason, a group of 15 parents and guardians were selected as proxy interviewees because of their experience and involvement in the welfare of disabled young people.

However, in the course of in-depth interviews, some key issues arose that disabled young people did not have much experience about, such as female initiation ceremonies, the role of traditional healers and counsellors in dealing with disability issues. Such issues necessitated the incorporation of other groups into the study who were previously unplanned for, to shed more light on specific issues. Thus 15 senior citizens were recruited for their insight on Xhosa culture regarding the rite of passage, which prepares girls and boys for womanhood and manhood respectively. Five traditional healers (*sangomas*) were recruited for their role in dealing with disabled people, their involvement in HIV/AIDS prevention efforts and the authority they appear to have in the ancestral realm. Four ward councillors were recruited for their involvement in

allocation of housing in the community. This is because disabled young people have particular problems in being considered for houses of their own, because of the stereotype assumption that this group does not need houses, as they will always live with their parents.

All the groups, including the 15 physically disabled young people, participated in a total of 10 focus group discussions involving 4-10 people in each group. Although female (45) outnumbered male (13) participants, particular care was taken to ensure gender representation in groups other than parent groups, which were dominated by female participants alone. This is because men in Nyanga are not involved in the day-to-day care of their disabled children (see Chapter 5).

Furthermore, 8 Key informants (Appendix B) were selected on recommendation from disabled young people themselves. These included 4 disabled and four non-disabled people drawn from Disabled People South Africa, Association for Physically Disabled Persons, government departments, and service providers. Disabled young people considered that Key informants were more experienced and knowledgeable about the issues being investigated.

#### **4.6. DATA COLLECTION PROCEDURE**

For the purposes of the current qualitative case-study design, document reviews, in-depth interviews, and focus group discussions were utilised. This combination of data collection methods was chosen with the view that such methods complement each other. The strength of one makes up for the weakness of the other (Marshall and Rossman, 1995). The three data collection methods helped describe the case study both in depth and breadth. It was important to collect essential and relevant data to answer the research questions.

Intensive and systematic data collection started in January of 2005 and ended in July the same year. However, the data collection process was ongoing

because whenever there were issues to be clarified during the analysis, I returned to the field for more information (see details in the analysis section). I was aware of the concept of flexibility in fieldwork, which allowed me to recognise situations that required modifying the data collection and analysis process. For example, fewer physically disabled young people were interviewed than had been planned for, because a point of saturation had been reached when interviews were not eliciting new information from the participants. In addition, there were areas in Nyanga that could not be visited due to perceived high crime rates and so disabled young people in such areas were left out.

#### **4.6.1. Document Review**

Prior to conducting in-depth interviews and focus group discussions, a wide selection of programme and policy documents was reviewed. The aim was to establish the extent to which disabled young people's right to express their sexuality is enshrined in the said documents. It was also to find out whether this group's right to accessing sexuality education and HIV/AIDS prevention and support services is reflected in policy documents; and the extent to which such programmes are implemented. The following documents were identified as some of the most important in advancing the cause of disabled young people with regards to the subject under study:

1. The standard rules on the equalisation of opportunities
2. White paper on an Integrated National Disability Strategy
3. Framework for the development of an integrated national disability strategy for South Africa (Discussion paper)
4. Treatment Action Campaign (TAC)
5. Disabled People South Africa (DPSA)
6. Disability Rights Charter of South Africa (DRCSA)
7. Report of the Special rapporteur on Disability to the 42<sup>nd</sup> session of the commission for social development
8. Report of the African decade of disabled persons (2000-2009)
9. United Nations report on accessibility

These documents from government, disabled people's organisations, civil society and international bodies all advocate for a common theme, that is, disabled people have the rights to equal access to opportunities and social services that are available to mainstream society, such as education, health and employment. However, none of the reviewed documents has explicit guidelines on how social and physical barriers should be removed to allow disabled young people to express their sexuality freely or to access sexuality education, sexual and reproductive health services, and HIV/AIDS information and support services.

The National AIDS Commission for South Africa and the National Youth Commission fail equally to be explicit about inclusion of disabled young people in existing services (Saiti, 2001). The assumption is that disabled young people automatically benefit from programmes that exist for all young people, but the opposite is true. Disabled young people have unique circumstances (see Chapters 5 and 6) that prevent them from expressing their sexuality and accessing services that are available to the non-disabled peers. There is a need to explore ways of making the above documents more sensitive and, therefore, inclusive of disabled young people's special circumstances. After a review of the documents, it was important to interview disabled young people about their experiences on the matter, hence the individual in-depth interviews that followed.

#### **4.6.2. In-depth Interviews**

In-depth interviews were conducted with 15 physically disabled young people. Ten of these interviews took place in the homes (shacks) of the participants or their parents' homes; only five interviews took place in a room at a protective workshop. This is a workshop that provides sheltered employment for disabled people.

Information was gathered on how this group experiences, perceives and responds to issues of sexuality and HIV/AIDS risk, in the context of Nyanga.

Disabled young people were asked to describe their experiences of living with a disability first, then they were asked to describe their experiences and perceptions of sexuality and HIV/AIDS. This covered areas such as sexual expression and access to information and support services. It also covered disabled young people's preferences for the provision of sexuality education and HIV/AIDS prevention programmes, so that appropriate recommendations would be made on disabled young people's preferences. Through in-depth interviews, disabled young people were asked to describe their perceptions about the threat of HIV/AIDS risk and to what extent they are participating in existing prevention programmes.

The issues that disabled young people had difficulty responding to in individual interviews, were brought to focus group discussions among disabled young people themselves as well as with other groups that were mentioned above.

After training the intermediary on how to translate word for word, where possible, Vuyo assisted with translations of interview sessions, which lasted one to one and a half hours. At the beginning of each interview after getting to know each other, I explained the purpose of the study to each participant. It was crucial for the current study to hear disabled young people's own voices and opinions on the concepts under study.

Some ethical issues were considered prior to commencing the study and throughout the process of data collection. To that effect, all participants were assured of their right to participate or decline or indeed withdraw from the study at any time should they feel uncomfortable. Participants were further assured that their participation in the study would remain confidential, as well as the final report at the end of the research exercise. All the participants gave verbal consent first, and then a fact sheet/consent form (Appendix C) about the present study was read out to parents; if they were in agreement, they signed a consent form on behalf of their 15-18 year-old disabled children. Participants between the ages of 19-24 signed their own consent forms (Appendix D). This is based on UNICEF's (1999) classification of 15-18 year-



olds as adolescents and 19-24 year-olds as young adults or youths. Pseudonyms were used in reporting to protect disabled young people's individual identities.

Participants were assured of their freedom to withdraw from the interviews at any time should they feel uncomfortable without consequences to them. Arrangements had also been made through the UWC Community Rehabilitation Project for referrals to other services should any participant feel distressed during the process (see Chapter 6 for a case of one participant who was referred to social workers after reporting sexual abuse).

Each interview started with some relaxing topics about the weather or a participant's birthplace so participants could relax. A semi-structured interview guide was used to direct in-depth interviews. A mixture of hypothetical, devil's advocate, ideal position and interpretive questions were used to tease out as much information as the participants could provide. Probes were used to follow up on issues already asked. These ranged from short questions like *what next?* to *silence*, to *head nodding*, and to other utterances like *ahah* or *yes, yes*. This is where being a primary instrument of data collection had its advantages. The issues under investigation were very sensitive and awareness of this fact allowed me to probe gently to gain more information without pressing too hard.

Each interview was tape-recorded and transcribed. The transcribed data (Appendix E) were returned to the field and read out to participants who were illiterate, highlighting the main themes so they could confirm or modify the content. Others read their own transcripts and made necessary comments or changes. Additional field notes in terms of hunches and comments were recorded in a reflexive journal during in-depth interviews, to augment the tape-recorded data.

At the end of the interviews, each participant was thanked personally and asked if they would participate again in follow-up interviews should any questions or need for clarification of certain issues arise. Most participants

agreed and expressed happiness for the fact that we had visited and engaged them in discussing sexuality, an aspect of their lives that is normally not a subject of discussion with parents or older people.

#### **4.6.3. Focus Group Discussions (FGD)**

As mentioned above, topical issues, which had emerged during in-depth interviews with disabled young people, such as cultural beliefs regarding disability and sexuality, and female initiation ceremonies were explored in more detail in focus group discussions to gain collective views. Invitations to participate in focus group discussions were sent by word of mouth, using the intermediary and the UWC Community Rehabilitation workers. A pre-determined interview guide, based on the main issues arising from in-depth interviews was used to direct the focus group discussions. The 15 to 18 year olds formed separate groups from the 19 to 24 year olds, because their sexual roles and experiences might be different due to age differences (Potgieter and Fredman, 1997). Participants preferred discussions in combined groups of males and females. This helped them appreciate some gender specific problems. For example, male participants were shocked to learn about the extent to which female participants reported incidents of rape.

Disabled young people's focus groups met at the *Thembaletu* and *Vukuhambe* Protective Workshops where some of them worked. Parent and guardian groups met at the house of one of the UWC Community Rehabilitation workers after prior permission had been obtained. The elderly men and women met at a Community Hall, where they usually gathered for recreational activities three to four days a week. The sangomas were provided with bus fares in order to meet them at the UWC Community Rehabilitation Project office and the Ward Councillors met at the Guguletu Community Centre hall.

At the beginning of each focus group discussion, I introduced Vuyo and myself and welcomed everyone to the session. Participants were all thanked for agreeing to participate in the discussions and permission was sought to

tape-record the interviews. The aim of the study was explained and why each one of them had been asked to participate. They were told that they were expected to give insight into relevant issues that had arisen from in-depth interviews with disabled young people, as well as to shed more light on the specific questions that would be put to them. As a translator during discussions, Vuyo also pointed out any diversion, and thus helped me to intervene and re-focus the discussions to the topic under study. Vuyo's familiarity with people in the area and his command of the Xhosa language enabled him to carry out this role effectively. Sometimes, Occupational Therapy students from the UWC were present at these focus group discussions, by virtue of working with the same population that participated in the study. Sometimes they assisted in translating when female participants were uncomfortable talking to a male intermediary about sexuality matters.

Multiple discussion sessions were conducted with each focus group, so as to discover the trends in perceptions and opinions and until no new data were brought forth. Field notes were documented to catch interesting issues or thoughts that arose during interviews. Thus, all the 10 focus groups discussed, contrasted, endorsed and refined common issues, although each group focused on some areas more than others, such as the elderly focusing on cultural beliefs and sangomas on their role in dealing with disabled people. In this way the multi-vocal 'case' of disabled young people in Nyanga was explored and described both in depth and breadth.

All the discussions were commenced with a word of prayer motivated by the participants themselves, sometimes they sang hymns. Singing created a conducive atmosphere for every one to relax before commencing the discussion sessions. Each focus group was conducted more than once to clarify certain issues as well as to get feedback on the transcriptions of the previous discussions. During the first two focus group discussions with disabled young people and the senior citizens, no refreshments were provided for fear of attracting people to the sessions for the wrong reasons. Subsequently, I learnt from Vuyo and staff at the UWC Community Rehabilitation project that participants would appreciate refreshments and so I

provided for the rest of the groups. Sharing a drink was not only a culture sensitive gesture, but it also brought the added advantage that participants relaxed more and were able to freely share their views on the subject at a personal level. Young people who had been shy and less eloquent during individual interviews became more expressive during focus group discussions. The presence of the less shy members encouraged the others to speak up. The diversity of opinions and experiences of all the focus group members are illuminated in Chapters 5 and 6.

Finally, topical issues that emerged from focus group discussions were explored further during more in-depth interviews with the eight key informants. This cyclical process allowed disabled young people to set the main agenda that were then explored widely by focus group discussions first, and later by key informants and vice versa. Since a case-study investigation involves a continuous interaction between theoretical issues being studied and the data being collected, I took advantage of the unexpected opportunities during data collection, rather than feeling trapped by them. In that way, only groups and individuals perceived as sufficiently experienced in specific areas were recruited. Findings from the emerging groups only served to enrich information gathered from disabled young people rather than altering it, and so the purpose of the current study was maintained.

#### **4.7. RESEARCH ETHICS**

Prior to commencing the study, approval was sought from the UWC Senate (Appendix F), and permission was granted. A letter was sent to each key informant asking them to participate in the study (Appendix G). This was followed up by a person-to-person contact to confirm some key informants' interest and willingness to participate in the study. Considering that the subject of sexuality and HIV/AIDS might make some participants feel uncomfortable due to some direct questions about sex that would be asked, they were assured that should anyone of them feel upset at any stage, referrals would be made to appropriate services. Ethical issues were described under data collection (see sections 4.6.2 and 4.6.3 above).

In reporting the findings of the present study, I am bound by the need for confidentiality of not only the research participants in general, but also the 'case study'; that is, physically disabled young people living in Nyanga. With regard to this, I have used pseudonyms for all disabled young people, and the initials 'FGD' 1-8, for all groups that participated in focus group discussions. Numbers were also assigned to key informants as key 1-8. Researchers agree that all research should be firmly grounded in ethical practice, which entails the following undertakings:

1. That people's right to privacy should be respected
2. That confidentiality should be respected
3. That participation should remain anonymous
4. That safety should be guaranteed
5. That trusting environments should be secured
6. That the research process should not be pursued at the expense of the participants concerned (Miles and Huberman 1994; Babbie and Mouton, 2001).

The above guidelines formed the basis for the consideration of ethical issues in the current study.

#### **4.8. DATA ANALYSIS USING ATLAS.TI**

After the decision was made to use the Atlas.ti computer package, I was encouraged by Barry's (1998) comprehensive work on the merits and demerits of the Nudist and Atlas.ti data analysis software. Barry (1998) espouses the view, among other qualities, that Atlas.ti is the easier of the two to learn. Nudist has its strengths too, but a discussion of such is beyond the confines of the present study. Preliminary instructions from one of my supervisors got me started with Atlas.ti and the Postgraduate Throughput Project (PET) at the University of the Western Cape helped me improve my skills.

The basic purpose of using Atlas.ti is to analyse, interpret, sort and administer textual, graphical as well as audio and video data (Strubing, 2005). The goal is the acquisition of analytic ideas and the foundation of full theories based on the data. There are multiple functions to administer, extract, analyse, compare or aggregate meaningful data from the stack of collected data. Furthermore, Strubing (2005) notes that an important feature of Atlas.ti is that it leaves space for creativity and flexibility in the researcher, which allows him/her to work systematically. Atlas.ti applies no limits to the scope of the data to be analysed or to the number of created concepts within the analysis.

The core of qualitative data analysis with this programme is twofold, firstly to select bits of data and secondly to give them meaning and assign them to a category, a process called coding (Dey, 1993). The analysis is concerned with the human situations and social processes. According to Dey (1993), facts are produced through conceptualisation and “facts” *per se* have been merely manufactured; depending on the researcher’s perceptions, which are shaped by his/her thinking. Thus, in using Atlas.ti to analyse data, the researcher is the main architect, while the computer package only assists in the organisation process as described below.

#### **4.8.1. Atlas.ti: the “VICE” Principle**

The main principles or predominant strategic modes of operation of the Atlas.ti methodology are termed “VICE”, which refers to “*Visualisation, Integration, Serendipity and Exploration*” (Muhr, 1994). These account for the strength of Atlas.ti, which is related to its immediacy, its visual and spatial qualities, its creativity and its inter-linkage. Muhr (1994) further asserts that the Atlas.ti programme has the ability to bring all aspects of the data analysis on screen at once. This allows the researcher to visually map out relationships between different parts of the data and theoretical ideas and to form links between them, then jump back and forth, encouraging the creative process of sparking ideas and pattern recognition. The “VICE” principle is defined as follows:

**a) *Visualisation***

It is posited that the visualisation component of the programme directly supports the way humans think, plan and approach solutions in creative, yet systematic ways. Atlas.ti offers tools to visualise complex properties and relations between objects accumulated during the process of eliciting meaning and structure from the analysed data. It keeps the necessary operations close to the data to which they are applied. The visual approach of the interface keeps the researcher focused on the data because all the functions are just a few mouse clicks away (Muhr, 1997a).

**b) *Integration***

Atlas.ti integrates all pieces that comprise a project, in order not to lose sight of the whole when going into detail. To achieve this, all relevant entities are stored in a container, called a Hermeneutic Unit (HU). This keeps all data within reach, like a spider in its web (Muhr, 1997b).

**c) *Serendipity***

In the context of information systems, serendipity means to find something without having searched for it. Thus the term is equated with an intuitive approach to data. "Browsing" is the operation that relies on the serendipity effect. This information-seeking method is likened to a genuine human activity of searching for books in the library using particular key words. But typically, researchers find themselves increasingly browsing through books that were not exactly what they originally had in mind (Muhr, 1997a). Other tools and procedures, which Atlas.ti offers for exploiting the concept of serendipity, are the object managers, the object explorer, the interactive margin area, full text search and the hypertext functionality.

**d) *Exploration***

Exploration in Atlas.ti is closely related to the above principles. Through an exploratory, yet systematic approach to data, constructive activities like theory building are of great benefit. Muhr (1997a) suggests that the entire programme's concept, including the process of getting acquainted with its

peculiarities, is particularly conducive to an exploratory, discovery-oriented approach.

#### **4.8.2. Data Analysis Procedure**

As explained earlier, the actual process of data analysis was ongoing as it was carried out simultaneously with data collection. The process involved transcribing interviews verbatim, reading transcripts over and over again and editing where necessary, until it was clear what information was relevant in relation to the questions and objectives of the current study. Reading through transcripts raised other questions and avenues that needed to be explored at the next visit to the field. Without losing focus, the study questions evolved and changed throughout the process of data collection and analysis. The next step involved manually highlighting relevant quotations of interest and also writing notes on the margins about hunches on the subject. This process enabled me to familiarise myself with the data prior to using the Atlas.ti computer package as illustrated below.

#### **4.8.3. Steps in Using Atlas.ti**

The first step in analysing data using Atlas.ti is described as managing the data (Muhr, 1997b). This involved entering data into the computer programme. The second step was guided by two principle modes, the *textual level* and *conceptual level*. The textual level included the segmentation of data files, coding text and writing memos. The conceptual level focused on framework-building activities such as linking codes, concepts and categories to form theoretical networks. This special feature of Atlas.ti, provides a comprehensive overview of the researcher's work as well as rapid search, retrieval and browsing functions. Below, is a detailed description of the textual and conceptual level work that took place in the present study.

##### **4.8.3.1. Textual Level Work**

###### *a) Creating a Hermeneutic Unit*

Textual level work involved creating three Hermeneutic Units (HU) (each HU being an idea 'container'); one to contain transcripts from physically



disabled young people, one for focus groups and the last one for key informants. Initially transcripts had been stored as Word documents and later converted into 'plain text format' prior to entering the information into Atlas.ti. This is because the 4.2 version of Atlas.ti does not read word-processed documents. It can only handle documents in 'rich text format' (Muhr, 1997b). Common themes and categories that were generated from each HU were later merged manually in the writing-up process.

*b) Assigning Primary Documents*

In Atlas.ti, field notes or raw data are referred to as Primary Documents (PU). Raw data or transcripts were imported into the computer programme one at a time, a process known as 'assigning Primary Documents' into a Hermeneutic Unit. Each of the three Hermeneutic Units stored the raw data including codes, memos and network structures for each group. However, each Primary Document maintained the capacity to be analysed or coded separately within the Hermeneutic Unit.

*c) Discovering relevant passages*

Text passages were then read while examining the meaning in order to identify concepts and segments, which were interesting and relevant in answering the research questions. Relevant passages or quotations were noted and segmented in small paragraph form in preparation for the coding and memo-writing steps described below.

*d) Creating codes and memos*

Coding refers to naming and categorising phenomena through close examination of the data (Henning *et al*, 2004). Henning *et al* (2004) state that open coding actually fractures the data into concepts and categories. While Strauss and Cobin (1990:57) state that coding "represents the operations by which data are broken down, conceptualised and put back together in new ways; it is the central way by which theories are built from data".

In Atlas.ti, initial ideas often find expression through their assignment to a code or memo, to which similar ideas or text sections also become assigned. The codes in Atlas.ti can be one word or a phrase that is used to assign meaning to sections of the text or quotations. For each relevant or significant section in the text, an appropriate code was assigned. The codes were then grouped into meaningful clusters or categories in the conceptual level phase.

Memos are a place for the researcher to write his/her thoughts concerning emerging theories. In the current study, I wrote memos to most single word codes, as these reminded me of particular hunches during the conceptual level of the analysis.

#### **4.8.3.2. Conceptual Level Work**

##### *v) Visualising and writing up reports*

Beyond coding and retrieval, Atlas.ti's network feature allows the researcher to visually "connect" selected passages, memos and codes into diagrams, which graphically outline complex relations. Muhr (1997a) states that in Atlas.ti networks are a graphical tool for constructing theoretical models. This is a graphical way of viewing and relating the various parts of the Hermeneutic Unit. Networks are a cornerstone of the emerging theory or the conceptual working phase.

##### *vi) Building theory; weaving concepts to network*

This process of network building is an integral part of the analysis, which lays the conceptual foundations upon which interpretations and explanations are based, those that make action meaningful to others (Dey, 1993). At this level, codes that carried the same meaning, cause and effect or other relationships were linked together to form categories. Such classification was done for a purpose, guided by the research objectives. Once data were classified, regularities, variations and peculiarities were examined and patterns were identified. Then relations between different categories were studied and a picture of the data created; this picture was complex but clearer than the initial impressions (see tables 1 and 2).

The aim of the current study was to understand the relationship between sexuality and HIV/AIDS in the context of disability, and thus contribute towards a theory, as detailed in section 8.2. Tables 1 and 2 below represent a summary of the main themes and sub themes that were generated using the Atlas.ti network-building exercise.

Table 1 is a summary of the two main themes discussed in detail in Chapter 5. The first theme demonstrates that disabled young people’s experiences and perceptions of growing up are determined by cultural and religious beliefs about causes of disability. Such beliefs lead to discrimination, acceptance and ambivalent attitudes towards disabled young people, which force this group to adopt fluctuating identities, which in turn increase their vulnerability to risk. The second theme shows that socio-economic factors of Nyanga are characterised by poverty and limited access to social services such as education and recreation by disabled young people, which increases their vulnerability to abuse and contracting infectious diseases such as HIV/AIDS.

Table 1: Experiences of growing up with a disability

	Themes	Sub themes	Consequences
1	Beliefs about causes of disability	<ul style="list-style-type: none"> <li>• Discrimination</li> <li>• Acceptance</li> <li>• Ambivalence</li> </ul>	<ul style="list-style-type: none"> <li>• Disabled identity</li> <li>• Non-disabled identity</li> <li>• Fluctuating identity/confusion</li> </ul>
2	Social economic factors	<ul style="list-style-type: none"> <li>• Limited educational opportunities at special and mainstream schools</li> <li>• Limited training, employment, transport, recreational facilities and health care</li> </ul>	<ul style="list-style-type: none"> <li>• Increase vulnerability to further discrimination, abuse and contracting infectious diseases including HIV/AIDS</li> </ul>

Table 2: Experiences of sexuality and HIV/AIDS

	Themes	Sub themes	Consequences
1	Cultural and religious beliefs/scripts about sexuality (tradition)	<ul style="list-style-type: none"> <li>• Rite of passage (discrimination)</li> <li>• The church</li> <li>• Prohibitions against sexual and marriage relationships</li> </ul>	<ul style="list-style-type: none"> <li>• Gender differences/ discrimination.</li> </ul>
2	Risk factors for HIV/AIDS (disabled asexuality)	<ul style="list-style-type: none"> <li>• Multiple sexual partners</li> <li>• Unfaithfulness</li> <li>• Financial exploitation</li> <li>• Sexual abuse/rape</li> <li>• Alcohol and drug abuse</li> </ul>	<ul style="list-style-type: none"> <li>• Increased vulnerability to contracting HIV infection</li> </ul>
3	Response to the HIV/AIDS pandemic (information)	<ul style="list-style-type: none"> <li>• Factual knowledge</li> <li>• Sources of information</li> <li>• HIV/AIDS services in Nyanga</li> <li>• Access to sexual and reproductive health services and care</li> </ul>	<ul style="list-style-type: none"> <li>• Disabled have limited information and are misinformed.</li> <li>• Believed to be asexual, yet contraceptives are imposed on them, also targeted for rape</li> </ul>
4	Perception of the threat of HIV/AIDS	<ul style="list-style-type: none"> <li>• Threatened</li> <li>• Unthreatened</li> <li>• Fatalistic attitude</li> </ul>	<ul style="list-style-type: none"> <li>• Not motivated to protect themselves, AIDS is like any accident</li> </ul>

Table 2 is a summary of the four main themes discussed in detail in Chapter 6. The first theme illustrates that disabled young people's experiences of sexuality are also determined by cultural and religious beliefs. These are manifested through the rite passage, and restrictions to sexual expression, that are characterised by gender discrimination. The second theme shows that a combination of cultural scripts and poverty lead to several risk factors for contracting HIV infection. The third theme points to individual and contextual responses to the pandemic that are characterised by limited information, misinformation and lack HIV services in Nyanga. This theme also reveals a paradox of disabled asexuality, in the face of this group being a target for sexual abuse and imposed contraceptives. The fourth theme

describes another paradox of risk, in that disabled young people who feel threatened by HIV/AIDS and those who do not feel threatened, all have not heeded to prevention efforts to protect themselves from contracting HIV infection

#### **4.9. RELIABILITY OF THE STUDY**

The concept of trustworthiness described earlier in this chapter was used to ensure the quality and reliability of the present study as described below.

**a).** The **credibility** of the study was achieved through the following ways:

- i. *Persistent observation*: The process of fieldwork allowed me to observe disabled young people in their own homes, most of whom spent their time in idleness. Owing to high unemployment rates, Nyanga residents are generally busy buying and selling merchandise or running shebeens to earn a living. Disabled young people in wheelchairs were hardly seen on the streets, perhaps because of the difficulty of moving around the narrow spaces between shacks and the high crime rate.
- ii. *Triangulation*: Triangulation was achieved through use of multiple sources of evidence established through multiple data collection methods. The chain of evidence was established between information gained from document reviews, in-depth interviews, and focus group discussions. I ascertained common themes that emerged across the groups and cross-checked findings between the different data sources. Using a combination of different data types increased credibility as the strengths of one approach compensated for the weaknesses of another approach (Marshall and Rossman, 1994).

*Member check*: As stated earlier, member checking was ensured by taking transcripts back to interview participants to clarify certain issues, re-construct ideas and sometimes change others.

**b) Transferability** was achieved through the following:

- i. *Theoretical and purposive sampling*: Purposeful sampling was used to recruit research participants at the beginning of the study. In the course of fieldwork, pertinent issues arose which required a purposeful selection and inclusion of other groups, whose ideas were deemed useful for adding depth to the study and were willing to participate (see data collection procedure).
- ii. *Thick description*: In reporting findings I have used a descriptive mode, which has exposed and articulated the issues that I dealt with in the case study, more comprehensively and from different perspectives. The case has been made as vivid as possible for the readers, thus creating a substantial basis for similarity judgements.

**c) Dependability** was achieved through interaction with other researchers at UWC, K. U. Leuven (Katholieke Universiteit Leuven), and in and outside South Africa. Different people read and discussed the findings with me, in the process enabling me to maintain focus on the objectives of the study. This process helped me refine the study to the most relevant aspects which needed examining.

**d) Confirmability** was ensured through triangulation and the personal journal that I kept to authenticate the research process and the findings. The procedure for checking and rechecking the data throughout the study was clearly documented. Input from other researchers who offered constructive and professional advice has also been documented. Finally, the complexity of the study as well as its limitations are acknowledged and documented.

#### **4.10. CONCLUSION**

In this chapter, I have outlined the broad precepts of qualitative research, in particular the case-study design. The outline includes the merits and demerits of a case-study design, as well as the steps taken to ensure the trustworthiness of the research and ethical considerations. The steps I took to

identify a research site and research participants have been described, including, the use of multiple data collection methods from multiple data sources to understand disabled young people in Nyanga. Analysing data with the Atlas.ti computer software allowed for a thorough exploration of participant's experiences and perceptions regarding sexuality and HIV/AIDS.

For clarity, the findings of the present study are presented and discussed in the next two chapters. Chapter 5 deals with participants' views concerning disabled young people's experiences and perceptions of disability. Chapter 6 deals with participants' views concerning disabled young people's experiences and perceptions of sexuality and HIV/AIDS in the context of disability.



# CHAPTER 5

## FINDINGS: EXPERIENCES AND PERCEPTIONS OF DISABILITY

### 5. INTRODUCTION

This chapter deals with disabled young people's experiences of growing up with a physical disability in Nyanga. The views of disabled young people, those from focus group discussions and key informants are used simultaneously to give a different view, support or strengthen each theme that was generated using Atlas.ti computer package. Disabled young people's experiences and perceptions are presented under two main themes. These are (i) cultural and relational factors and (ii) socio-economic factors impacting on disability. Sub themes are used to discuss the issues in depth. These two themes are in response to the first objective of the present study, which was to describe disabled young people's experiences of growing up with a physical disability. Figure 1 below shows theme 1 and its sub themes.

Figure 1: Experiences of growing up with a physical disability

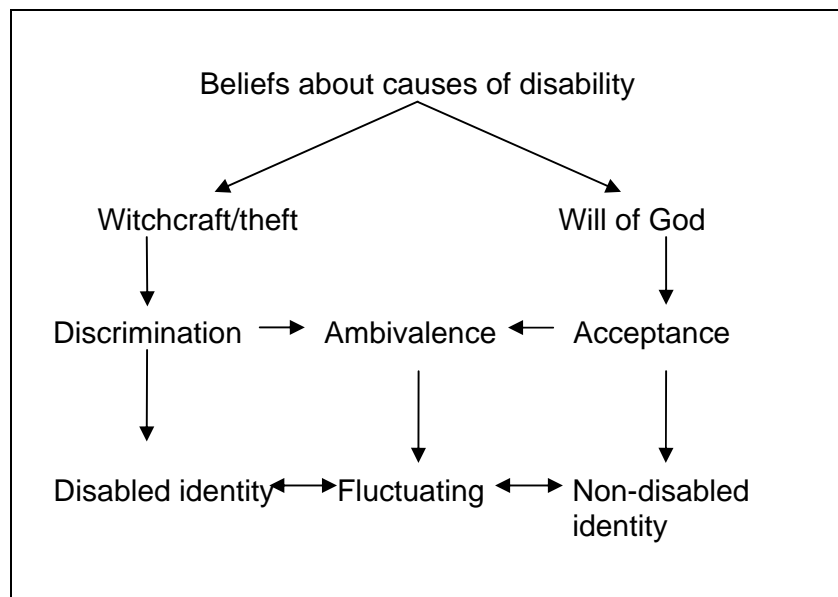




Figure 1 illustrates the fact that disabled young people's experiences of growing up are determined by cultural beliefs about causes of disability, either witchcraft or the will of God. Such beliefs influence the social construction of disability, which leads to acts of discrimination or acceptance of disabled young people, and sometimes ambivalence, that is, loved and hated at the same time. In order to cope, disabled young people respond by adopting disabled, non-disabled or fluctuating identities as will be demonstrated in the participants' own words in the rest of this chapter.

## **5.1. CULTURAL AND RELATIONAL FACTORS**

Pseudonyms are used to refer to disabled young people, the abbreviations FGD 1-10 represent focus group discussions and Key 1-8 represent key informants (see section 4.5.2). As stated in Chapter 4, the views of individual physically disabled young people are presented first, then triangulated with views from different 'focus group discussions' and from key informants. This is done in order to clarify, confirm or strengthen the issues under review. All the interviews with disabled young people were translated from English to Xhosa and vice versa except for Nceba, Themba and Philisiwe who spoke in English. All focus group discussions were translated from English to Xhosa and back to English, and all interviews with key informants were conducted in English.

### **5.1.1. Beliefs about Causes of Disability**

Participants were asked to describe what it felt like growing up in Nyanga as a physically disabled young person. Most responses centred on how society perceives and treats disabled young people, based on what is believed to be the cause of disability. Schoepf (1997) states that in Africa disability is explained through its causes, which are thought to be witchcraft, illness, misfortune or the will of God. Likewise, Xhosa-speaking people attribute to the power of witchcraft everything that cannot be explained, as demonstrated below:

*Nceba, 24 years old male with post polio paralysis of both legs and works in Information Technology: The Xhosa people have their own*

beliefs about disability. They say you have been bewitched when the cause of your disability is mysterious. Sometimes they think you were a thief, you stole things, got caught and you were bewitched. Like me, it is believed I stepped on snake... *laughter*.

Nceba is the only participant pursuing College education. Perhaps that is why he laughs about the idea that he might have stepped on a snake, when he knows that he suffered from polio. It follows that those whose disability is believed to be associated with witchcraft and theft are feared and resented as will be illustrated further under section 5.1.1.1. Another participant concurred with Nceba:

*Themba, 24 year old male with post polio paralysis of left leg and is unemployed: I was diagnosed with post polio at a very tender age ... basically to me it is the left leg which is weaker, my right leg is strong ... we differ in our sickness, us people with disabilities.*

No sooner had Themba said the above when he added the following:

They say that I have polio because white people do not understand these things. What actually happened is that I stepped on a snake when I was a child and that caused my disability.

Although Themba is willing to go along with the medical diagnosis of his disability, and the idea that disability is considered an illness, in his mind he believes differently. Some Xhosa-speaking people believe that disability is caused by witchcraft and others believe that disabilities are caused by illness or the will of God. Such contradictions do not only yield inconsistent responses from disabled young people, they also double their risk of discrimination and social isolation.

Historically, "every human culture has found its own explanations of why some of its members are born with or acquire disabilities" (McConkey and O'Toole, 1995: 4). Invariably, and as stated in Chapter 2, these involve some form of supernatural punishment, which invoke a sense of guilt and shame in the affected individuals. Consequently, people with disabilities and their families are spurned and excluded from community life. The *sangomas*

(traditional healers), who consisted of a male leader of traditional healers in Nyanga and a female trainer and her trainees, shared the following:

FGD 9: Some people (*with disabilities*) go to the hospital first, when they are not improving they go to *sangoma* ... I tell them they do not need treatment for their illness. They are being called by their ancestors to be sangomas. A disability like stroke is caused when you step on medicine.

While sangomas referred to stepping on medicine, parents, like their disabled children, referred to stepping on the snake. Yet both occasions imply the power of witchcraft that is believed to cause disability as supported by a member of one of the parent focus groups:

FGD 6: My child was born in Transkei, she was not disabled ... she cried all night and in the morning I tried to make him stand and he could not stand (*3 years old*). We went to sangomas and he said I (*mother*) saw a snake (*evil spirit*). So he came to drive evil spirits from the house. Then we went to the hospital.

The snake is used as a metaphor implying mystical or supernatural powers, which generate fear and suspicion of disabled people. According to Schoepf (1997), accusations of witchcraft can invoke revenge and punishment of the perceived perpetrators, who may in fact be innocent. Such beliefs hinder the integration of disabled young people into mainstream society because they are feared or resented by their community.

Based on the above quotations, disabled young people in Nyanga are at risk of being labelled as thieves, or those who have been punished for their wrongdoing or those whose ancestors may be calling them to be traditional healers. In spite of such beliefs, participants did not know any disabled person who is a *sangoma*, which points to the reality that this group is not readily initiated as traditional healers. Key informant 2, who is severely disabled himself with stiffness of the whole body and works as a coordinator in Vukuhambe disabled people's organisation, confirmed disabled young people's and FGD responses as follows:

Key 2: Through my job and seminars I have attended, I picked up something about beliefs out there. For instance if a disabled child is born, there is a belief in the family that this child is bewitched.

All the quotations in this section show that disabled young people are viewed suspiciously by society based on stated beliefs about the causes of their disability. Such is the basis for the discrimination that participants experience as explored below.

### 5.1.2. Discrimination at Family Level

Some participants reported that discrimination and rejection begin at family level when their own fathers walk away after the birth of a disabled child, blaming wives for giving birth to disabled children. As a result, most disabled young people in Nyanga have grown up with the idea that they are undesirable, which causes low-self esteem, as will be illustrated later in this chapter. Examples of rejection by fathers are given by the following disabled young people who participated in FGD 1:

*Andiswa, 16 years old female with cerebral palsy:* I have a brother and a sister. I live with my mother. My father left us ... he went to work elsewhere.

*Themba:* I grew up with my mum as a single parent. My dad is still there but he is ignoring us, I would say neglecting us... my mum is doing everything to show her love to us ...

These quotations are consistent with the views expressed by Kabzems and Chimedza (2001:150) who state that “children with disabilities have historically been looked on as a burden to the family and community”. As such, most men refuse to take responsibility for disabled children. Mothers of disabled children are blamed for bringing the so-called ‘undesirable’ children into the world. Such mothers are left to bear the consequences of their presumed ‘wrong doing’ alone. Although many non-disabled children in Nyanga today are also brought up in single-parent households, disabled young people are doubly disadvantaged because they are blamed for their parents’ separation as well. These views were also shared by:

FGD 7, *senior citizens group*: My sister gave birth to a child who could not move or even swallow. Her husband left her ... it is implied that it is a woman who gives birth to a disabled child. A man cannot produce a disabled child.

These views were further confirmed by Key informants 2 and 3 as stated below:

Key 2: Sometimes you will find that there are broken marriages if a disabled child is born. The father will just say, in our family we never had disabled people. The mother will be accused because she gave birth to a disabled child ...

Key 3, *has post polio paralysis of her right leg and is a supervisor at a protective workshop*: When a mother gives birth to a disabled child, the man walks away; he says he cannot give birth to a disabled child. It is the fault of the woman; it's like the end of the world, they run. But women are very strong; they bring up their disabled children alone.

In most African cultures, children are considered assets that will bring material wealth or hard labour to assist their parents in the future. Disabled children are not expected to meet such expectations. This is one reason why fathers use disability as an excuse to abandon their wives so they can avoid investing in a disabled child, who would not achieve and provide the expected benefits to his family. Nkabinde (1994) also found that it is a common occurrence in many African traditions for husbands to abandon their wives after the birth of a disabled child (see Chapter 2).

In response to above situations, most mothers in Nyanga are embarrassed to show that they have disabled children and so they keep these disabled children indoors, a process that increases the social isolation of this group. However, contrary to this finding, Ingstad (1999) found that in Botswana, parents do not hide their disabled children out of embarrassment. Instead, they keep disabled children in the house only because these children become too big to be carried around. This is because in Botswana disabled children are largely viewed as a gift from God rather than punishment for wrongdoing. While the current study also identified inaccessible transport as a problem that leads to the confinement of disabled young people indoors, hiding disabled

children because of embarrassment remains the main problem, as indicated below:

Themba: Some parents are still shy to show that they have a disabled child, but during paydays for disability grant, they are not shy to wheel them to the payment point. I would say disabled young people are only used for getting money into the house.

The issue of a disability grant was raised in Chapter 2 and is a recurring issue in this thesis, which will be discussed further in Chapter 7. Themba's view was supported by other young people in focus group discussions as stated below:

FGD 3: ... We are only loved because of our money (*disability grant*). When we go low on cash we are nothing.

FGD 3: My family treats me badly, they treat me like a child ... there is no difference in the way they treat me and my 3 children. They live on my grant and yet they decide everything for me (*supporting 13 people on 1 disability grant*).

Most participants feel unwanted and isolated except on paydays when they feel accepted because of the income they contribute towards the family. Participants revealed that in most households the stated disability grant is the only available income for the whole family. However, the acceptance that disabled young people experience is only transient, social pressure is too strong for their parents, as illustrated by the following key informant:

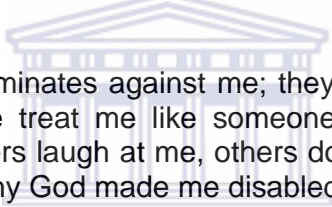
Key 3: Parents are still hiding their kids because they are very shy that they have got a disabled child ... to me it's nonsense, you do not apply to have a disabled baby ... it's a gift from God. So there is a big, big problem here. So the children still stay in the house in darkness instead of coming here (*Protective Workshop*) to meet others. People like to judge out there. When you have got a disabled child, then you are down (*feeling low*) ...

As a disabled person herself, Key 3 holds the view that disabled children are a gift from God. However, most mothers in Nyanga who are seen with disabled children risk being ostracised by society. Ostracism of mothers of disabled children is a practice that has also been reported by Schneider *et al*

(1999: 12); they found that parents of disabled children are often rejected and receive little support from their former friends after the birth of a disabled child, this is in addition to being rejected by their spouses. Another reason mothers in Nyanga hide their disabled children, is the high crime rate in Nyanga that will be examined further in Chapter 7.

### 5.1.3. Discrimination at Community Level

It is widely acknowledged that prejudice, social isolation and discrimination are the greatest impediments to the lives of disabled young people (Despouy, 1993). Some participants in the present study experience teasing, being laughed at and ridiculed by family members, peers at school and by the community in general. As a result, disabled young people feel hurt and rejected as indicated by participants of FGD 1:



The community discriminates against me; they see me as a useless person. Some people treat me like someone who does not know what he is doing, others laugh at me, others do not like talking to me ... sometimes I ask why God made me disabled.

Some children of my age, if they see me they laugh sometimes, they walk like me [*imitating*] although they are normal. They walk like me and laugh. At school there is nothing like that but at the location.

These quotes indicate that participants are not accepted, they are made to feel small and insignificant purely on the grounds of having a visible disability. Although Schneider *et al* (1999: 13) point out that “unless efforts are made to educate children about issues around disability, they will become prejudiced and discriminatory as many adults are today”; the above quotes indicate that children in Nyanga are already prejudiced against their disabled peers. To this end, some participants in the present study are resigned to the realisation that society and peers would always treat them unfairly and so it is up to disabled young people to accept and learn to live with that reality as stated below:

Themba: You know ... attitudes will always be there. There are some people who do not bear that we are on the same planet. We can't run away from the fact that we are disabled and we do the things that they do. Whatever affects us affects them as well.

Most participants expressed regret that society does not recognise them as equals. Similarly, disabled participants in the Department of Health survey of 1999 also expressed a need to be treated 'like normal people' or with equality (Schneider, 1999: 32). Part of the difficulty of interpreting the notion of 'equality', is that society assumes that no extra effort is required to meet the needs of this population. As equals, it is assumed that disabled young people should survive and access available services like everyone else. However, such a view ignores the special 'disability specific' circumstances that make the situation for disabled young people different and needing special focus.

Proponents of the cultural model of disability espouse the celebration of 'sameness' and 'difference' (Devlieger *et al*, 2003), implying that it is not enough to attempt addressing issues of equality without dealing with issues of difference as well (see Chapter 2). For example, disabled young people who use wheelchairs have difficulty negotiating their way around shacks in Nyanga, yet there remains no effort at community or policy level to regularise the building of shacks so as to accommodate or provide for the needs of the said group. The irony is that, on the one hand, society has difficulty dealing with difference. On the other hand, society constantly reminds disabled young people that they are in fact different, as illustrated below:

*Key 7, with post polio paralysis of both legs and training to work in the post office: I grew up in the Eastern Cape, to be a disabled child there was difficult because children laugh at you and the distance to school is far. In those days if a person was disabled he must be locked inside, nobody should visit him and he will never socialize again. Even when you go and try to socialize, people will ask, 'Why are you here?' I know for myself, if I go to a party at night, people will ask, 'You disabled person' (isilima), what are you doing here, go, go to sleep' they associate this person with abnormal personality ... they don't see you as a person who can be among them, advise them or work with them. They just make you feel inferior.*

This quote illustrates a number of deep-seated frustrations of growing up as a physically disabled child, such as inaccessible schools, social isolation and



feeling dehumanised. Furthermore, Key 2 indicated that some churches are not without prejudice against disabled young people as reported below:

Key 2: I don't want to mention names, but some churches will just want to pray for the person with a disability. They think that these are demons ... For example even myself, when I want to attend a service, when they want to pray for people and I am sitting there I am not going forward to be prayed for, some elders of the church will just come to me to pray over me because they think I have failed to go to the front, I really hate that ...

Although the church is known for works of charity among disabled people, equating disability with demons causes the church to either discriminate or attempt to drive away the demons before they can accept a disabled person. According to the cultural model of disability, the idea that disabled people are sick and that they need a cure might be described as failure by society to accept the concept of 'difference'. Normality has been prized more than disability, there is a drive to cure and if cure fails the affected are discriminated against (Oliver, 1990, Shildrick, 2002) (see also Chapter 2). This is why some churches feel compelled to exorcise the perceived demons of disability and restore the affected to normality.

#### **5.1.4. Response to Discrimination**

In response to discrimination, some disabled young people reported that they retreat into self-isolation as a means of escaping the negative input from society as indicated below:

*Thandiwe, 18 year old with cerebral palsy and out of school, working in the protective workshop: I don't know how to talk to people outside...so I always stay in the house...When I was at school they would drop me (school shuttle) at the front door of my house...so I don't have to walk long distance to the house...children laughed at me so I took that shortcut to avoid meeting them...*

While Thandiwe chose to avoid the teasing by going into self-isolation, Lindiwe managed to make friends in spite of the teasing she endured as she explains:

*Lindiwe, 21 year old with severe flexion contractures of both hip joints and working in the protective workshop: I have many friends, disabled and non-disabled. Yes, people just look at me so much when I am walking; they are not nice ...*

Some participants are afraid or simply lack the skills to stand up against unfair treatment from their peers, hence Thandiwe's response to teasing and so they develop a disabled identity. Others respond by ignoring negative input and in the process develop resilience within themselves to resist teasing, thus adopt a non-disabled identity. Some pretend to accept that the teasing they experience is normal when in fact they resent being treated that way. Others simply withdraw from unfriendly peers and choose to associate with fellow disabled young people as a way of escaping:

*Nomthandazo, 22 year-old with left Hemiparesis and works in the protective workshop: I had no problems growing up...as you know, people will always call you names, tease you...but I would always pretend that I do not hear...I would group myself with other disabled persons...because we strengthen each other.*

It might well be that Nomthandazo accepts the discriminatory attitudes because she lacks appropriate skills to respond differently. It might also be that she, like other participants, has limited opportunities to interact with non-disabled peers, where they might learn how to challenge teasing. Consistent with this interpretation, Shakespeare (1994) and Oliver (1996) report that social isolation is an ever-present feature in the lives of disabled people. However, not all participants succumbed to acts of discrimination; others like Themba resisted and asserted himself against all odds as expressed below:

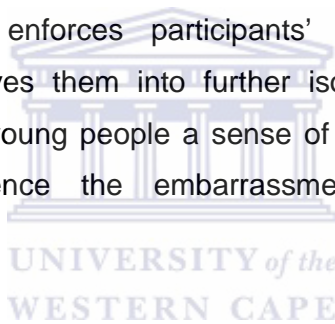
*If they ignore me, I fight to show that you cannot just do anything to me because I am like this ...think twice. Sometimes they beat you and they try to run away. My friend will pursue him and bring him to me, then I will show him what I have ... they used to provoke me because they know I won't run ... I had this problem at school, they used to tease me and say hey, why are you going to school? Stay at home.*

Themba did not only fight for recognition among his peers, he also made friends with non-disabled peers who helped him to fight his opponents.

Themba also ignored those who discouraged him from going to school, which is why he is one of the only three disabled young people in the current study, who completed matric. His assertiveness could be attributed to his level of education. A point has been raised in literature to the effect that many disabled children face barriers to education because some families and societies do not perceive that such children need education (Elwan, 1999). Apart from the likes of Themba, most disabled young people cope with discrimination by adopting a 'disabled identity', as illustrated by Nceba and key 7:

Nceba: At special school ... to be honest, at that time I wore shorts but now ... I wouldn't be able to wear shorts ... I feel embarrassed of how I look.

The 'disabled identity' enforces participants' feelings of shame and embarrassment, and drives them into further isolation. A visible physical disability gives disabled young people a sense of being 'different' from their non-disabled peers, hence the embarrassment about exposing the impairment:



Key 7: I used to cross a river to go to school in the Eastern Cape. It was difficult, that is when I felt disturbed that I differed from other children, my mother used to help me cross the river.

Proponents of the social model of disability and the ICF would argue that if Key-7 had been able to cross the river on a bridge with his crutches, he would not have needed to feel different from his non-disabled peers. The environment hindered his participation. Key 7 needed his mother to carry him because he could not wade across a river using crutches. The inability of public policies to provide a bridge in the village or the inability of a village committee to build a temporary bridge to facilitate accessibility are barriers to access to education for physically disabled young people. However, the social model and the ICF fail to emphasize the fact that being paralysed and using crutches are real problems at personal level that cannot be addressed by the provision of a bridge alone. Thus a balanced view is required that focuses on

the individual as well as his/her environment. Apart from discrimination, there is also a positive aspect to the experience of disability as expressed below.

## 5.2. ACCEPTANCE OF DISABLED YOUNG PEOPLE

Along with the marginalisation and exclusion of disabled young people described above, some participants reported that they feel more accepted by society, at family, school and church level. Such acceptance allows this group to feel good about themselves. Non-disabled peers who play with disabled young people without prejudice demonstrate this acceptance:

Nceba: Basically my friends did not take me as disabled. When they were playing football, I was playing with them. I can remember one day when we got the results (*won the match*) they forgot that I was disabled and jumped upon me ... I had to catch my balance.

Themba: Some of them like us, they treat us normally. Whatever problem they have, some of them come to me and say, I have this, how can you help me?

These quotes illustrate that some members of the community treat disabled young people like any other young person. For example, Nceba's friends did not think about him as disabled or incapable before leaping on him with joy, following their victory in a football game. This is evidence that given the right information and support, society or young people have the capacity to embrace disabled people as 'equals' without ignoring the difference, as Nceba's friends did. According to the cultural model of disability, embracing sameness also means being sensitive to 'difference'. If Nceba had not managed to maintain balance, the leap for joy could have easily resulted in injury.

Furthermore, the belief that disabled children are a gift from God or that they are sick is the basis for the acceptance of disabled young people in general and this group can take advantage of the situation as illustrated by a member of disabled young people in FGD 2:

Me, I am loved by all people. Sometimes they give me money; sometimes they pay for my shopping when I have forgotten my money ...

People are more likely to feel sorry and believe a disabled young person who claims to have forgotten his/her shopping money, than they would a non-disabled young person. In such situations, then disability can be described as an advantage as it provides opportunities that are not accessible to non-disabled young people. Similarly, some parents in focus group discussions demonstrated how they favour their disabled children over the non-disabled ones as stated below:

FGD 5: I have four girls and one boy. She (*Buhle*) has more clothes than her able-bodied sisters ... I tell the others to treat her like them. When I buy underwear, I buy the same for all of them to show them (*Her brother and sisters*) she is a human being like them. When I have been out of the house, the first thing I ask them, have you given her food? I tell them, if you are eating, you must give her also, the same amount as you.

This quote shows that Buhle's mother tries to find a balance between focusing more attention on Buhle because she is disabled and different, and at the same time encouraging her siblings to treat her like one of them. Similarly, key informants indicated that beliefs about the will of God and that disabled people are sick, account for acceptance of this group:

Key 2: Some families will just say it's a gift from God so it would mean that the child is supported by both parents ...

Key 5: Basically, disabled people are sick, we feel sorry for them and we try to help where we can ...

The above quotes illustrate a sense of compassion and the moral obligation that parents and society have to protect or sometimes overprotect disabled children. Overprotection prevents disabled children from playing or associating with peers, which denies them the opportunity to learn some social skills from their peers. Although overprotection is intended as a positive

gesture, it in fact prevents disabled young people from expressing even their own sexuality as will be elaborated further in Chapter 6.

### **5.2.1. Acceptance in the Church**

Most participants feel accepted in their churches, with two exceptions who can not tell whether the silence over disability issues in the church means acceptance or avoidance. The following quotes demonstrate some of the experiences:

Nontsikelelo, 24 year-old female with fistled fingers, she uses her bent thumb against the rest of the flexed fingers: I am Zionist, the church treats me like every one else.

Nomthandazo: My church says disabled people are equal to non-disabled people they are not segregating against.

These sentiments indicate that some churches make disabled young people feel accepted. In some instances, the church is considered a source of encouragement for participants:

FGD 3: In the Rasta faith they say nothing about the disabled; it's up to you to come to church or not ... they don't force you.

FGD 3: In the Apostolic Faith Mission, they treat me well; adults as well as children respect me. They chose me to be a Sunday school teacher. This is all because I did not tell myself that I was disabled and sit back ...

FGD 8: What I know is that we have to treat disabled people like any other human being. In Nyanga, there is no other church except Christianity ... a disabled child is from God ...

Although some churches are silent on disability matters, participants reported that most churches are welcoming of disabled young people. Historically, the church has tended to incline towards the medical model of disability and has supported the giving of alms and welfare to a passive population of disabled people (ODP, 1997). This is in contrast to the social model of disability, which prizes self-confidence and equal access to resources by encouraging

disabled people to stand up for their right to participate in mainstream activities (see Chapter 2). Acceptance of disabled young people by society yields positive responses, albeit at social level as such acceptance does not take away the reality of the physical impairment.

### **5.2.2. Response to Acceptance**

Disabled young people who feel accepted develop a heightened sense of confidence in themselves and in relating to others. Consistent with this assertion, McConkey and O'Toole (1995: 4) claim that "society can reduce the handicapping effects of disability if they are given appropriate knowledge and skills regarding the many facets of disability". Although such knowledge is important, it would not necessarily take away the reality a physical disability at a personal level, for example, negative attitudes or lack of self-confidence. These emotions do not just go away by being accepted. Acceptance only helps a person to learn how to handle their situation better. However, participants in the present study feel accepted by society when they are treated as equals in spite of their functional limitations. In turn, they adopt a 'non-disabled identity', which improves their sense of self-worth as indicated by the following participants:

Themba: ... Even though I was disabled, I did not consider myself as disabled because I used to play soccer with other kids. I was doing every thing that my friends were doing, sometimes I used to leave my caliper and crutches at home and crawl.

Lindiwe: Nothing...I do not take myself as disabled...I am normal like everyone else.

For these participants, being disabled is nothing more than just a feeling they have adopted rather than a manifestation of their physical impairment. This seems to be a way of denying the real impact of the physical limitations, which cannot simply be wished away. Key 2, concurred with Themba and Lindiwe as follows:

Key 2: I have always had a feeling that I am not disabled despite my limitations. That is why I am not let down although people would just

say anything to me that will make me feel down (low), because inside of me, I have got a feeling that I am not disabled.

Finding a balance between one's feelings and the physical reality is a big challenge that needs constant review. Based on the ICF's conceptual level of classification, disabled young people's level of functioning or participation within the environment is what determines their status, more than the limitations caused by their impairment. This view erroneously implies that removing social barriers would also remove the 'disabled identity'. As stated above, such a view underestimates the real challenges caused by physical impairment. For example, providing ramps for wheel chair users does not take away the challenges of getting in and out of the wheelchair and wheeling themselves around. The reality is that disabled young people's experiences are driven by complex and sometimes contradictory forces both at individual and contextual levels.

### 5.2.3. Ambivalence

It has been shown that in Africa, attitudes towards people with disabilities vary greatly, ranging from discrimination to acceptance and even to the positive attribution of supernatural powers (Edgerton, 1970). Similarly, in the current study, disabled young people's experiences are characterised by inconsistencies. Although society mistrusts and discriminates against them, some members of society show compassion and solidarity for this group. Such inconsistencies are shared below:

*Zandile, is a 20-year old with right Hemiparesis and not employed:*  
...some treat me badly and others treat me good. Asked what she meant by being treated badly, she responded, they laugh at me.

Thandiwe: My friends are nice...others do not love me...they laugh at me, they tease me, they make me cry.

Members of FGD 1 concurred with Zandile and Thandiwe over the stated inconsistencies as demonstrated below:



FGD 1: Obviously some people love me and others do not, they tease and laugh at me, but because I did not ask to be like this, I ignore them.

These quotes demonstrate once again that it is because disabled young people are the 'same' and 'different' that they elicit such opposite reactions from society at the same time. Even key informants shared similar views on inconsistencies by society:

Key 7: That is just what people are like ... they have wrong sympathy. As a person with a disability, they think that you are in pain ... They think it is difficult for that person to do this and that; he must stay in one place and be provided with everything. Since they see that it's difficult for you to do things, they think you must be treated differently. That is why people will do everything for you.

It is clear from the above quote that sympathy is not only motivated by the presence of a visible disability, but the difficulty with which disabled young people perform everyday activities. Although not wrong in itself, sympathy shown out of ignorance of the real needs of disabled young people, is not appreciated as it encourages this group to be passive recipients of charity. Yet most attempts by disabled young people to participate in mainstream activities are not supported with the necessary resources to accomplish the intended goals. Thus disabled young people feel trapped in the middle of two extreme positions, none of which eases their experience of disability. Some churches are equally inconsistent in handling disabled young people, as expressed below:

FGD 3: My church (*Methodist*) did not take much notice of me when I became disabled and started using a wheelchair. One day the Holy Spirit came upon me and I stood up and joined the dancing in church. They were very surprised when I danced with them so that at the end of the service, one member gave me a lift to my house ...

FGD 3: (*Kushe church*) I was given nice clothes (*uniform*) to honour me because I was active in church, but when I got the accident, the pastor sent people to come and get the clothes ... because now I was useless to them.

The above quotes indicate that religious communities would rather see disabled people as active participants in the church than as passive recipients of charity, as referred to earlier in this chapter. A disabled key informant also grappled with the stated inconsistencies as demonstrated here:

Key 7: At home there is my mother and father not taking me as a disabled person; they take me like any other child. As a result, at some stage they had to remind me and say you mustn't do this and that, for example drinking a local brew [umqomboti], because you are disabled. How are you going to walk when you are drunk? I was thinking and feeling bad, that was painful. So you must always understand that you are not like them.

The above quote shows that Key 7 and his parents struggled with the concept of 'sameness and difference'. On the one hand, key 7 was happy that his parents treated him as if he were not disabled. On the other hand, key 7 felt that his parents were overprotective of him because he is disabled. He felt that his parents used his 'disability' to stop him from drinking beer instead of discouraging beer for its own sake.

### ***Summary of Theme One***

It is clear that disabled young people's experiences of growing up are complex, as they are determined by contradictory cultural and religious beliefs/scripts about causes of disability and disabled young people's responses to the same. Cultural scripts lead to public 'invisibility' and high risk to vulnerability, while the church leads to public 'visibility' and low risk. Consequently, disabled young people adopt fluctuating identities in order to cope with different prevailing moods in their environment. The fluctuating identities increase their vulnerability to abuse as will be demonstrated in Chapter 6. It is also apparent that most succumb to discrimination and go into self-isolation, while others develop resilience and try to fight against discrimination. Cultural scripts are not the only factors influencing disability as shown below.

### 5.3. SOCIO-ECONOMIC FACTORS WITH AN IMPACT ON DISABILITY

In addition to cultural and relational contextual factors as described above, socio-economic factors also impact negatively on disabled young people's experience of disability. The poverty situation in Nyanga is the principal social factor that contributes to limited access to social services by disabled young people (see profile of Nyanga in Chapters 1 and 4). According to McConkey and O'Toole (1995: 5), "disability and poverty go together" because many people with disabilities live in poverty. Thus, poverty is the single greatest barrier to disabled young people's development. Participants in the current study appear to have interacted more with the educational system than with other social services as expressed below.

Figure 2: Socio-economic factors impacting on disability

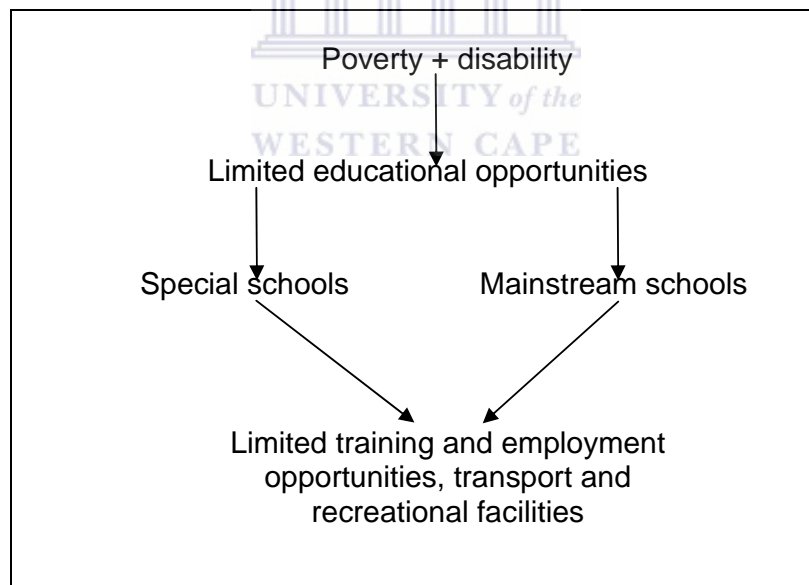


Figure 2 demonstrates that the poor living conditions of Nyanga, coupled with the social construction of disability, combine to limit disabled young people's educational opportunities. Such limitations are experienced at special schools and mainstream schools alike. Moreover, a combination of poverty and

disability constructs also limits disabled young people's access to other social amenities such as transport, recreational and health facilities.

### **5.3.1. Educational Opportunities**

Since education is key to the personal development of disabled young people, participants were asked to share their experiences of schooling. Some reported that they have never been to any school, others dropped out of school prematurely and only 2 out of 15 participants were still attending special schools. The reasons given for not going to school or leaving prematurely range from illness, finances to being over-age. Consistent with this finding, Elwan (1999; 2003) notes that in Africa, many children with disabilities do not attend school. Using the World health Organisation estimates, the South African Education White Paper 6 (EWP6) estimates that there are between 293,000 and 346,000 disabled children in the country, which is 2.2%-2.6% of approximately 13,312,000 learners in the system. This system currently holds 64,200 disabled learners, which leaves 260,000-280,000 disabled children without care and provision (Department of Education, 2001b).

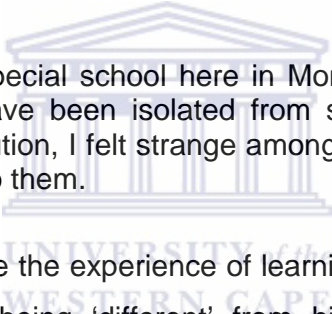
Most participants in the present study went to special schools up to the age of 23 years, regardless of the level of education they had attained at that age, that is whether, they had completed matric or not, participants were asked to leave. Some disabled young people are nevertheless grateful for any level of education they attained in a society which views them as sick and helpless as stated below:

*Vuyiseka, 17 year-old with cerebral palsy:* I never went to school...my mother says I was very sick that is why they never sent me to school.

*Nomthandazo:* I went to Thembaletu (special school), but I stopped early because of money problems.

*Lindiwe:* I went to Thembaletu school up to grade 9. I could not go further with education because they told me I was old. I was the only one who went to school in my family ... me the disabled one. My brothers and sisters are able bodied and they did not go to school ...

In spite of the barriers to education stated above, the majority of disabled young people in the current study obtained some basic education. They missed the opportunity to go to secondary school or to complete secondary education mainly because of financial problems or policy issues (only allowed to be at special schools up to the age of 23). The fact that most disabled young people attended school is evidence that some parents tend to encourage their disabled children to obtain a better education than their non-disabled siblings or peers (Groce, 1997). Such parents feel that the future of disabled children, especially disabled young women, lies in education, since they may never marry because of social prejudice. Some participants complained about the social isolation they experience at special schools, as stated below:



Nceba: I went to a special school here in Montana, at St. Joseph's home. Where you have been isolated from society. By the time I came out of the institution, I felt strange among able-bodied people. I saw myself different to them.

Nceba does not appreciate the experience of learning at a special school that reinforced his sense of being 'different' from his non-disabled peers. In contrast, going to a special school offered Lindiwe a better opportunity for basic education compared to her non-disabled siblings who did not go to school. In such a situation, it can be argued that sometimes disability works out to disabled young people's advantage over their peers and siblings. In line with this argument, a disabled lawyer (Blumberg, 1980) states that one of the good things that happened to her apart from studying law, was that she came to better terms with her physical self. Her level of education helped her realise that there was so much about her body that was right, including a measure of good health. Having established disabled young people's experience with education, it was important to find out their perceptions about the education system in South Africa.

### 5.3.2 Perceptions about the Education System

Participants were asked to state the school system they would prefer for themselves if they were given an opportunity to choose. Only participants who had been to secondary school and the key informants, all of whom were educated, felt comfortable to share their experiences on the subject. They gave different reasons for their preferences as expressed below:

Nomthandazo: I started school Emaxhoseni (the Eastern Cape) in a normal school, when I came here (Cape Town), my aunt took me to Thembaletu. Therefore, I have no problems with schooling; I can go any where, except non-disabled children always tease disabled children. They make you feel stupid.

Although Nomthandazo claims she does not mind going to either school system, she complains about the teasing of disabled children at mainstream schools. Yet Philisiwe asserts that she had no problems at a mainstream school, but foresees problems of reintegration back into society for those who go to special schools:

Philisiwe: Special schools are not needed. I was going to school with normal people and I was the only one who was disabled the whole school ... I was not getting any problems there. I would choose mainstream schools because special schools isolate you ... if you were educated at special schools and you come out to work, they discriminate against you, but if you are educated at mainstream schools, there is no discrimination.

Like disabled young people above, members of FGDs had different views on the subject as illustrated below:

FGD 5: I prefer that our children should be educated together with able bodied children because the able-bodied would be able to teach our children certain things and they would also learn to see that disable children are just like them ... if they learn together, they learn from each other.

FGD 5: Our disabled children are slow therefore they should learn from the non-disabled. They should learn together to avoid discrimination

FGD 6: I prefer them to learn separately because the able-bodies tease the disabled children and they cannot concentrate on their school

Similarly, key informants' views are in favour of mainstream education for disabled children:

Key 3: No, not special schools because you will always be with disabled people when you finish school that's when you must meet normal (*non-disabled*) people and it's so difficult. People are always looking at you and you can't even address [express] yourself. But when you learn with able people you are strong and you are not shy.

Key 4: When children with disabilities are able to attend mainstream education, they should not be stopped ... you find that parents are very protective of their disabled children. There are all sorts of things like school learners will push you and you fall or they will laugh at you. In my case the opposite happened, the learners were supportive, they would assist me to sit, to carry my bags even without asking them.

Key 7: Learning at mainstream school was a good thing because people with disabilities should not be treated differently from society, they must be inside with other people as well so that people will get familiar with them.

The above quotes demonstrate that mainstream schooling is preferred by many because it provides the much-needed interaction between disabled and non-disabled young people, in a way that special schools do not. Yet, mainstream schooling is not suitable for all disabled children, especially those with severe forms of physical disability. Contrary to parents' fears about disabled children being teased at mainstream schools, Key 2's positive experience testifies against such a problem being universal. It is apparent that most disabled young people do not like the isolating experience provided by special schools. They would rather interact with non-disabled peers and share the same educational experience. Consistent with these findings, Albert (2005) found that education at special schools isolates disabled children from

society and society from disabled children. He also found that such education is more costly and focuses on vocational rather than academic subjects. In spite of the negative perceptions about special schools, Key 2 felt there are particular circumstances when special schools may be necessary as stated below:

There are special cases where you find disabled children with serious conditions they cannot fit schooling in mainstream so they need special schools.

Key 2 raises a point, which needs to be borne in mind when planning for inclusive education. Research into the role and effectiveness of disability legislation in South Africa, found that there are many disabled children in mainstream schools who seem to be 'dumped' there because there are not enough special schools to accommodate all disabled children (Albert, 2005). This finding is in contrast to the aim of inclusive education, which calls for the development of a system that is open to change so as to accommodate all learners that are able to participate as equal members of society (Struthers, 2005). This means recognising that special schools and mainstream schools need to be transformed in order to enable them accommodate learners of diverse needs.

For this reason, specials schools would still be needed for dealing with severe levels of disability. At the same time, attention needs to be paid to the curriculum at special schools so it is comparable to mainstream education. There needs to be a balance between the provision of mainstream and special schools for disabled children depending on the nature and severity of disability.

### **5.3.2. Perceptions about other Social Services**

The basic education obtained at special schools did not help any of the participants in the present study to secure skills training or gainful employment. Apart from limited opportunities available to this group for further education, it is evident that basic education is not enough to empower



disabled young people to seek vocational training and other social services necessary for their development. Consistent with this observation, UNICEF (1995) states that, worldwide, disabled young people are at higher risk of unemployment, partial employment or full employment at lower wages than adult workers. Adolescents with disabilities are at even greater risk of unemployment as they come on to the job market with little education and few or no skills and so have difficulty competing (UNICEF, 1995). Participants' experiences about training and job opportunities are presented below:

Lindiwe: If that person will be more than 23 years by the time he/she is doing matric he/she does not fit to be in school. That has a detrimental effect to the boys and girls because there is nothing else to do apart from education. There are no training facilities where they can be trained to do certain jobs.

Philisiwe: First of all disabled young people need jobs, education, gospel music and activities because they have time to go to activities like football and netball ... but there is no place for them to go and play. In some cases you can join mainstream, in some cases you cannot because they are so far and you have no transport.

While Lindiwe underscores the importance of education in facilitating opportunities for any job training, she also points at the limitation of the special education system that does not give consideration to the fact that disabled young people start schooling late in life so that by the age of 23 most have not completed matric. Chances for training are very limited for those with little education. Philisiwe expressed the need for gainful employment and pointed out the difficulty of access to recreation facilities that are situated outside Nyanga, with regards to public transport. Key 6 reported one-off vocational training programmes supported by DPSA, which have not lasted beyond the implementation phase because of funding problems:

Key 6: Look, we had a programme where we did training ... We had computer training for young people with disabilities to help them get employed ... because of the marginalisation of people with disabilities in the past, they were not properly prepared to access the employment market ...

Limited educational opportunities have dire consequences in terms of disabled young people's ability to access all other services like training and employment and access to health services. Besides there are not many facilities that offer skills training for disabled young people anyway. Furthermore, most companies have architectural barriers that do not allow them to employ people with mobility problems:

Key 7: ... It is difficult really to be disabled because in the first place companies in this country do not adapt their situation to suit people with disabilities. I mean accessibility in terms of their buildings and tables for people with wheelchairs ...

Key 6: There is a disabled woman who is doing leadership training for disabled young people at the moment ... she is in a wheelchair. 'Daly ride' (*special buses for people with disabilities*) can't always provide her with transport ... she makes use of a taxi and a train ... and that is very problematic because trains are not accessible for people with disabilities.

Lack of accessible transport and recreation facilities are some of the contextual factors that hinder the integration of disabled young people into mainstream society. Key informant 5 is a retired schoolteacher who summarised her perceptions of life for young people in Nyanga as follows:

There is nothing good for young people in Nyanga. Maybe if they were involved in clubs to take them away from the streets. Also things like soccer, music, netball and all that; I am sure some of the things would be controlled. Some of them want to go school, but their parents have no money, so they need something else to do. A summary of life for young people in Nyanga is about beer drinking, rape, scolies [thugs] carrying guns around, using drugs, hi-jacking cars and killing their owners. Burglaries are common here too; they break into houses, steal and kill.

Given the above picture of a risky environment in which disabled young people are growing up, positive and negative experiences of disability have emerged. In spite of their difficult circumstances, some have overcome risks and seek opportunities to better their lives. Yet others have succumbed to risks because of circumstances beyond their control. Consistent with this finding, it has been pointed out that the lack of infrastructure, services, and

accessible transport for disabled people living in townships contributes to making life difficult for them (Schneider *et al*, 1999).

### ***Summary of Theme Two***

Educational scripts are manifested through special schools (public invisibility) and mainstream schools (public 'visibility'). Such scripts lead to high risk as they do not pay off in expected ways. Although the two school systems have positive and negative aspects about them, participants favour mainstream education, which does not isolate them. It is evident that limited educational opportunities have a bearing on the development of disabled young people in terms of accessing tertiary education, skills training and job opportunities and other social services. Although mainstream schooling is ideal, participants have pointed out the need for special schools to cater for those with severe disabilities.

## **5.4. CONCLUSION**

In this chapter, I have demonstrated that disabled young people's experiences of growing up in Nyanga are precarious in many ways. It is evident that the different belief systems are responsible for the different ways of understanding disability, which are responsible for the diverse ways in which society treats this population, positively and negatively. Disabled young people respond by adopting fluctuating identities that allow a few to assert themselves and develop resilience, while the majority fall victims to their precarious circumstances. In this chapter, I have also highlighted the fact that Nyanga is a risky environment because it does not provide the necessary amenities for disabled young people's development. The socio-economic circumstances of Nyanga expose these young people to poverty and its consequences. In particular, the limited educational opportunities that have a bearing on how this population accesses job training, gainful employment, recreation and health services.

In the next chapter, I demonstrate how disabled young people's experiences and perceptions of sexuality and HIV/AIDS are directly influenced by their

experiences of growing up with a physical disability, in terms of the cultural beliefs and socio-economic circumstances of Nyanga.



## CHAPTER 6

### FINDINGS: SEXUALITY AND HIV/AIDS IN THE CONTEXT OF DISABILITY

#### 6. INTRODUCTION

In this chapter, the paradox of risk is explored as it is manifested in disabled young people's experiences, and their perceptions of sexuality and HIV/AIDS. In particular, I look at the ways in which the construction of disability and the poverty situation in Nyanga affect disabled young people's expression of their sexuality. The common risk factors that this group is exposed to and the way they have responded to the pandemic in general and to the threat of the HIV/AIDS risk in particular are described. Lastly, the extent to which disabled young people have access to formal and informal sexuality education, sexual and reproductive health, and HIV/AIDS and support services is investigated.

Chapter 6 is presented in response to the following main objectives (see section 1.6):

1. Objective 2: To identify specific contextual and individual factors that increase disabled young people's vulnerability to HIV/AIDS risk.
2. Objective 3: To describe disabled young people's response to the HIV/AIDS pandemic and the threat of HIV/AIDS risk.
3. Objective 4: To recommend HIV/AIDS intervention strategies that would be inclusive of disabled young people's needs.

These objectives are presented in detail before each main theme under which they are explored. The four main themes include the experience of sexuality, risk factors for HIV/AIDS, response to the HIV/AIDS pandemic and perceptions about the threat of HIV/AIDS risk. Each theme is explored in depth using sub themes as detailed below.

Figure 3: The experience of sexuality

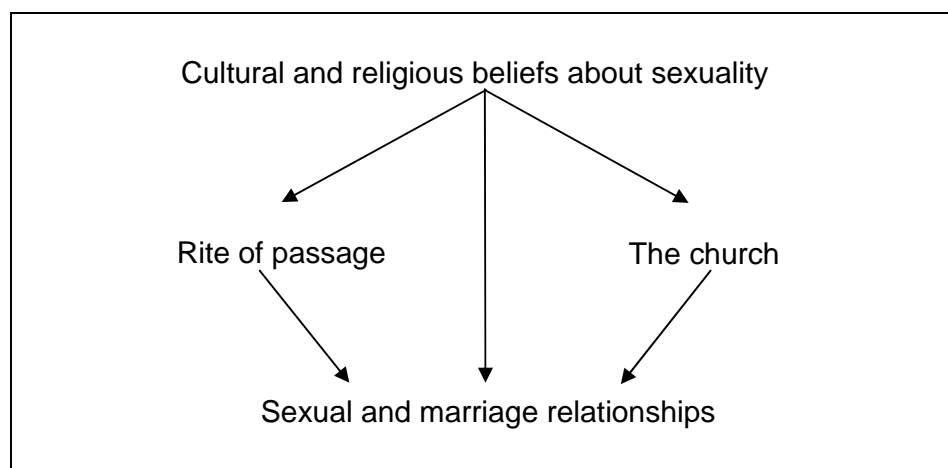


Figure 3 shows that sexuality is socially constructed by cultural and religious beliefs (rite of passage and the church). Such constructions determine how disabled young people are socialised to express their sexuality, in terms of the cultural risk and protection factors supporting or hindering their involvement in sexual and marriage relationships. The theme represented by figure 3 was generated in response to the second objective of this thesis revisited below:

## **Objective 2**

To identify specific contextual and individual factors that increase disabled young people's vulnerability to HIV/AIDS with regard to:

1. Cultural beliefs or scripts regarding sexuality and HIV/AIDS in the context of disability.
2. The spectrum of risk and protection factors, including family influences, political, economic and individual factors.

### **6.1. CULTURAL BELIEFS ABOUT SEXUALITY**

Participants were asked to describe what they know about sexuality matters and to state their sources of such information for the same. Although most responses focused on cultural beliefs that promote silence and consequent ignorance on the subject, others provided alternative ways in which disabled

young people get such information. The view that culture promotes silence on the subject of sexuality was described in Chapter 3, stating that in most African belief systems sexuality is considered a taboo subject and that, as such, intergenerational discussion on the subject is prohibited (Caldwell *et al*, 1998; Van Dyk, 2001). Participants' responses confirmed the above findings, indicating that in the Xhosa culture, parents are not allowed to discuss sexuality matters with their children because it is taboo to do so:

Zandile: No-one (*told me about sex*)...my mother told me to clean the house and to wash myself when I have my periods ... I wash my own clothes and clean the yard.

Bonginkosi, 18 year-old male, and is in grade 9 at a special school: My brothers told me (*about sex*)...basically ancient (*adults*) people do not discuss such things with us ... Bonginkos's brother who was present during the interview added: in our culture, parents do not speak to their children about sexual issues.

Both participants found it difficult to mention the word sex. This difficulty is evidence that the subject of sexuality is taboo, therefore, generally not discussed between parents and their children in the Nyanga community. From the parents' point of view, it is apparent that concerns about personal hygiene for their daughters during menstruation and maintaining cultural proscriptions about sexuality discussion are more important than the right of disabled young women to receive sexuality information. However, culture provides for other members of the family to give such information like the case of Bonginkosi, whose brothers taught him about sex. Other participants reported that they rely on friends and older siblings for sexuality information or they discover sex on their own. This finding is in line with Nosek *et al's* (2001a) revelation that most disabled women do not receive any information on sexuality except through reading and sometimes sexual violence. Parents in focus group discussions agreed with disabled young people about cultural scripts, but also indicated their own difficulty or shyness to discuss the subject with their children as indicated below:

FGD 5: In our culture, it is hard to talk about sex with children.

FGD 5: I do have my fears ... it is also difficult to talk to your own child about sex

This matter was then brought to key informants who shared the following:

Key 3: Parents are very shy, but at the end of the day they are getting problems with their children; because they have got friends who tell them ... You must have a boyfriend, you must have sex and now they do it wrong ...

Key 5: In our culture, we don't talk to children about such things ... we just let them be. We think by keeping quiet, and then our children don't know anything. But when they go out into the street, they will get wrong teaching ...

The above quotes demonstrate that parents assume that silence about the subject will keep disabled young people away from sex. On the contrary, the reality is that silence breeds curiosity that compels this group to either get information from anyone or to go out and discover sex by doing it. As a result, disabled young people engage in sexual activities without prior knowledge about the responsibilities or the dangers associated with their actions. Some key informants confirmed the cultural silence about sexuality, but pointed out that disabled young people who go to school and those who are brought up by their aunties and grandmothers, rather than by their own parents, are getting some teaching on the subject as stated below:

Key 3: My daughter (niece) knows that I am wearing pads; I speak to her about sex and AIDS. I say first thing is education, sex before marriage is wrong. You have to respect your body and finish your studies.

There is a sense in which cultural and religious teaching implies that sex out of wedlock is a shameful thing to do. Hence Key 3's advice to her niece that she should respect her body by avoiding sex before marriage. Meanwhile, Key 5 feels for disabled children who do not go to school, as they may not receive any sexuality information if they do not have older siblings or other family members to consult:



Key 5: Sexuality is now being taught in schools. So those who do not learn from home, learn from school. For those who never went to school, then it's too bad, nothing can be done.

Based on above quotes, the role of aunts and grandparents in teaching sexuality matters needs to be investigated further and strengthened to make up for the lack of parental involvement on the matter. It was pointed out earlier that disabled young people, especially disabled girls have limited opportunities for education. This situation, coupled with living in Nyanga without the extended family support system, places disabled young women at added risk of being excluded from any teaching on sexuality. This is because young men in Nyanga continue to benefit from protective cultural teaching compared to disabled young women, who do not.

#### **6.1.1. Rite of Passage**

Culturally, and historically, many African people, including the Xhosa-speaking people have used initiation ceremonies to mark the transition of boys and girls from childhood to adulthood (Carstens, 1982). Among other rituals, initiation ceremonies include teaching about sexual matters, marriage and responsibilities. However, participants reported that initiation ceremonies for girls are no longer practiced in Nyanga, while boys still undergo circumcision. Consequently, girls miss out on traditional teaching about transition to womanhood and boys benefit from the same as stated:

*Xolani, a 24 year-old male with cerebral palsy, he uses a wheelchair and works in the protective workshop: Circumcision is our culture...it is given to help you not to depend on your parents any more...when you are circumcised you are grown up and you should be independent.*

All male participants in the current study expressed satisfaction that they had undergone circumcision, but they were not prepared to divulge their cultural secrets on the subject except that it helps them to be independent. This independence also means that after circumcision they are ready to marry

should they wish. But disabled young women had different experiences as illustrated below:

Nomthandazo: I did not do *intonjane* (*female initiation ceremony*). My mother taught me...she told me I am old now when I got my period...so I must look after myself... do not sleep with a man, otherwise you will get pregnant...

Nomthandazo did not undergo *intonjane* because she grew up in Nyanga where the practice has stopped. It is apparent that Nomthandazo's mother is more concerned about preventing her daughter from having an unwanted pregnancy rather than contracting a sexually-transmitted disease or HIV infection, which she does not mention.

Philisiwe, a 24 year-old with post polio paralysis of her right leg: There was *intonjane* at Eastern Cape, but my mother was strict, so I did not go to *intonjane*. *Intenjane* had boys there ... may be they rape you so it's better to stay here (*I thought intenjane was only for girls?*) sometimes there are boys there and they rape other girls ...

Philisiwe grew up in a rural area and was actually stopped from participating in *intonjane* by her own mother for fear that Philisiwe might be raped. The concern about the risk of rape at the initiation ceremony arises from the fact that, traditionally, among the Xhosa speaking people, there was a permissible pseudo-sexual intercourse known as *metsha* that was practised at such ceremonies (Laubscher, 1975). It was practised from pre-adolescent age and was performed by placing the penis between the fleshy parts of the thighs which were then pressed together. Custom forbade that the penis be placed too close to the genital organs. However, there was always a possibility that some men would go beyond the prescribed *metsha* practice and deflower the girls, hence the stated concern. Such practices might contribute to the secrecy surrounding the female initiation ceremony. The above responses from disabled young people were brought to members' parents and senior citizens in focus group discussions for clarification. These groups were asked to explain what *intonjane* is all about and the following were some of their responses:

FGD 7: ... Some people say you can seek for it (*intonjane*), if you don't, you just do bad things. Like I can pee (*wet the bed*) at night or do something wrong in my marriage so older people say it's a sign that you need *intonjane* ... that old lady who is in charge of *intonjane*, we call her *inkazana*, but there is a man called *Dindala* ... that *Dindala* looks for everything that is short (*supplies*), what they need, they have to tell him.

It is ironic that a man was appointed to oversee at a female ceremony and yet women do not have a role to play in ceremonies for men. However, traditionally, *Dindala* was the man who was appointed to keep order at the female initiation ceremony. He was supposed to make sure that the *metsha* ceremony, described above, would be carried out without breaking the rules (Laubscher, 1975). Participants found it very hard to explain what *intonjane* is:

FGD 7: I can't really say what it is for ...it's part of your health. Like the boys from the age of 18 years upwards, they have to go to the *Umkhweta*. It's like when I am sick; I have to go to a doctor. When you come from *intonjane* you feel right because there is a change ... something changes ...

Although surrounded by secrecy and mystery, it appears that the female initiation ceremony served more purposes than transition to womanhood. Married women could choose to go for the ceremony to learn about cultural norms or to be healed of illnesses. Key informants were asked to contribute on the subject and most stated that they never went through the process themselves, but others shared their views as follows:

Key 4: It is the rule, it is culture (*intonjane*). There are things that are taught there that those who have not been will never know. I cannot say it because it is my culture ... *Intonjane* can't happen here in the cities, there is no kraal, it used to happen in the Eastern Cape, in the rural areas; but circumcision still happens here ... because the people who do it are all here.

Key 5: I actually don't know anything about that. I did not do *intonjane* because I grew up in town. Even in the Eastern Cape, they do not practice *intonjane* now. It was done in the early 1900s ...

Urbanisation seems to have contributed to the disappearance of the female initiation ceremony because of lack of culturally-prescribed venues for the

same. In the absence of cultural social control, the ward councillors reported that the population of Nyanga is mostly Christian, as such, the church plays a major role in regulating the social behaviour of its members.

### 6.1.2. Perceptions of the Church

Participants reported that most churches are silent about sexuality matters except to emphasise absolute abstinence before marriage. Some churches discourage disabled young people from associating or socialising with non-disabled peers, lest the non-disabled corrupt disabled young people's minds by introducing them to sex and the whole subject of sexuality. Such teaching contributes to driving disabled young people into further social isolation as stated below:

FGD 4: (Zion Church): In my church, my child, they are taught how to conduct themselves (*abstain*). They are told about all these things...that is why my child sits in the house all day because she has been taught these things.

FGD 4: (Gospel Church): They are all taught the same thing [*abstain*] that they must not go around...they must not do all these things (*having sex*).

FGD 4 (Zion Church): They warn young people, that you must know how to conduct yourself. You must not do all these things (*abstain*). When they come back from the choir they must do house chores and not go out.

FGD 4 (Converted Church): They don't talk about such things (*sex*)

It is evident from these quotes that silence and total abstinence is promoted by most churches. What is obvious too is that the church does not provide alternatives for disabled young people to express their sexuality responsibly, which leaves them with no choice but to engage in risk-taking sexual behaviour. Participants refer to the subject of sexuality as 'these things' because mentioning the word sex is culturally inappropriate.

### 6.1.3. Sexual Relationships

A combination of the social construction of disability and sexuality leads to social stereotypes and prejudices against disabled young people's sexuality and sexual expression. Participants reported that most parents do not allow their non-disabled sons and daughters to date disabled young men and women because of stereotypes about this group as expressed below:

Themba: They told their daughters they do not like me because I am disabled. When the mother of one girl died, her sisters started liking me ... they changed their mind when they saw that their sister was not going back on me. Their friends told them never to separate two people who are in love because they do not know what is between them.

However, disabled young men are not without their own prejudices against dating disabled young women, whom they perceive as physically unattractive and unsuitable as possible partners. Thus, disabled young women are doubly discriminated as disabled, and as unattractive women:

Nceba: to be honest I have only gone out with one disabled girl, as for non-disabled girls, the number is countless ... laughter ... First of all you look at the physical attraction and you ask, can she make me happy in bed? ... Secondly you look at the relationship and after that you are tired (you go for another one).

Nceba's perceptions about disabled girls as unsuitable partners are shared by disabled and non-disabled men alike. This finding was raised in Chapter 3, where Nganwa *et al* (2002) indicate that disabled women are not considered attractive because of their visible disability. Consistent with the notion of beauty, Nganwa *et al* (2002) point out that in Africa beauty lies in physical appearance and strength, and not necessarily in beauty of soul. For this reason, only women who fit the stated definition of beauty are likely to be considered for marriage. However, some disabled young women have difficulty forming sexual relationships for the reasons expressed below:

Mcumisa, a 17 year-old female with cerebral palsy: I have one who is after me, but I am afraid to say yes. I am afraid of my parents ...

Another disabled young person who participated in FGD 1 expressed similar sentiments:

FGD 1: It's hard for me (*to form sexual relationships*) because I am afraid that boys would like to sleep with me then leave me.

From the above quotes, it is evident that a combination of parental prohibitions and individual factors make it very difficult for disabled young people to secure partners and to form sexual relationships. Widespread beliefs within families and society about disabled people's asexuality and perceived lack of interest in sexual relationships, or their lack of ability to perform a sexual act, are additional barriers to forming sexual relationships by this group (Shakespeare, 1996). Even key informants concurred with the idea that parents do not allow disabled young people to engage in sexual relationships:

Key 7: My parents were not saying anything about sexuality issues. To be honest people were not interested in me falling in love and having sex because they were telling me how are you going to do certain things (*sex*). When I am trying to enter that department, really the world was pushing me away from (*love and sex life*). Girls were interested to be with me, but not interested to fall in love with me because I am disabled, but God; I am a person like you.

Here, a combination of parental prohibition, the belief about disabled asexuality, and discrimination on the grounds of a visible disability all contributed to denying Key 7 opportunities to date. These issues are further elaborated below:

Key 3: Parents of disabled kids are very shy to talk about sex and sexuality things. They know that their children have sex because it's normal. Then they say disabled girls who like men are amahule (*prostitutes*). It's not like that, each and every person must have a partner, it's natural.

Key 3 raises paradoxical issues on two fronts. Firstly, parents know that it is normal for their disabled children to engage in sexual activities, yet they do not discuss the subject with them. Besides, should parents or society notice that these disabled young people are sexually active, then society labels them as prostitutes. Secondly, it is a cultural expectation that everyone should have a partner, yet any attempt by disabled young people to secure one is sneered at. Consistent with such paradoxes, Kroll and Klein (2002) describe a common misperception of disabled people's sexuality, which assumes that they are perverse, oversexed with uncontrollable urges. While Shakespeare (1996) asserts that, according to society, disability and sexuality are incompatible, disabled people are not expected to have sexual lives. Yet in spite of such negative perceptions, this group are still considered easy targets for sexual favours.

#### **6.1.4. Marriage Relationships**

Traditional Xhosa and religious belief systems revere the institution of marriage. To this end, sexual intercourse is supposed to be reserved for procreation in a marriage relationship only (Van Dyke, 2001). Similarly, children represent future wealth for their families, as they do not only carry the family name forward, but they are also expected to look after their parents in old age. Yet disabled young women in the current study are socialised to believe that sex, marriage, childbirth and rearing children are not good for them. Consequently, most disabled young women seem uncertain about their need for marriage as stated below:

Lindiwe: No, I do not want to marry him although I am staying with him in his parents' house...I am not sure I want to marry him. [*She was forced to live with her boyfriend after she fell pregnant*].

In spite of general sanctions against disabled girls getting married, when they fall pregnant out of wedlock, like Lindiwe did, then the barrier is lifted.

Nomthandazo: Whether I marry or not it's my boyfriend's choice. [*lacks self-esteem and confidence to state her case on the subject of marriage*].

Sibongile, a 23-year old with cerebral palsy, working in the protective workshop: answered with a tone of irritation in her voice - I have no boyfriend ...I don't want him ...I don't want to marry ... I don't want children ...I want to be alone. [*demonstrates the consequences of being socialised to perceive men negatively*].

The above quotes show that these participants are not sure about their need for marriage. This uncertainty is a direct consequence of the way they have been brought up and taught. Fine and Ash (1988) and Begum (1992) observe that disabled women in the developed and developing worlds are erroneously perceived as child-like and asexual or less attractive and less able to carry out the physical labour expected of wives within the household. As a result, there is often little expectation that women with disabilities will marry. Helander (1993) states that in many countries marriage to a woman with a disability is opposed by both families. This is because of the belief, among other things, that a disabled woman is likely to produce defective children (Ingstad and Whyte, 1995). Some parents reinforced female participants' uncertainties about marriage as illustrated by the following quote:

FGD 4: No, I don't want her to get married and my daughter does not want [at which point the daughter (*Vuyiseka, who participated in the interview nodded in agreement*)].

It is certain that some disabled young women, do not have support from their parents to get married. This means they are left with no choice except to express their sexuality secretly or easily succumb to abuse in their search for intimacy. Such behaviour increases their vulnerability to contracting HIV infection. This situation is in contrast to that of disabled young men who not only have the freedom to make choices about their sexual lives, but their parents allow them to express their sexuality and to choose who to marry as illustrated below:

FGD 6: I wish him to get a family of his own ... also disabled, but not physically disabled like him so she can help to push his wheelchair ... it does not matter the disability ... deaf at least. If she is disabled ... has good knowledge of disabled. You think about it from your heart ... you understand the other person.



This parent in FGD 6 expressed the wish for her son to marry a fellow disabled woman who would assist him through his physical limitations. This wish implies that marriage is not necessarily considered for companionship but to carry out activities of daily living for the benefit of the prospective husband. The issue of marriage was brought to key informants for their opinion as expressed below:

Key 2: We all have sexual feelings as people with disabilities. We need to be loved and we want to love our partners ... we want to have wives, marriages or something like that. Families would like to see their disabled children married one day you know ...

The idea that parents would like to see their disabled children marry probably applies to disabled young males only, for the reasons given above.

Key 7: When you meet a person with disabilities you marry her and when you meet a normal person, you just marry. But I don't appreciate to marry a non-disabled person ... because she might think that she is doing you a favour by marrying you. There are a number of normal people who marry disabled people and betray them by going out with many boyfriends ...

Although Key 7 suggests that it is all right to marry disabled or non-disabled partners, he still expresses reservations about disabled young people marrying non-disabled persons. To this end, Key 7 indicated that his girlfriend also has a physical disability like him.

### ***Summary of Theme One***

I have demonstrated that sexual scripts lead to public invisibility of disabled young people, which in turn, leads to high risk of vulnerability. In other words, the sexuality of disabled young people is characterised by silence and strict cultural and religious control, yet there is also lack of social control as disabled young people find ways of expressing their sexuality in secrecy. Paradoxically, both situations prevent disabled young people from expressing their sexuality openly or engaging in sexual and marriage relationships. Such barriers are experienced more by disabled young women than disabled young men.

## 6.2. RISK FACTORS FOR HIV/AIDS

As demonstrated in Chapter 3, all the factors identified as increasing the risk of young people in general contracting HIV/AIDS have also been identified in the current study to be true for disabled young people. However, the significant difference is that disabled young people in the current study live in a particularly risky environment that is poor and characterised by high crime rates. As such they face a double risk of contracting HIV/AIDS because of the social conditions they live in and the special circumstances created by disability as demonstrated below.

Figure 4: Risk factors for HIV/AIDS

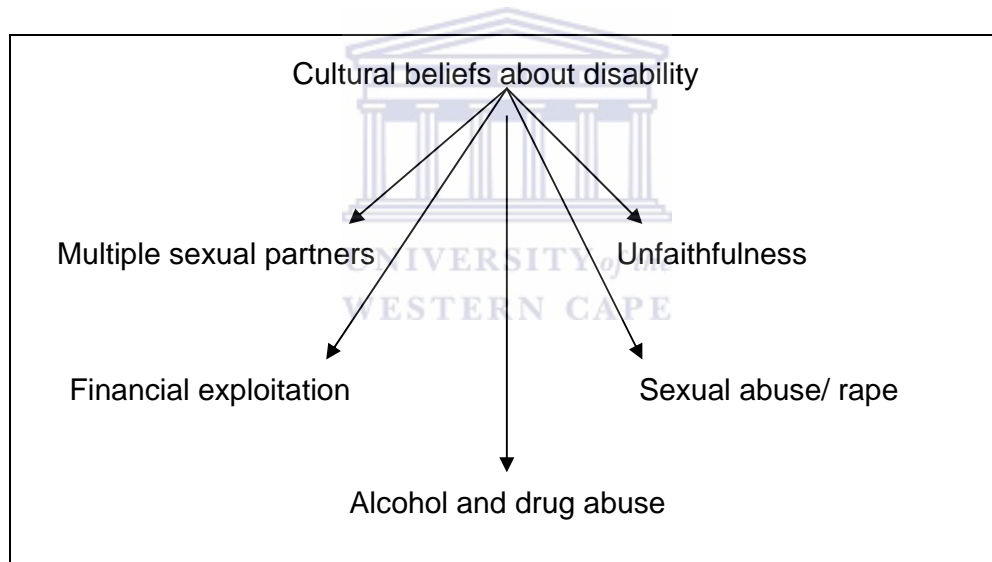


Figure 4 illustrates the specific contextual and individual risk factors identified in the current study as responsible for increasing disabled young people's vulnerability to HIV risk. The cultural scripts and poor social conditions under which this group lives in Nyanga not only expose them to financial and sexual abuse, but they also drive them to engage in risk-taking behaviours such as alcohol and drug abuse and engaging with multiple sexual partners. Such situations increase their vulnerability to HIV risk.

### 6.2.1. Multiple Sexual Partners

Participants were asked to name HIV risk factors that they are exposed to. They pointed at some of the issues that were raised in the previous section. In particular, disabled young people's difficulty in securing sexual and/or marriage partners, and the belief that they are asexual. These factors lead disabled young women to engage with multiple sexual partners in a search for affection. Some male participants indicated that being teased about their manhood drives them to sleep with many partners in order to disprove the misperception about their asexuality, but also to prove their manhood. Others consider sleeping with many girls as a play activity. Such considerations seem to take precedence over any precautions against contracting HIV infection as illustrated below:

Thembaletu: If you ask to go out with a girl, she always asks, "Can big daddy stand up?" (*erection*). Sometimes they will say no because they think that big daddy cannot stand up. Sometimes they will speak out and say, "I do not want to waste my time", like they are teasing you, but the message has been passed (*that you are impotent*). Some of your actions (*sleeping with many girls*) are to prove yourself that you are capable of having sex and children.

Nceba: Before I knew about AIDS ... to say I am a man meant I can score (sleep) with as many girls as possible just for 'sexual healing'. The thing of having a relationship with that girl does not occur to your mind yet.

'Sexual healing' is the pleasure derived from sex as a play activity. There is no sense of obligation or responsibility or punishment that goes with such behaviour. Nceba is certainly unconcerned about the risk of contracting HIV through his perceived play activities. In contrast, Xolani shared, with difficulty, the number of girlfriends he has had in the past:

Researcher: How many girlfriends have you had in your life?

Xolani: I have 1 girlfriend only.

Researcher: But you said you broke up with your first girlfriend and now you have another one?

Xolani: Yes, I have had 2 only.

Researcher: I still think you are not telling us the whole truth, what are you hiding?

Xolani: ... *laughs* ... What have you heard?

Researcher: I have heard about your child.

Xolani: ... *laughs again*...ok I have had 3 girlfriends.

Researcher: You do not have to be going out with all of them now; I just wanted to know the past if I may?

Xolani: I have had 6 girlfriends.

Although tolerated in the Nyanga community, having multiple sexual partners is still considered shameful, hence the difficulty Xolani had in revealing such personal information to us. When the question of risk factors was brought to key informants, they agreed with the experiences shared above and blamed both disabled young people and society as follows:

Key 3: I think it's a big problem (*sexuality*). I think disabled people challenge it wrong. They fall in love because they want to show people that we can do it also (*have sex*). These people take a chance; they want to see if we've got the same thing as them (*genital organs*), it's where AIDS starts. There is no love, they are really abusing us.

It is apparent that the potency script denies the sexuality of disabled young people, which leads to high risk of vulnerability. In their quest to dispel misconceptions about their sexuality, some disabled young people engage in risk-sexual behaviours, which increase their vulnerability to sexually-transmitted diseases including HIV/AIDS.

### **6.2.2. Unfaithfulness in Sexual Relationships**

Unfaithfulness in sexual relationships applies to engaging in more than one sexual relationship at the same time or having other lovers aside from a stable partner. Unfaithfulness appears to be a worldwide phenomenon driven by the need for men to prove their manhood in the wake of changing patterns of men/women relationships that call for gender equality. But in some African societies, it is considered a norm for men to engage with multiple sexual partners, while women are expected to be faithful to one sexual partner (Shisana, 2004). Such double standards in sexual relationships continue to

place both men and women at risk of contracting HIV infection as expressed below:

Themba: Yes, I am still going out with three girlfriends. We are still calling each other with the mother of my baby, but you cannot believe things on the phone (*she is in Johannesburg*). The one who aborted my baby from peer pressure is also good. She has good qualities for a wife. This one who is about to get married ... it's a bit difficult, I might lose.

Themba speaks about his three girlfriends with ease and quite oblivious of the risk of contracting or transmitting HIV infection. He even takes pride in the power he has over these non-disabled girls in the face of sanctions against dating them by some of their parents. In spite of their knowledge of each other and the fact they are being cheated on, none of the girls seemed courageous enough to break the relationship or to practice safe sex. One of them has a child by Themba, another one has aborted his child and the last one was pregnant by another man whom she was about to marry, yet the engaged girl was still dating Themba in her pregnant state. It is also worth noting that Themba is one of the few participants who is well versed in the facts about HIV/AIDS, the paradox is that his sexual behaviour is nevertheless not driven by what he knows about the risk, but by his need to prove his sexual abilities to the three women in his life. Even some members of focus group discussions perceive such behaviour as normal among human beings:

FGD 2: You get these disabled guys like any other human being they go for one-night stand, get their satisfaction, after that say tomorrow, there is nothing anymore, they go for another one. People are always the same.

The above quote represents some men's perceptions about the matter. Disabled young women are concerned exactly about what their male peers think are play activities as shared below:

FGD 2: They (*disabled young women*) get AIDS because of these boys roaming around (*unfaithfulness*). Sometimes a disabled lady believes in this guy ... this guy has many girlfriends and so he will come back to the disabled girl and infect her ...

FGD 2: You trust your husband (*partner*), you wake up in the morning and see him going to work and back, whereas he is with another woman all this time ...

Female participants blame their own vulnerability to HIV risk on men's unfaithfulness and irresponsible sexual behaviour. However, most participants think rape is one of the biggest risk factors for HIV/AIDS among disabled young people in Nyanga.

### **6.2.3. Gender Differences - Sexual Abuse**

Differences in social norms for rearing girls affect disabled young women's ability to control sexual situations, thus making them vulnerable to gender-based violence and coerced sex (UNICEF, 2002). Sexual abuse is considered a big problem in Nyanga, but more so for disabled young women. Contextual factors such as socio-cultural scripts and poverty contribute to high rates of sexual exploitation and rape. For example the belief that it is impossible to ignore an erection, places pressure on some people to rape the vulnerable members of the community, such as disabled young women.

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In addition, in a patriarchal Xhosa culture, women are expected to be submissive to men and have no power to negotiate a sexual activity, let alone safer sex (Shisana and Simbayi, 2002). Thus women remain at the mercy of their sexual partners. Makeshift housing that characterises accommodation for the majority of people in Nyanga can easily be broken into by perpetrators of rape. Disabled young women's inability to escape from the confines of their parents' shacks, or any other compromising situation, is another factor that increases their vulnerability to sexual abuse. These findings are consistent with what was described in the Global survey conducted by the Yale University (Groce, 2003); see also (section 3.2), which found that disabled women are more vulnerable to sexual abuse because of their inability to escape dangerous situations. Participants shared their experiences as follows:

Philisiwe: Every disabled person is at risk of being raped. Even when you are walking with crutches, you must be with someone always, don't walk alone.

This quote paints a grim picture of disabled young people's safety, suggesting that they must always be accompanied everywhere for fear of being sexually abused. It is for this reason that I have chose to label Nyanga a risky environment, as pointed out in Chapter 1. If it were a safe place, there would be no need for disabled young people to feel unsafe on its streets. Based on the ICF, an unsafe environment is a barrier to disabled young people's privacy and their right to freedom of movement. Nceba points at illiteracy as another contributing factor to risk of rape:

Some of them (*disabled young people*) are illiterate; the level of your education helps you to know what to do and not to do. Some of them are abused at home by family members. That family member might have HIV and other girls no longer accept him for relationships because they know his status. So he goes to the disabled, saying, I won't die alone with this.

Nceba implies in the above quote that the educated disabled young people are more capable of asserting and defending themselves from sexual exploitation compared to their uneducated peers. Yet it was revealed in Chapter 5 that disabled young people have limited access to education, which means the majority of this population may not have the skills (acquired through education) to defend themselves. Participants reported that most times, familiar people or family members abuse disabled young people within the 'safety' of their parents' homes. Such incidents go unnoticed because disabled young women are too afraid to report for fear of further punishment by their abusers. Failure to report rape means that perpetrators of this crime escape unpunished. Below are participants' views on the subject:

Philisiwe: Disabled girls are raped more than non-disabled girls ... there are different disabilities, the intellectually disabled can't remember who do that to them. If you are physically disabled you are in danger also because you can't run, somebody can grab you and rape you.

Given the widespread experiences of rape among disabled young women in particular, it can be inferred that sexually-transmitted diseases including HIV infection might be widespread among this group. Without prevalence studies or disabled young people seeking sexual and reproductive health care, such assumptions cannot be confirmed. Parents agree that rape is a big problem in Nyanga as stated below:

FGD 4: Rape is very common here ... sometimes my own husband can abuse my child.

FGD 4: We are very worried because our children are disabled and they can be raped by people they do not know [who would infect them with the virus].

While some parents agree that rape is a big problem in Nyanga, their own response is that of helplessness as they appear powerless to stop the abuse. As a result, both parents and their disabled children live in constant fear of rape as illustrated by the following participants:

FGD 5: Yes, this is a big problem to me because I work, when I am at work maybe someone can come to rape my daughter (*and infect her*).

FGD 5: It's hard; there is nothing I can do. The only thing I do is watch over my child. When I am not there, I must make sure who gets in the house because anything can happen ... I know some people can come and rape her.

These parents appear helpless to do anything about their situation. In such circumstances, ignoring the problem can actually be a way of coping. Thus parents live in the hope that their disabled children are safe. The absence of formal or informal intervention programmes to stop or control rape, reinforces parents' helplessness about their situation. Occasionally, action is taken against perpetrators of rape as expressed here:

FGD 6: Yes, there is a disabled young girl that I know. She was left alone in the house and asleep, a man entered and raped her. The whole community know the story ... the matter was reported to police and the man was arrested.



In this thesis, sexual violence and rape are considered as contextual or community rather than individual disabled young people's problems alone. This means that in order to intervene, the whole Nyanga community needs to be targeted and supported to fight such crime. This view is supported by Parker (2001) who points to the importance of focusing on a complex set of social, structural and cultural factors that create situations of risk in every community. Such a wide focus is the only way to reach perpetrators of rape, with appropriate education about the seriousness of rape and/or the application of the justice system. Vuyiseka shares her experience of sexual abuse by a family member:

Vuyiseka: When my mother is not at home, he (*mother's partner*) used to call me to the bedroom and ask me to play with his private parts. When I am bathing, he also used to come to play with my private parts until I told my mother. *Vuyiseka's mother agreed with her daughter and added: My boyfriend's brother raped my own daughter some 4 years ago in my own house and he is now in prison for 8 years ... then my boyfriend has been abusing her also, it is difficult.*

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Vuyiseka could not remember how many times she had been sexually abused before she reported the matter to her mother.<sup>11</sup> During this time she might have contracted HIV infection. In the absence of HIV prevention services for this population in Nyanga, Vuyiseka does not know her HIV status.

Furthermore, 'date rape' or coercion is neither recognized nor reported in Nyanga. Mcumisa does not describe her sexual encounter with a man who had invited her to a meal as date rape or coercion. She appears incapable of making a connection between unprotected sex with a man believed to be HIV positive and the possibility of her getting infected. Fear of pregnancy is not a deterrent to unprotected sex because Mcumisa is on forced contraceptives. This shows that Mcumisa lacks skills to tell appropriate from inappropriate

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<sup>11</sup> One of the ethical considerations I undertook for the present study was that I would refer anyone who might need help during the course of the study. To this effect, we referred Vuyiseka to the . UWC Community Rehabilitation Project, who in turn referred her to social workers for intervention. The social workers worked with the police to stop the sexual abuse.

sexual behaviour, or facts about transmission of HIV infection, hence a man she felt sorry for took advantage of her inexperience:

Mcumisa: We were just gossiping about him people in here (*in the 'Protective Workshop'*)... they said that the man was infected with HIV, one day the man invited me to visit him in his house to have Christmas with him...I went because I felt sorry for him. I felt sympathy...we had Christmas food and after that we had slept together. Asked what she meant by sleeping together, she answered, having sex.

Mcumisa's heedlessness shows lack of introspection or awareness of the risk she took in the name of sympathy. This situation confirms that some disabled young people in Nyanga lack information and appropriate skills for resisting coercion or making responsible decisions about sex. In the same vein, most disabled young people succumb to peer pressure to take drugs and alcohol against their will, which increases their vulnerability to risk-taking behaviour.

#### **6.2.4. Alcohol and Drug Abuse**

Owing to high unemployment rates, many families in Nyanga run shebeens from their own homes where they brew local beer to earn a living. Participants reported that most residents, young and old, disabled and non-disabled, spend their evenings in these drinking places. Shebeens are easily accessible to disabled young people because some live in homes that run such shebeens and others can only too easily get one. Participants pointed to alcohol abuse as a major contributing factor to the high incidence of the rape of disabled young people in Nyanga as expressed below:

Zandile: School-girls who go to shebeens loose control of themselves and then men take advantage of them ... these are all big men, they cannot leave the girls alone.

Nontsikelelo: Shebeens, scolies (*thugs*), they are everywhere, they are using cocaine and you get it through sneezing (*sniffing*) the drug. In my area, they use a lot of drugs afterwards they do not have control over their sexual drives; they sleep with many girls, even raping them.

Members of FGD concurred with disabled young people about the problem of drug and alcohol abuse in this community:

FGD 2: People like to get drunk, disabled and non-disabled. When they are drunk, they do anything ... they want to sleep with any woman especially the disabled who can't say no. (*Why can't the disabled say no?*). Many things you know, no-one wants to marry you because (*of the assumption that*) you are not going to fetch water for him; you are not going to cook well for him and all that nonsense.

FGD 2: Drinking is a big problem. Once we disabled people are drunk, we do what others do ... we take shirlies (*girls*) to go and sleep with them for the night. Instead of helping to take us home, away from these shirlies, people ask why we drink like this.

These quotes show evidence that Nyanga is a highly risky environment. Many people rely on brewing and selling beer, and the community supports such an industry, with obvious consequences in drunkenness and rape. Once people are drunk, they lose inhibitions and take advantage of the unsuspecting disabled young men and women for sexual favours. It is also possible that some disabled young people consent to casual sex after a drink of beer because they have limited opportunities of engaging in regular sexual relationships. Key informants shared similar views:

Key 2: Yes, drugs and alcohol are a big problem, but it is also a way of passing time. Because they have friends in the neighbourhood they share with them, but these friends also take advantage as well because they know these people have a disability grant. When you have got an income, you are always taken as a king. You forget that in two weeks all these people will be gone. This is also lack of skills to protect themselves (*disabled young people*) from people who use them.

Key 3: Most disabled young people are drinking and their parents are drinking. It's where the problem of rape starts. The guy has the chance of grubbing the girl and putting her in a shack the whole night. Because parents are also drinking, they don't know what is happening. They get shocked in the morning when they don't see their daughter.

It is apparent that alcohol and drug abuse is a problem in Nyanga, which impairs disabled young people's judgment over sexual behaviour and

increases their vulnerability to HIV/AIDS. However, apart from church-going, this industry serves as the main form of socialisation and entertainment for disabled young people and other community members. It also gives disabled young people the opportunity to show financial power over their non-disabled peers. There are no alternative and safe ways of entertainment and recreation or job opportunities for disabled young people in Nyanga.

#### **6.2.5 Financial Exploitation**

The system of a social or disability grant for disabled young people was described in Chapter 2 and mentioned by Key 2 above. This grant sets disabled young people apart as financially better off than their unemployed non-disabled peers and family members. Such a position places this group at risk of financial exploitation because many opportunistic lovers are attracted to disabled young people so they can offer sexual pleasures in exchange for cash. The system is manifestly well-intended but it is double-edged, and it can increase disabled young people's vulnerability to HIV risk as illustrated below:

Lindiwe: There were many guys who came to me ... they were just using me (*getting her money in exchange for sex*); they wanted my money.

The desire to feel loved and accepted not only increases disabled young people's vulnerability to sexual and financial exploitation, but also causes them to succumb. Both disabled young men and women are targeted for such exploitation as expressed by key informants:

Key 2: What I have noticed is that even disabled boys are abused by non-disabled girls. Especially when the person is receiving a social grant or any income, the girls will ask for cool drinks or clothing items and disabled young men will treat that as love you know. Sometimes these boys do not even receive sex from these women; they have got their own partners who are not disabled. They only come to disabled boys because they want to benefit financially.

Some participants report that lack of social skills also contributes to sexual and financial exploitation of disabled young people as revealed below:

Key 5: Men are involved in abusing disabled boys as well. One of the reasons for this is that there is lack of skills among disabled people on how to form relationships. Once you are not skilled enough, then you will be abused.

As shown earlier, most disabled young people live in isolation and they have limited opportunities for regular dating; hence they lack the skills to tell appropriate from inappropriate sexual behaviour and they have no choice over whom they can sleep with.

### ***Summary of Theme Two***

Disabled young people's sexuality is determined by societal over-control and under-control because of misperceptions and stereotypes about this group's sexuality. Disabled young people respond by seeking affection or proving their manhood and such actions increase their vulnerability to HIV infection. This group is exposed to the same risk factors for HIV/AIDS as their non-disabled peers. However, the belief that this group is asexual and the fact that they are not able to escape dangerous situations increases their risk of rape and contracting HIV infection. Furthermore, the disability grant increases disabled young people's risk of financial and sexual exploitation. Living in shacks also makes it easy for this group to be abused by family members or strangers. One of the consequences of high unemployment rates in Nyanga is drug and alcohol use and abuse, which lead to sexual abuse and increased vulnerability for HIV infection.

### **6.3. RESPONSE TO HIV/AIDS RISK**

Disabled young people's response to the threat of HIV/AIDS risk is explored from different angles guided by the third objective of the current study revisited below.

### Objective 3

To describe disabled young people's response to the HIV/AIDS pandemic and the threat of HIV/AIDS risk through an exploration of:

1. Their knowledge levels about HIV/AIDS, including sources of information on sexuality education and on HIV/AIDS prevention.
2. The availability and accessibility of formal or informal health services including sexuality, reproductive health and HIV/AIDS services at community or national level
3. Their perceptions about the threat of HIV/AIDS risk.

Figure 5: Response to HIV/AIDS pandemic

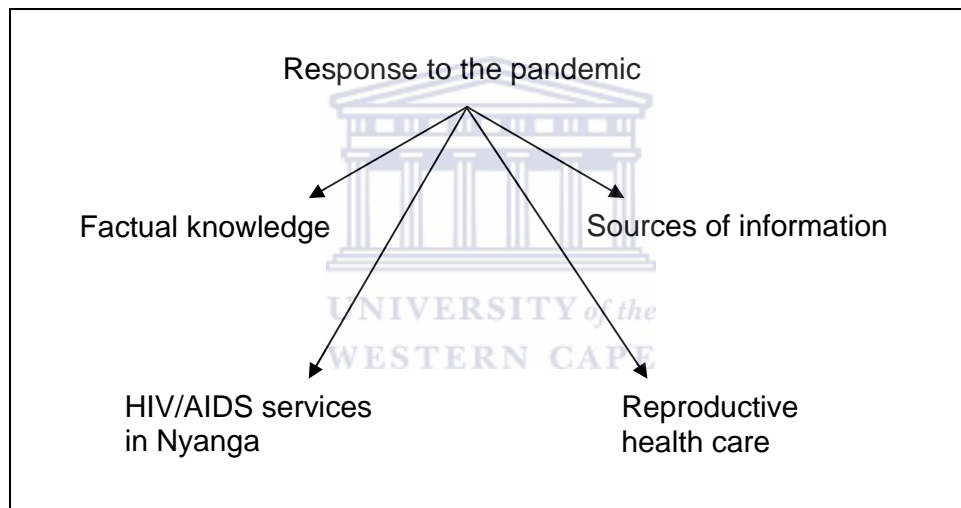


Figure 5 outlines the response to HIV/AIDS at individual and contextual levels. The individual level is determined by disabled young people's limited knowledge levels about HIV/AIDS and the informal sources of information available to them. The contextual level is determined by the inaccessibility as well as the limited HIV/AIDS, sexual and reproductive health care services in Nyanga.

### 6.3.1. Knowledge and Sources of Information

Participants were asked to state what they know about HIV/AIDS and their sources of information. Some participants reported that they do not know much about HIV/AIDS because there is not enough information available to them. Others reported that the little information they have comes from friends, siblings and the media. This informal way of accessing information on such an important subject affects the quality of facts about HIV/AIDS that disabled young people retain, as shared below:

Bonginkosi: I know nothing...Oh...I have just remembered, when you share a toothbrush with someone who has bleeding gums you can get HIV/AIDS (*only if they are HIV+*).

Xolani: They told us at the clinic that you get AIDS if you sleep with someone who has got a discharge (*may certainly transmit other STDs, unless they are HIV+, it is not any discharge that will transmit HIV infection, although the presence of an STD increases chances of contracting HIV*).

Thandiwe: I don't know...you get HIV/AIDS when you have sex...using a refrey (*cloth used to clean sexual fluids*) ...we don't talk about such things...(*sharing a refrey is more hygienically inappropriate than a medium for HIV transmission*). I usually hear from friends about Vuyani [Centre for Voluntary Counselling and Testing (VCT)] others say don't go there because they will inject you with AIDS...they also say that is a clinic for TB and birth pills (*the very life saving centre has inaccurate publicity*).

The above quotes demonstrate a combination of limited factual knowledge about HIV/AIDS and lots of misinformation that participants believe in. It is on the basis of such misinformation that disabled young people make or do not make decisions about protecting themselves from HIV infection. Thandiwe refuses to go for HIV testing at a centre that is believed to be injecting people with the very virus she is trying to avoid, which leaves her with no access to existing HIV prevention services. These findings are an indication that disabled young people and the whole Nyanga community have limited access to information on HIV/AIDS. This finding confirms the assertions by Brown and Brown (2004) that disabled people are not accessing HIV/AIDS information in spite of the abundance of such that has been generated and

disseminated over the years. Participants were asked to state their sources for HIV/AIDS information and they reported:

Zandile: On TV they say that HIV is transmitted by a man who you do not know and also when you do not use a condom when doing sex. (*she may be misled by believing that any man she knows is safe to sleep with*)

Sibongile: The teachers taught about HIV/AIDS at school. Some information I saw on TV programmes and some pamphlets given at school.

These quotes confirm that disabled young people access HIV/AIDS information from informal rather than formal sources. Informal sources like the TV, provide information to the population in general and do not always help individuals to personally identify with the problem or information themselves. This explains the limited and misleading information this group holds. However, some participants have accurate information about HIV/AIDS and know how to protect themselves from the infection as stated below:

Philisiwe: AIDS comes with sexual intercourse (*with an infected partner*), if you have an accident and an open wound and blood mixes. You prevent AIDS by condom and one boyfriend, you trust and they trust you.

Philisiwe's accurate knowledge about HIV facts can be attributed to her higher level of education. A direct link has been demonstrated between the level of education and comprehension of HIV/AIDS messages (UNICEF, 2002), stating that it is very difficult for illiterate or people with little education to comprehend the facts about HIV/AIDS (see section 3.2). Participants who attended sexuality and HIV/AIDS sessions at mainstream schools reported that they experienced condescending attitudes in class from both their non-disabled peers as well as from presenters of the talks. This discouraged the participation and learning process of disabled young people as shared below:

Themba: You could tell, you could see that even in class when you are asking a question, being a disabled person ... there is that laughter you know, wondering if you know what you are going to do

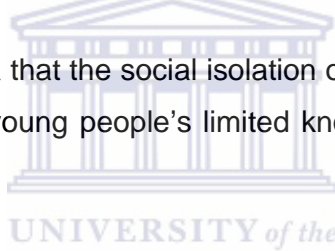


with this information. Whereas if a non-disabled person is asking everybody is listening carefully ... this thing is really annoying you know.

This quote demonstrates that even at school there are some teachers and learners who believe that disabled young people do not have a sexual life and that they therefore, do not need any information on sexuality and HIV/AIDS. Nceba asserts that educated disabled and non-disabled young people are well informed about HIV, the illiterate are the ones without knowledge on the subject.

Nceba: Disabled young people who go to school have the same HIV information like those non-disabled who are educated. Those who are illiterate are like victims because they are isolated from every thing. They feel sorry for themselves; they don't feel free to walk on the streets because they think society separates them.

Key 3 concurs with Nceba that the social isolation of disabled young people is responsible for disabled young people's limited knowledge on the subject as stated below:



Key 3: I think there is a problem of disabled young people who stay in the house all the time. I think they don't know anything what is happening. They know about AIDS but they don't really know it. If you ask what is AIDS? They cannot answer.

Participants who are out of school and confined to their parents' homes are the most disadvantaged in terms of accessing HIV/AIDS information. The situation is worse for disabled young people who do not have access to TV or radio.

### **6.3.2. Sexual and Reproductive Health Services and Care**

The provision of sexual and reproductive health services is key to controlling sexually-transmitted diseases, including HIV infection. For this reason, all young people need to have access to such services. The current study has revealed that the provision of contraceptives is the only reproductive health service that parents impose on their disabled daughters. Although parents do

not expect their disabled daughters to marry and have children of their own, they nevertheless are aware of the risk of these disabled young women being raped, which would result in unwanted pregnancy. For this reason, teachers, parents and clinic staff collaborate to impose contraceptives on disabled young women without giving them any information on possible options:

Thandiwe: At Mpumelelo school usually what they do is ask your age...they will take you to a place for needles (*injecting contraceptives*) ... I did not know that I was starting periods...they took me to that room where they do needles...first they called my mother and told her that your daughter has done this and this...it is time now that she get family planning...that is how I got into family planning. Asked whether her opinion had been sought over this matter she replied: The school told my mother and I just do what they tell me ...

Mcumisa: She (*mother*) took me to the hospital to get birth pills (*contraceptives*)...but I have never had a boyfriend and I do not have one now. My mother is just being careful because I move around alone, so I can be raped.

Thandiwe: I am trying to be on the safe side because I might be raped. I stay alone in the house sometimes when every one has gone out...but they tell me not to open the door for a stranger...it has not happened to me...I hear others get raped like that.

As pointed out above, parents are more concerned about preventing pregnancy than rape or HIV/AIDS. Ideal prevention strategies should not only be concerned with preventing negative outcomes, they should promote positive outcomes as well. In this case, preventing pregnancy and HIV infection should be accompanied by promoting more positive sexual experiences as well, but such is the missing element.

Owing to the cultural silence considered earlier, when disabled young women get raped or contract a sexually-transmitted disease, they are not likely to notice any change or to report the matter to parents for fear of reprisal. Consistent with this finding, Nosek *et al* (2001a) state that some disabled women are not able to detect when they have contracted a sexually-transmitted disease because of either the lack of knowledge to identify

symptoms or the loss of sensation due to paralysis. This fact raises the question of how disabled young women may be assisted to be 'in touch' with their bodies when they do not feel them anymore. Certainly, giving information about the dangers of HIV or unwanted pregnancy alone is not sufficient. Planned parenthood is one of the objectives of good reproductive health care, but parents in the current study do not want their disabled children to have children of their own:

FGD 2: They don't want us to have children to look after us when we are old, yet they have children of their own ... most of us take tablets (*contraceptives*) because we are not allowed to have children. These people (*parents*) think they love us, but they are only interested in our disability grant. When they die, we will only have our disability grant (*instead of children to look after us in our old age*).

FGD 4: I say to my child ... if you go out to have a baby it's your own business ... I have taken care of you so I cannot take care of another child ... if you have a baby, you must know that you will take care of your child yourself.

Disabled young people however, take a dim view of their parents' and society's interference with their right to have children of their own. Again, the issue of a disability grant is raised as the only reason most parents appear to care for their disabled children because they benefit from the grant. Otherwise, the idea that disabled young people are sexual beings and desire to have children of their own seems unthinkable for most parents. It follows, that any consideration for disabled young people's need for sexual and reproductive health care needs or possibility of falling pregnant is equally unthinkable for such parents:

Key 3: When a disabled girl becomes pregnant, it is then that parents become shocked because people with disabilities are treated as if they have got illnesses, they are sick, they are not normal people. Parents will be furious with the male who impregnated the young woman because they treat their child as abnormal, so why are they (*man responsible*) doing that to their child, they are cruel.

It is a paradox that most parents worry that in the event of the death of parents, their disabled children would have nobody to look after them. Yet the same parents deny these disabled young people the opportunity to have children of their own who would look after them in their old age. Besides, it was stated in Chapter 2 that having children in African societies is regarded as security for the future of parents as their children are expected to look after them. To this end, Ingstad (1995) describes the notion that it is through having children that an African woman is fulfilled and respected by her family and society, and paradoxically, she often becomes more independent than her male counterparts because she has someone to rely upon. Yet disabled young people in Nyanga are denied these perceived benefits of child-bearing.

### **6.3.3. Sexuality and HIV/AIDS Services in Nyanga**

Although officially, every township in the Western Cape has an HIV/AIDS programme in place, in practice, participants in the current study reported that they do not know any such services that are available, especially for disabled young people. In addition, there is neither a medical clinic nor a centre for Voluntary Counselling and Testing (VCT) in Nyanga except the ones in neighbouring Guguletu:

Nceba: I do not know any HIV programmes here in Nyanga, but in Khayelitsha there is Treatment Action Campaign (TAC).

The *sangomas* (traditional healers), who are commonly the first line of contact for HIV positive clients, reported not having ever been consulted by a disabled person who is HIV positive.

FGD 9 - *Sangoma*: These people (*Nyanga community members in general*) come to me for HIV treatment, but I have not seen a disabled; also, we do not have HIV prevention programmes ... it is something we are thinking of ...

The fact that disabled people do not consult sangomas might imply that they do not know their HIV status or they are too shy to consult because of the stigma attached to being disabled and HIV positive as well. However, a

serious possibility is that disabled young people are not accessing HIV/AIDS services from neighbouring townships because of accessibility problems.

Key 6: There is none (HIV/AIDS programmes in Nyanga) that I know of because even the programme that was taking place in our organisation in 2003/2004, it was just a one-off thing, and there was no continuation. The funding finished and so the programme stopped ... DPSA raised money for that programme, it was called HIV/AIDS peer group counselling.

Key 5: I don't know about HIV programmes in Nyanga. Nyanga is so dull, nothing is taking place here. Some of our children go to Guguletu and Khayelitsha to school and other programmes.

These quotes confirm the finding that disabled young people are not accessing HIV/AIDS prevention and support services as reported in Chapter 1 by Kelly *et al* (2002a).

### **Summary of Theme Three**

I have demonstrated that disabled young people have limited information and factual knowledge about HIV/AIDS and that their sources for such information are all informal, such as friends and the media. This is because there are no formal HIV programmes in Nyanga especially targeting this group. Besides, disabled young people in Nyanga do not seek sexual and reproductive health services except for imposed contraceptives to prevent them from having children of their own.

## **6.4. PERCEPTIONS OF HIV/AIDS RISK**

It was important to explore whether disabled young people feel personally threatened by the risk of HIV/AIDS or not and to seek their opinion on the vulnerability of other disabled young people. To this end participants were asked to state whether they feel at risk of contracting HIV infection or not.

Figure 6: Perceptions of the threat of HIV/AIDS

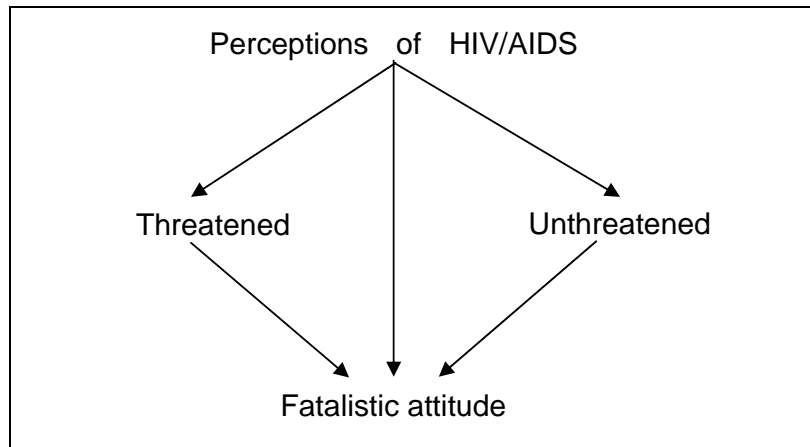


Figure 6 demonstrates a paradox of risk as manifested in disabled young people's perceptions of the threat of HIV/AIDS risk. Some feel threatened by the pandemic, others do not feel threatened, but both groups adopt a fatalistic attitude towards the pandemic in that they do not take any precautions to protect themselves from contracting HIV infection.

#### 6.4.1. Threatened by HIV/AIDS Risk

Participants advanced different reasons why they feel threatened by HIV risk. Firstly, disabled young men and women accuse each other of being unfaithful in sexual relationships. Both groups admit to sleeping with many sexual partners for various reasons considered earlier, such as men engaging in sex for play while women do it in a search for affection and lasting relationships. Secondly, some participants point out that the very fact that they are sexually active automatically makes them vulnerable to contracting HIV infection, as if they are completely helpless in the matter. Hence this group feels threatened by the virus as illustrated here:

Xolani: Yes, I am at risk of contracting AIDS...because the girls I have slept with were unfaithful to me.

Themba: Yes ... yes I am 100% at risk of catching AIDS because I am sexually active. What else could stop me from getting it?

On the one hand, it is a game of blame and on the other hand it is full knowledge of risk, which is met with a fatalistic attitude. In addition to the above sentiments, participants suggest that the extent to which all physically disabled young people are exposed to HIV/AIDS risk is the same. For example, a wheelchair user may physically not be able to escape rape, while the one who uses crutches might be involved with multiple sexual partners. Both situations expose disabled young people to HIV risk as shown below:

Themba: Risk of HIV for physically disabled is the same. For example a lady in a wheelchair might get raped and a guy like me roams around with girlfriends, so we are the same.

Lindiwe: Yes, they are more at risk because disabled girls like men...they sleep with many men...They go to the shebeens (*drinking places*) and when they are drunk the men take them to their house and sleep there the whole night...parents do not know until morning because they are also busy drinking at night.

Asked how she knew what she had just said, Lindiwe replied:

I know because I am one of them...I also drink...laughs ... It happened to me ... I went to the shebeen and got drunk...this man invited me to his house and raped me. (*Did you report this incident to anyone?*) No, I was afraid...I just kept quiet. There are many disabled girls like me...they are afraid to report when they are raped...because when their parents know, they will go to the police and their life is in danger. These men would also attack the disabled girl when she is walking alone...so people are afraid... Now I know it is not good to keep quiet...because it is just good to know.

The above sentiments are shared by members of focus group discussions as expressed below:

FGD 6: My daughter is at risk ... she is 21 years old and she loves men. As I am speaking just now, she is probably busy with boys ... she has had two abortions without my knowledge ... so my daughter is at risk because she does whatever she likes.

FGD 3: We are also at risk of contracting AIDS because we have sexual desires. We are also victims of rape ... able-bodied and disabled men rape both men and women ... I know some disabled people who are in prison because of rape.

The idea that disabled people are also perpetrators of rape is unusual, because most disability studies portray disabled people as helpless victims who are at the mercy of society. Nevertheless, it was acknowledged earlier that the law does not make any allowances in favour of disabled people – once convicted they face the full consequences of any crime they have may have committed. Disabled young people who do not take precautions are likely to contract HIV infection:

FGD 3: If a disabled person does not use a condom, he will get the disease in the same way as a non-disabled person.

FGD 5: If a disabled walks around in the street (*having indiscriminate sex*) he will get HIV/AIDS ... those with sexual desires need to be educated ... those with no sexual desires should also know ...

At least FGD suggests that some disabled young people are sexually active and others not, as opposed to the belief that all disabled people are asexual. The above quotes further illustrate the point that disabled young people cannot be immune to contracting HIV if they engage in risky sexual behaviour. Yet there are some disabled young people who do not feel threatened in spite of their sexual behaviour.

#### **6.4.2. Unthreatened by HIV/AIDS Risk**

Nonetheless, in spite of the evidence presented above about disabled young people's vulnerability to HIV/AIDS risk, some participants do not feel personally threatened by the pandemic because they claim that they trust their sexual partners. Furthermore, should they contract HIV; it would be through other means than sexual intercourse. This is in spite of existing evidence that in the whole sub-Saharan region and South Africa in particular, the commonest mode of HIV transmission is through sexual intercourse (Abdool-Karim, 2000). A misperception about self-vulnerability and the mode of HIV-transmission is presented below:

Nomthandazo: No, I am not at risk because I have one boyfriend and I trust him...but this does not mean that I can not get it, I could be unlucky...Other accidents happen, my sister could be involved in a



car accident and I go to help to save her life without putting on gloves...I can get AIDS.

Asked how many times she has been called to assist at an accident scene or what chances she has of being involved in that way, Philisiwe just shrugged her shoulders. It appears easier to deny the possibility that she might be at risk than to acknowledge the reality and take the necessary precautionary measures. Other participants also believe they are not at risk from HIV:

Zandile: No, they (*disabled young people*) are not (*at risk*)...but I am only speaking about myself...I do not know about others...school girls who wear short skirts encourage rape and those who go to shebeens also lose control of themselves and the men take advantage of them...these are all big men...they cannot leave the girls alone.

Based on the cultural beliefs about disabled people's sexuality detailed earlier in this chapter, the above quotes are a reflection of how the Nyanga community perceives HIV/AIDS risk. The absence of formal HIV/AIDS programmes in Nyanga also sends a message that HIV/AIDS is not a serious problem; as such disabled young people do not feel the need to be cautious. Many parents are not concerned about the risk of HIV/AIDS because they believed that their disabled children are either asexual or they are safe from rape in the confines of their homes. Thus policy issues and parents' cultural scripts influence and in fact, go hand in hand with disabled young people's coping strategies of denial. Parents share their views:

FGD 5: I don't think my son has sexual desires ... when I see a girl, I always point her to him and he shakes his head ...he does not want.

FGD 5: No I do not have any worries about AIDS; my daughter is always at home ... she is safe in my house.

FGD 6: When my child comes back from school she eats washes plates and goes to sleep. She doesn't go outside. I have asked God ... so it's God who is keeping her in the house so she doesn't do all these things (sexual activities).

Although some parents believe that their disabled children are safe from rape and that they do not engage in sexual activities, it has been revealed earlier in this chapter that in fact they are not infrequently raped in their own homes. As such, it is exactly in their own homes that disabled young people can contract HIV infection.

#### **6.4.3. Fatalistic Attitude towards HIV/AIDS Risk**

Paradoxically, participants who feel threatened and those who do not feel threatened by HIV/AIDS respond to the issues in much the same way. They either deny the threat or are resigned to their fate. Participants claim that if HIV infection is the ultimate consequence of their sexual activity, then let it be as stated below:

Themba: When I learnt about AIDS, I taught all my girlfriends. It's not only in the sex ways to get it, you can get it anyhow, but most common way is through sex. But I trust all my girlfriends. I am also sexually active; nothing can stop me getting AIDS.

Clearly, knowledge about HIV/AIDS has not resulted in behaviour change for Themba and his girlfriends, whom he claims to have taught about the pandemic. Similarly, members of focus group discussions hold the view that abstaining from sex is not possible. Some believe that the only remedy for an erection is to have sex; therefore, every sexual urge needs to culminate in sexual intercourse regardless of the consequences:

FGD 2: Hey, abstaining is very difficult; can we have erection and ignore it? It's not that easy you know. Also most of us disabled, we will never get married; no-one wants us (*therefore, our opportunity to have sex is now*).

FGD 2: This business of don't have sex is not possible; we are also human beings ... we have feelings you know. Normal (*non-disabled*) people want us to stop having sex and they do not change themselves and they are the ones who give us this disease.

FGD 2: You have to accept that us disabled people also have sexual feelings to relieve. We are not taught to offset (control) the erections. You don't know how it feels; when it comes, you can't do

anything. If you are married or you have a girlfriend ... you must have sex now that is the only way to offset the erection.

Contrary to society's common perceptions about disabled young people's asexuality, this group indicate that they are sexually active. As such, most participants perceive messages about HIV prevention as a way of denying them the pleasure of sexual expression. They are suspicious of any teaching that promotes abstinence before marriage. Since most families do not expect disabled young people to marry, participants question why they need to wait to have sex, if they are never going to marry anyway. According to some participants, the threat of HIV infection is a secondary issue; their primary concern is to enjoy sex without having to worry about HIV/AIDS or any other consequences. By shifting the blame onto the able-bodied for transmitting HIV infection, disabled young people can justify their own continued involvement in risky behaviour such as unprotected sex. The following are some responses from key informants:

Key 7: To be cautious, I think we should not be looking to sex only. There are so many other ways of contracting the disease.

Again, by focusing on the so-called 'many ways of contracting HIV infection', participants justify their continued involvement in risky sexual behaviour. Should they get infected, they can claim other means of contracting infection rather than sexual intercourse, which is riddled with taboos and social prejudice. Yet, Key 2 suggests that inaccessibility of condoms to this group is another reason they do not take precautions to protect themselves from contracting the infection.

Key 2: Because they are disabled, they don't know where to get condoms ... they don't go to the clinic or to our centre (*Vukuhambe*) so they don't have condoms. Others may get them if they want but they don't like to eat a sweet with its paper.

This quote also points out that even those who have access to condoms do not like using them because of the perception that sex is not enjoyable with a condom. Another reason for the fatalistic attitude towards HIV and the reluctance to use condoms is the need for intimacy and for children.

Participants argue that it is difficult for disabled young women to negotiate safe sex because they have been raised to be submissive to men (see Chapter 2). Although disabled young women feel insecure and unsafe in their sexual relationships, they also feel helpless to do anything about it because demanding safe sex might cost them a sexual partner:

FGD 4: It is very difficult for those who are not married because they also want sex ... but any way use condoms every time you have sex, trust your boy/girlfriend (*the last sentence was said so unconvincingly put across, as if to say this is what you want to hear, for that is what the ABC messages say to us*).

FGD 4: It is very difficult you know ... you advise married couples to use condoms how are they going to get children? Is there a chance to prevent (*avoid*) using condoms? There is always trouble in the house ... the husband will ask, why should I use a condom now, do you not trust me? This husband will not go for testing. You as a wife see him as a risk and you decide to use a condom, but you can't get hold of him, it's very difficult to fight here ... women are being beaten by their husbands.

Both quotes show that disabled young people do not readily accept the use of condoms. They also illustrate the dilemma faced by disabled young women who would like to secure long-term relationships including having children of their own. When faced with messages about protecting themselves from AIDS by condom use, they are afraid of bringing up the subject with their partners. Some disabled young women reported that they had been assaulted by their spouses/partners when they suggested using condoms. For these young women, finding a balance between their need for sex, securing partners, and having children, and also avoiding HIV infection is a major problem.

#### **Summary of Theme Four**

It has been demonstrated that some disabled young people acknowledge their involvement in risky sexual activities and so feel threatened by HIV/AIDS. Others do not acknowledge their vulnerability and so they do not feel threatened as they perceive the threat of HIV/AIDS in the same light as any other challenge of their lives that they have to deal with, such as lack of employment and living in shacks. As stated above, the paradox is that all

disabled young people adopt a fatalistic attitude towards HIV risk in order to cope.

## **6.5. PREFERRED HIV/AIDS INTERVENTION STRATEGIES**

Having established that there are no HIV/AIDS intervention services in Nyanga, participants were asked to state how such services might be carried out should they be made available. This question is in response to the fourth objective of the current study, which is to recommend HIV/AIDS intervention strategies that would be inclusive of disabled young people's needs.

Some participants indicated that they prefer to learn about HIV/AIDS from fellow disabled people, with whom they identify. While others do not mind learning from anybody who knows the subject well. Some prefer separate programmes for disabled young people only and others prefer inclusive ones as illustrated below:

Nceba: According to my knowledge, disabled people feel calmer when fellow disabled people are talking to them about HIV/AIDS. Because they see that these people who are like us are teaching us these things (*sex and HIV/AIDS*). So these things happen to people like us too. Most of the time it is able-bodied people who are teaching about AIDS ... disabled people might feel inferior ... they may not ask certain questions.

Nontsikelelo: Disabled people should teach fellow disabled persons...those who are not disabled also teach those who are not disabled.

Zandile: Able-bodied person should give information because they think wiser than disabled people ...

Most participants indicated that they prefer to be taught about sexuality and HIV/AIDS by fellow disabled people, with whom they identify and who have no ulterior motives for teaching the subject. Such participants are suspicious that AIDS prevention messages are designed by non-disabled people to stop disabled young people from having sex. For it is paradoxical indeed that, on the one hand, society believes that disabled young people are asexual and on

the other hand, society calls for disabled young people to abstain from sex, which they are presumed not to be having in the first place. Meanwhile, some parents feel it is their own responsibility to teach disabled children about HIV/AIDS as stated below:

FGD 5: Parents of disabled young people should be responsible for teaching their children because they know how to communicate with them.

FGD 5: It should be the parents to teach them because we stay with our children all the time.

These quotes indicate a consensus that parents are the best teachers for their disabled children about sexuality education and HIV/AIDS prevention. However, the only concern parents raise is the limited information they have to be able to teach their disabled children effectively as stated below:

FGD 5: There should be a school where we should attend with our children to be taught how to protect them from getting HIV/AIDS. We need the government to give us information on how to protect them as human beings ... also they must be taught how to use condoms.

Other participants prefer integrated HIV/AIDS prevention programmes. They argue that disabled and non-disabled people are exposed to the same risk factors and so they need the same HIV prevention programmes. Besides, these groups need to interact and get to know each other better. Consistent with the concept of integration or inclusive HIV services, Groce (2004b) and De Greve (2005) have called for mainstreaming disability into existing HIV/AIDS programmes and services (see Chapter 8). Such a move would still need to take into consideration the special circumstances of each disability group, considering that there are some disability groups that would always need separate programmes, such as those who cannot be moved from one point to the next and those who cannot hear, see, or talk. The following are views from Themba:

I think information should be given together so as to clarify some points you know. Also to tell people stop being stereotyped you know.

Whatever affects you affects us because we are human beings too so do not treat us in a different way ...

Themba sees inclusive HIV/AIDS programmes as a way of dispelling false images about disabled young people. Inclusive programmes should enable disabled and non-disabled young people to appreciate each other's uniqueness and special needs. In that way, barriers and prejudice against disabled young people would be reduced.

## **6.6. CONCLUSION**

I have demonstrated, firstly, that disabled young people's experiences are complicated by factors, such as ignorance, poverty and limited education. As such, their experiences of sexuality and HIV/AIDS are complex and riddled with paradoxes at individual and environmental or contextual levels. This is because of contradictory cultural and religious beliefs, which prohibit sexual or marriage relationships for disabled young people in Nyanga. Secondly, it is evident that some parents in Nyanga believe that disabled young people are not affected by HIV/AIDS because they are asexual. Such a belief is common even at society and policy level; hence little attention is paid to HIV/AIDS prevention needs for this population. This is evidenced by the limited factual information on HIV that disabled young people have and the lack of HIV/AIDS prevention services in Nyanga.

Thirdly, I have demonstrated that disabled young people's vulnerability to HIV/AIDS risk is exacerbated by the special circumstances of disability, such as the disability grant that exposes them to financial and sexual exploitation, the need to disprove that they are asexual; the need to feel accepted and loved as sexual partners and their inability to escape dangerous situations. Lastly, I have found that some disabled young people feel threatened and others do not feel threatened by the risk of HIV/AIDS, but that neither group takes precautions against contracting HIV infection. Such attitudes have negative implications for containing the HIV pandemic. The next chapter draws on the key findings of this study for further discussion.

# CHAPTER 7

## DISCUSSION

### 7. INTRODUCTION

In this chapter, I discuss the key findings that constitute the paradox of risk in disabled young people's experience of sexuality and HIV/AIDS in the context of Nyanga. I begin by considering contextual and individual factors, in terms of how environmental and cultural issues influence disabled young people's experiences of risk. Then I discuss how such experiences are played out at individual level in revealing the paradox of risk. I also consider the effect of responses to the pandemic at different contextual levels, looking at social rights, access to HIV/AIDS services and biomedical approaches to the pandemic. A brief discussion about the limitations of existing sexuality education and HIV/AIDS prevention programmes and an introduction to recommended programmes is presented. The chapter concludes with personal reflections on the research journey.

#### 7.1. EFFECT OF CONTEXTUAL AND INDIVIDUAL FACTORS

Throughout this thesis, I have demonstrated that disabled young people are not accessing existing sexuality education and HIV/AIDS prevention services. I have also established that a combination of contextual and individual factors combine to produce a paradox of risk through influencing disabled young people's experiences and perceptions of the issues at hand. Although these factors are so intricately linked, I discuss them separately for clarity.

##### 7.1.1. Environmental Factors

In many different ways, Nyanga is incontestably a risky environment, because of the history of apartheid and the consequent socio-economic circumstances under which disabled young people grow up (see Chapter 1). Although the majority of participants in the current study indicated that they moved to Nyanga from the Eastern Cape, there were some whose parents and



grandparents lost their homes when they were forcibly removed from District six under the Group Areas Act in the 1950s and 1960s. This was a destructive form of institutionalized racism in South Africa (Bozalek, 1997), that is responsible for most of the economic hardships still experienced by the majority of black people today.

As stated in Chapter 4, all participants in the current study live in overcrowded shacks made of materials ranging from cardboard, plastic paper, old iron sheets and wood or a combination of all these. Some families have divided their shacks internally to create extra rooms, while others have built extra shacks outside for older children or visitors. Most use communal toilets and others are still using the bucket system, especially disabled young people who use wheelchairs. This group is not able to access communal public toilets and so the bucket system is the only option. None of the shacks I visited had bathrooms and so all the disabled young people in the current study only take bed-baths, that is, wiping their bodies with a wet cloth.

Furthermore, all but three disabled young people still live with their parents. The three moved out of their parents' homes and are renting their own single roomed shacks for privacy. Disabled young people are often not considered for the so-called match box houses (very small) that the government is currently providing, because the criteria for consideration is that one should prove that he/she has lived in Nyanga for many years as confirmed by the counsellors

FGD 8: On housing, everyone should apply for the house within the house committee. The criteria is how long have you stayed in this place, they are not just giving you ...

Based on the stated criteria, disabled young people of the age group that participated in the current study, 15-24 year-olds do not qualify for housing of their own, as they are not considered to have lived in Nyanga for long enough. Besides, participants revealed that disabled young people are often considered as perpetual children who should live under the care of their parents regardless of age or severity of their disability (see also section 3.1).

It is also evident that Nyanga community creates conditions of risk for disabled young people because it is generally an unsafe environment. One of the legacies of the apartheid past is the persistence of a violent social context characterised by high levels of unemployment, extreme differences in wealth and poverty, xenophobia, easy access to guns and ongoing public and interpersonal violence (Sass, 2005). As such, participants in the current study live in constant fear as they are at risk of crime all the time and any where, be it on the streets of Nyanga, on public transport or in their own shacks. South Africa continues to be rated as one of the most violent countries in the world (Bundy, 1992; Minaar, 1994). This perception has not changed as violent crime is regularly reported by the media on a daily basis. Crime is particularly rife in Nyanga as reported below:

Key 5: Many people in Nyanga are not working, so selling beer is about buying food for the family. Even those who are selling sweets or maize [informal trade], the scories [thugs] come and say they want the money, sometimes these scories point a gun ... Since the pass laws were removed, this is not a safe place to live anymore ... So people here are living in fear.

Although apartheid is mostly remembered for its negative impact on people's lives, Key 5 expresses a sense of security from crime that people experienced during apartheid that they no longer do in a democratic South Africa. It was not uncommon during my field work that I would fail to go to Nyanga because the Taxi Associations were shooting at each other or burning each other's taxis. It is apparent that crime has become so much a part of life in Nyanga and other South African townships, so that people are constantly developing strategies for keeping safe rather than curbing crime (Lindegaard and Henriksen, 2004). One safe strategy adopted by parents of disabled children is to confine their children in shacks, thereby isolating them from society. Another environmental difficulty disabled young people face is the lack of accessible public transport. In Chapter 5, participants also suggested that disabled young people are confined to homes because their parents are embarrassed to show their disabled children. Parents also experience considerable difficulty in transporting disabled children from one place to the

next, especially those who use wheelchairs or when they become too big to be carried around. Again members of FGDs confirmed this:

FGD 3: When they [taxi drivers] see a wheelchair, they avoid you. I have problems going to church, the taxi drivers see a wheelchair and they think you are a burden and they don't stop for you.

FGD 8: Providing for disabled people is one side we are weak on ... we have no institution for disabled people ... if we analyse the situation of our roads, they do not cater for them ... if people are moving from home to clinic, there is not even enough space for them. This is a weakness which needs to be clarified in terms of town planners who are doing these institutions.

It follows that disabled young people in the current study do not participate in youth or other community activities because of mobility problems. In fact, Bongiwe, a 15-year old girl with spina-bifida had her wheelchair packed away, and it was being used as storage space. Bongiwe's mother claimed that she did not know where to take the wheelchair for repairs. Besides, when Bongiwe uses her wheelchair and has to board a taxi, she is required to pay an adult taxi fare for the wheelchair, which is another deterrent to public transport.

As stated in Chapter 1, Nyanga has only one clinic and participants mentioned a Voluntary Counselling and Testing (VCT) centre for HIV and other sexual health services, both of which are situated in neighbouring Guguletu. These services are largely inaccessible to physically disabled young people due to transport and other structural and architectural barriers. The reality of public transport in Nyanga does not allow disabled young people easy access, and that has far reaching consequences on how this group accesses sexual and reproductive health, and HIV/AIDS prevention services.

Similarly, some participants expressed regret about the transport situation that does not allow them to access recreational facilities that are not there in Nyanga but present in Khayelitsha. Lack of opportunities for sports and recreation leads to idleness, which causes disabled young people to turn to sex as the only free and enjoyable activity that is available to them. Such

behaviour in turn, doubles their risk to HIV/AIDS. Furthermore, my own direct observations in Nyanga confirmed the problems of transport – wheelchair access around shacks, the need for multiple bus journeys to get to clinics/centres, the costs of such travel, the exhaustion factor, all are elements that contribute to these difficulties. Thus poor housing, poor sanitation, high crime rates and inaccessible public transport are some of the contextual factors in Nyanga that isolate disabled young people and expose them to different kinds of risk.

### **7.1.2. Cultural Factors**

The main findings of the present study confirm the practical manifestation of culture-based misconceptions of disability and sexuality in the context of Nyanga and its socio-economic setting. In his study, Blackburn (2002) also found that the subject of disability and sexuality is contentious, because of the complex belief systems surrounding the two phenomena. The main difficulty experienced by disabled young people, be it in their experience of life in general or sexuality, is that culture and society at large continue to struggle with the idea of accepting them as equals. This struggle is so well captured in this quote:

There is no doubt that the disabled body on the one hand and the black body on the other are positioned in a similar relationship of threat to the putative norm. It is then not simply the possibility of the morphologically aberrant body that disrupts the boundaries of the normative subject, but the being of any/body that signals difference (Shildrick, 2002: 29).

Here, Shildrick (2002) implies that the perception of the disabled body as other is a complex one, as it speaks to a deep and abiding unease that society has with the distorted bodily forms in general, let alone how such bodily forms can begin to express sexuality. At the very least, disability is considered beyond the normative, because it stands against the values associated with what we choose to call normality and that is a focus of normative anxiety manifested in the construction of disability.

It follows that disabled young people's experiences are determined by struggles within society about how and where to place this group and their needs. Similarly, the sexuality of disabled young people is marred by the struggles outlined above, as well as the indistinct view of African sexuality that has been presented by Caldwell *et al* (1989); they claim that sexuality has never been placed at the centre of the African moral system. Caldwell *et al* (1989) further claim that African sexuality has always been permissive towards pre- and extra- marital sexual activity and that the African conjugal bond is emotionally weak.

This view is in contrast to findings that most African cultures, including the Xhosa, prohibit sex before marriage (Laubscher, 1979). Participants in the current study also confirmed that sex before marriage is culturally forbidden; therefore, it is likely that Caldwell *et al* (1989) have generalized African sexuality, based on a few cultures they studied. However, it is also true that African sexuality has evolved and is no longer practiced as dictated by culture; because of urbanisation and the changing social and cultural patterns that shape sexuality, family and kinship in African societies today (Bibeau and Pedersen, 2002).

It is evident from the current study, that some of the primary cultural factors impeding the impact of HIV/AIDS prevention are cultural beliefs and taboos. Although cultural beliefs about disability, coupled with beliefs about disabled asexuality are universal, I found that these have multiple negative consequences for the way disabled young people in Nyanga express their sexuality. This population's sexuality is characterised by strict social control that manifests through prohibition, suppression and secrecy.

It is perceptible that the social constructions of disability and sexuality create complex situations of risk for HIV/AIDS. In the current study, participants frequently expressed the cultural beliefs that disabled young people have been bewitched or they are sick, beliefs that lead to discrimination and the assumption that this population is asexual too. The reality that this is an

irrational conclusion, a logical non sequitur, is irrelevant – it remains the reality on the ground nonetheless.

The association of disability and witchcraft and illness are factors that will continue to impede the integration of disabled young people into mainstream society and any HIV/AIDS intervention strategies, unless they are specifically addressed. I found that the stated misperceptions of disability and sexuality taboos are mutually reinforcing. These belief patterns are a form of social control regarding how disabled young people may or may not express their sexuality. It is on the basis of such belief systems that parents in the current study often treat their disabled children as perpetual children who have no need for sexual expression, as evidenced by some of their comments:

FGD 4: When I look at my son (22 year old with cerebral palsy), it seems he does not have the physical feelings or desires to have a wife, that is why he does not have one.

FGD 4: My child (17 year old with cerebral palsy) has no sexual desires, when a man comes in she will be cheeky and refuse to talk to him.

These quotes demonstrate why some parents have no need to offer their disabled children any sexuality education, let alone worry about the risk of HIV infection. This is in addition to the finding that the Xhosa culture all but prohibits intergenerational discussion about issues of sex, which is another reason parents avoid teaching their children about sex. The consequences of such avoidance are social isolation, silence and ignorance about sexual matters. I found that these cultural contextual factors lead to parental over-control of disabled young people's sexuality. Such parents prevent their disabled children from socialising with peers, engaging in sexual or marriage relationships, or having children of their own (see Chapter 6). As a result, disabled young people are socially isolated and confined to homes where some become victims of rape.

The other side of the same coin is that other parents appear unconcerned about their disabled children's sexuality. Such parents exert no control at all

on the assumption that their disabled children do not have a sexual life. Consequently, disabled young people who are not controlled appear to express their sexuality in secrecy by engaging in risk-taking sexual behaviour.

This dichotomy of parenting approach clearly illustrates one of the major aspects of difficulty in designing responses to the HIV/AIDS pandemic. One parental approach (overprotective) or the other (overly permissive) might be easy to design address to. The reality of the prevalence of both in the parenting of physically disabled young people means that a scientifically researched understanding of the problem is required for the design of systems to offset two such contrasting kinds of parental disservice to this population. Consistent with this finding, Bell (1993) suggests that the social construction of disabled people as devalued, sexless beings (see section 3.1) negates the sexuality of this population by suggesting that they have no sexual feelings, are too sick or depressed to have sexual needs or are incapable of sexual performance.

Social constructionists claim that any of the varied constructions of sexuality flowing from the interplay of complex social interactions may become dominant discourses. Such discourses create a stable, normative 'reality', which appears to the individuals subscribing to it as a reality that is natural, inevitable and ideal (Bell, 1993). What this means, in essence, is that the consensus view of a social 'norm' of behaviour in sexual matters is perceived as unquestionable in practice. In the process of pursuing the norm, an important aspect of disabled young people's lives is neglected. In reality, such consensus social perceptions need to be challenged and modified so they can be relevant to the populations in question. However, the means of changing and shifting such perceptions of social norm and of personal behaviour are difficult. Exactly because alternative patterns of thought and behaviour are considered profoundly destabilizing of the social norms that are considered unquestionable.

Furthermore, it is evident that neither the over-controlled nor the under-controlled disabled young people receive any information regarding rights and

responsibilities of sexual expression or promotion of healthy sexual expression. Thus, many disabled young people acknowledged openly that they engage in indiscriminate sex without information on self-protection against sexually-transmitted diseases. These findings are consistent with those reported by Nganwa *et al* (2002) and Groce (2003) suggesting that disabled people are likely to engage with multiple sexual partners because of social isolation and limited opportunities for dating – that is to say, loneliness and unhappiness.

### **7.1.3. Gender Dimensions**

Unequal power relations between men and women are part of the cultural norms that make it difficult for all women, but more so for disabled young women, to negotiate for safer sex. Participants in the current study indicated that disabled young women no longer benefit from the traditional preparation of girls into womanhood compared to the young men who still benefit from traditional ceremonies such as circumcision. This implies that disabled young women enter into sexual relationships without any preparation or any information on sexuality matters. Consequently, the majority rely on their male partners for guidance on the subject, but end up being taken advantage of through sexual exploitation and abuse. Although most disabled young women in the current study indicated that their friends or themselves had experienced sexual abuse, there were others however, who indicated that once they had realised that they were being abused by the men they relied on for affection and guidance, they asserted themselves and withdrew from abusive relationships. The myth of men being more informed about sexual matters has also been described by Shisana (2004), who points out that it is generally believed that men are more knowledgeable about sex and women accept what they get without questions.

Furthermore, in the current study, I confirmed the finding by Elwan (1999; 2003) that disabled women experience higher levels of discrimination and disadvantage than disabled men. Women also experience discrimination in their attempt to accessing sexual and reproductive health services. Mgwili and



Watermeyer (2006) report on the results of a study they conducted with disabled women who attend family planning clinics in the Eastern Cape of South Africa. Clinic staff appeared to communicate the idea that disabled women are asexual and they have no business attending a family planning clinic. Similarly, Saiti (2001) also described comparable attitudes by clinic staff (see section 3.2), following countrywide workshops on disability and HIV/AIDS that she conducted. According to the ICF, misperceptions about disabled young women's sexuality lead clinic staff to create attitudinal barriers that prevent this group from exercising their sexual and reproductive rights.

In the current study, I found that clinic staff in conjunction with teachers and parents did not hesitate imposing contraceptives on disabled young women instead of providing sexuality education and giving them a chance to decide what they want. Similarly, Mgwili and Watermeyer (2006) report on parents of disabled young women who are urged to bring their daughters to the clinic for contraceptives. Since disabled young women are not allowed to engage in regular sexual or marriage relationships, parents' first assumption is that their disabled daughters might be raped, therefore, it is important to prevent pregnancy by imposing contraceptives on them. Parents' second assumption is that disabled young women are not capable of looking after children of their own and so they should not be allowed to conceive as stated below:

FGD 4: I have not seen anything unusual in my daughter, but once I see that she is getting sexual desires, then I will take her to the doctor.

FGD 4: I know that if my daughter gets pregnant, she won't take care of the child.

Erroneous assumptions that lead to above actions are not only a violation of disabled young women's rights to and their ability to bear and raise children (Mgwili and Watermeyer, 2006), but they also force this group to seek comfort and love through risk-taking sexual behaviour, in the process doubling their vulnerability to HIV risk. Thus, as stated in Chapter 1, and in the context of HIV/AIDS, disabled young women face a triple disadvantage. Firstly, they are

disadvantaged by a physical disability and are perceived as either unattractive personally or socially, or both. Secondly, if they become HIV positive, they are accused of being promiscuous and so they are blamed and marginalised. Thirdly, and in the context of an African society, by definition, women are perceived as a second-class group, where men and society at large do not hesitate to do things to them (abuse) or for them (overprotection) without consulting their opinion first.

Another aspect of gender discrimination revealed in the current study is the violence and sexual exploitation, rape and coercion perpetrated against disabled young women. Although violence and rape are considered a big problem in South Africa (Sass, 2005), disabled women are more at risk. Some disabled young women in the current study indicated that they are not able to escape rape because of physical difficulties such as inability to run when using crutches or a wheelchair. This finding was also described by Groce (2003), who pointed out that disabled women are prone to rape because they are not able to escape dangerous situations. I also found that some disabled young women do not know appropriate from inappropriate sexual behaviour and these become victims of date rape or coercion. Similarly, the majority do not have the skills to assert themselves or to negotiate for safe sex or indeed to report rape. As a result, when this group contracts HIV infection, no-one gets to know until it is too late.

What became evident also is that unfaithfulness in sexual relationships is perpetrated by disabled young men while disabled young women remain faithful to their partners. Unfaithfulness appears to be a social norm that is tolerated by the Nyanga community in spite of the HIV risk associated with such practices. Shisana (2004) has also pointed out that engaging in extramarital relationships and unfaithfulness are social norms that are accepted for men and not for women. Most disabled young men in the current study reported engaging with multiple sexual partners as a way of proving sexual potency and dispelling the false image about disabled asexuality. Thus cultural scripts play a major role in influencing gender-based disadvantage,

discrimination and violence, all of which affect the individual experiences of HIV risk.

## **7.2. RESPONSES AT INDIVIDUAL LEVEL**

The information given by interviewees illustrates that many of the elements of HIV risk are common to both physically disabled and non-disabled young people in Nyanga, in particular poverty. I found that poverty is the umbrella factor that leads to cumulative disadvantage and risk in the experience of sexuality and HIV/AIDS. In line with this finding, UNESCAP (2002) reports that disabled young people remain among the poorest people in their communities, which earns them a low status in society and exposes them to all risk factors for poverty, including exposure to infectious diseases, such as HIV/AIDS (see Chapter 2).

Although the diverse and complex social, structural and cultural factors of risk affect all people, some are of higher risk content specifically for disabled young people, such as poor housing. Informal and overcrowded housing provides no privacy and leaves disabled young people vulnerable to rape and increased vulnerability to HIV infection. Unless political decisions are speeded up to improve the housing situation for disabled young people, this group will continue to feel unsafe and to be abused in their shacks. Creating safe environments requires joint efforts between the government, the community and families to work together. Individual behaviour change alone is not a solution.

Another aspect of the individual experience of HIV risk is the financial exploitation experienced by disabled young people in the current study. There is a double-edged aspect to what is designed to be an advantage that should offset poverty among this group (as expressed in Chapter 5), and it is the disability grant which the South African government provides to eligible people with disabilities who are not able to support themselves financially (Swartz and Schneider, 2006). While the grant is laudable in principle, it also has the

effect of exposing this population to opportunistic lovers who offer sexual favours in exchange for money.

Furthermore, disabled young people in the current study readily acknowledge the reality of sexual exploitation and even rape as a result of being considered financially better off than others. The double-edged nature of this situation, and the double risk element of life in Nyanga, is that members of the general community exploit disabled young people both financially and sexually (see Chapter 6); a practice that increases disabled young people's vulnerability to HIV risk. Thus, on the one hand, the disability grant is meant to be a solution to problems of poverty and unemployment and on the other hand it multiplies the risk of contracting HIV for disabled young people. But most particularly, the disability grant in reality, demonstrates the need for a holistic approach to the interplay of problems as can best be identified by consultation with physically disabled young people themselves. The unique feature of the said grant is that it has as much potential for negative impact as positive, within the environment and socio-economic context where it is delivered.

Unemployment was mentioned earlier as one of the characteristics of Nyanga. Participants in the current study indicated that lack of cash leads many disabled young women to engage in transactional sex in order to meet their financial needs. This notion was confirmed by one of the parents as stated below:

FGD 5: I do not have a husband and so I do not have everything that my daughter may need. So she decides to go and be an 'escort' (mistress) so that she can bring food in this house ...

It is evident from the above quote, that some disabled young women are forced by poverty to sell sex for money, in the process, exposing themselves to HIV risk. For this reason, it is imperative that disability activists and disabled people's organisations should work with government to ensure that declarations for equal opportunities to employment are adhered to in practical terms and not just on paper. Another consequence of widespread unemployment in Nyanga is that most households run shebeens in order to

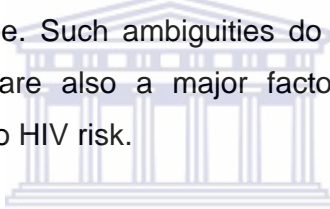
earn a living. The lack of recreation facilities for disabled young people leaves shebeens as the only places where disabled young people can go for entertainment. The ensuing alcohol and drug abuse that happens in such environments commonly leads to the sexual abuse of disabled young people and increases their vulnerability to HIV risk.

Furthermore, participants in the current study had lots of reservations about the education system. I have demonstrated that most had limited basic education, limited opportunities for tertiary education and skills training, which lessens their ability to compete on the open labour market. As stated in Chapters 2 and 5, low literacy levels also limit the extent to which disabled young people can comprehend the HIV prevention messages for self-protection. Most participants in the current study displayed limited factual knowledge about HIV/AIDS; they also held lots of misperceptions about the pandemic, which do not help them to make informed decisions about protecting themselves.

In summary, the impact of the above social factors on disabled young people's experience of HIV/AIDS is undisputable. All the features of life as it is lived in Nyanga, tend to place disabled young people in double jeopardy, greater than their able-bodied peers. Such findings have also been described in other studies on disability and HIV/AIDS, which state that disabled people are at the same or increased risk of HIV infection compared to their non-disabled counterparts (World Bank, 2004b; De Vries, 2004). So, although disabled and non-disabled young people may be exposed to broadly the same risk factors for HIV in many respects, structural barriers and common negative attitudes greatly magnify the risks for disabled young people. In the same vein, providing one-size-fits-all intervention strategies does not meet the specific needs of disabled young people because of the said barriers that hinder their access to existing HIV prevention and support services.

### 7.2.1. Paradox of Risk

The paradox of risk is mainly a function of the diversity of the risk factors that have been explored so far, in combination with the inconsistencies that plague the experiences of sexuality and HIV/AIDS in the context of disability. On the one hand, disability activists view the sexuality of disabled people by definition, as a human rights issue; that is, all disabled people are entitled to express their sexuality freely. On the other hand, society constructs disabled people as sexless beings and so disabled young people are impeded from expressing their sexuality. Again, on the one hand, this population is viewed as asexual therefore, undesirable and unsuitable as sexual or marriage partners. On the other hand, society considers this sexless status as a sign that disabled young people are free from HIV/AIDS; therefore, they must be safe to have sex with; and so this group becomes a target for sexual exploitation and even rape. Such ambiguities do not only confuse disabled young people but they are also a major factor in the increase of this population's vulnerability to HIV risk.



Similar contradictions have also been described in literature, where it is noted that people with disabilities are predominantly seen as “asexual, unlovely and undesirable” (Shakespeare *et al*, 1996: 14) and to a lesser extent as oversexed and dangerous (see section 3.1). Disabled people's lack of physical integrity is a visible signifier of their 'otherness' and in the context of the sinister, pervasive power of the able-bodied norm; disabled people's right to express their sexuality is significantly affected. Deviance from the physiological, functional and sexual norms is seen as justifying discriminatory practices aimed at curbing the sexual expression of persons with disabilities (Shakespeare, 1996). Thus, the dominant discourse of the sexuality of disabled people largely revolves around inferiority and illness on the one hand and evil and danger on the other (Shakespeare, 1996).

Yet there are other people who are intrigued by disability and may be driven to have sex with this group out of curiosity. Such people may also think they are doing disabled young people a favour because most people do not want

to date this group. Such inconsistencies lead to further disadvantage for disabled young people, in terms of feeling accepted and being allowed to express their sexuality like everyone else. This research has not identified any element of social attitude or treatment that can be described as positive or advantageous to the disabled young people in their experience of sexuality and HIV/AIDS.

### **7.3. RESPONSES AT CONTEXTUAL LEVEL**

An important feature of the information that emerges from interviews, is that disabled young people experience a double risk because of the special factors that are 'disability specific'. This is an important finding, not only in terms of natural or social justice, but it also has serious implications for the design of systems for intervention in the pandemic. These design implications have been explored and presented in more detail in Chapter 8, in terms of the practical development and application of effective community-based programmes.

#### **7.3.1. Social Rights**

South Africa is said to be one of the few countries in the world that has included disability issues in the constitution, proclaiming that persons with disabilities may not be discriminated against in any way (Matsebula, Schneider and Watermeyer, 2006). To this effect, Article 15 of the Disability Rights Charter of South Africa (2000:3), states that "Disabled people shall have the right to make their own decisions in all areas of social life and this shall include freedom to engage in sexual relationships and to have a family". In addition, Disabled People South Africa (DPSA) (2001) also called for equitable access to basic socio-economic rights for people with disabilities (Howell, Chalklen and Alberts, 2006).

In spite of this social rights mandate, I found that disabled young people's rights to sexual and reproductive health are violated, and also their right to accessing sexuality education, and HIV/AIDS information and support services, as will be explored later in this chapter. There seems to be no

mechanism for translating formal rights into practical realities for this population. Blackburn (2002) notes that balancing the sexual rights of disabled young people, whilst protecting them from sexual exploitation, is work that continues to challenge health and legal professionals, as well as public policy in general. There needs to be a system for monitoring the implementation of formal rights in ways that benefit disabled young people at grassroots level and in practical terms.

Furthermore, disability legislation in South Africa upholds equal rights and equal access to social services (ODP, 1997). In spite of these theoretical rights, the present study found that disabled young people's sexual and reproductive rights are denied and often abused. This finding has implications for a wide range of policy issues including the systems of monitoring the implementation of disability policies. It also has implications for the training of medical and therapy professionals in sexuality and HIV/AIDS matters for people with disabilities, and provision of sexual and reproductive health services, and HIV/AIDS prevention and support services, as illustrated below.

### **7.3.2. Access to Services**

I found an absence of HIV intervention services for disabled young people in Nyanga. As a result, this population depends on the media, friends and older siblings for information on sexuality and HIV/AIDS (see Chapter 6). It is evident that most participants in the current study either have limited factual information about the subject, or they are seriously misinformed. This finding might be explained by the reality that many existing HIV-prevention programmes focus on raising public awareness through newspapers and written materials which are inaccessible to many disabled young people who are illiterate or have little education (De Vries, 2004). Others may fail to access information because they do not have a TV or radio.

I also found that only one out of the 15 disabled young people had ever been invited by a friend to attend an HIV/AIDS awareness campaign in Nyanga. The rest received one-off information from peer educators who had been



trained by the Treatment Action Campaign (TAC), an HIV/AIDS civil rights organisation, on behalf of Disabled People South Africa (DPSA). I was informed that DPSA received one-off funding for the project, which lasted for only one year. This situation also explains why most participants in the current study have limited factual knowledge and sometimes inaccurate information about HIV/AIDS; they obviously have not had enough input on the subject. Further evidence to demonstrate the limited information upon which disabled young people make decisions about HIV prevention, is illustrated by the fact that none but three had had an HIV test. This is an indication that the rest do not yet perceive the importance or need to know their HIV status, as most expressed fear of getting tested for HIV. It follows that this group may contract or transmit HIV infection without knowing. Besides, most do not even know that they can seek sexual and reproductive health services and so there is no way of knowing they have contracted HIV infection until it is late.

Given the complexity and the sensitivity of the subject of HIV/AIDS, it is unlikely that such one-off information efforts as DPSA embarked on, can yield the desired results. A concern that arises from such training programmes is the extent to which the trained peer educators are competent enough to deliver information of such importance and complexity. My field experience with Vuyo, the intermediary who was trained as one of the HIV/AIDS peer educators is that he taught fellow disabled young people that a *refrey*, a cloth used to clean sexual fluids (see Chapter 6), transmits AIDS. Such misinformation might mislead others in believing that as long as they use a clean cloth each time they have sex, they would be free from contracting HIV infection. However, when the issue of the *refrey* was brought to focus group discussions with parents, senior citizens, and even key informants, no-one knew what a *refrey* is except Vuyo and the disabled young people whom he taught. It is thus imperative that the effectiveness of one-off training programme be evaluated, especially if non-medically trained people are involved in delivering such complex information about HIV/AIDS.

In addition, Vuyo had volunteered in one focus group session to answer a question from a parent who wanted to know what AIDS is. Vuyo's response

was that 'when a person has TB, pneumonia, diarrhoea and shingles, then that person has AIDS. Clearly, such misunderstanding and misinformation is a result of the difficulty of comprehending the medical facts about HIV/AIDS. Yet disabled young people like Vuyo were entrusted to deliver HIV information to whole institutions of disabled young people. Obviously, such groups were misinformed, and in the absence of alternative formal sources of information, they remain misinformed. This revelation further calls for evaluation of the effectiveness of peer educators from time to time to ascertain their need for more training.

### **7.3.3. Bio-Medical Approach**

Although HIV/AIDS is at base a medical problem, the deep causes are of a social nature and, therefore, not immediately easy for a person of a medical rehabilitation background to apprehend. As a physiotherapist, I was trained to assess patients, come up with a diagnosis and implement an intervention programme. Although physiotherapists are encouraged to be aware of the many other challenges that patients may have, apart from the presenting medical or rehabilitation problems, they are also trained to refer patients they cannot assist to appropriate specialist programmes. Such is the essence of multidisciplinary team-work.

Sexuality and HIV/AIDS are among the problems that physiotherapists, in Africa at least, do not normally deal with directly, except for treating patients whose disability is a complication of HIV/AIDS. The challenge arises when there are no specialists to refer patients with sexuality and HIV/AIDS questions to, especially in most parts of Africa where there are no sexologists and professional HIV/AIDS counsellors. Disabled young people who have questions or problems in these areas go without help, despite being in contact with therapy professionals. For this reason, it was a challenge for me to grapple with the social issues of disabled young people in the context of their experience of sexuality and HIV/AIDS.

Although most physically disabled young people will have spent their formative years going in and out of hospitals and rehabilitation centres, many medical and therapy professionals appear to avoid the subject of sexuality and sexual health when dealing with disabled young people. Cheausuwantavee (2000) notes that many therapy professionals continue to shun the subject of disabled sexuality, claiming that it is not their responsibility. As a result, these professions may also ignore the problem of HIV/AIDS among disabled young people because of its association with sexuality. This is in spite of the fact that HIV/AIDS has been named a health crisis for sub-Saharan Africa including South Africa (UNAIDS, 2005) and that all strata of society need to be involved in efforts to contain the pandemic.

The results of this avoidance by professionals for disabled young people who have no-one else to consult on sexuality matters include confusion, irresponsible sexual behaviour, unwanted pregnancy, unhappiness, sexual exploitation or abuse, and sexually-transmitted diseases including HIV/AIDS (Shakespeare, 1994). Thus, parents and professionals, the two groups who have the most contact with physically disabled young people from a young age, appear unequipped to deal with sexuality and HIV/AIDS matters as they affect this population. The question that arises from this discussion is, how can the training of physiotherapists in sub-Saharan Africa be made relevant to the pressing issues that disabled young people are faced with on a daily basis, such as HIV/AIDS? This question has implications for future training of medical and therapy professionals in the context of HIV/AIDS and the sexual and reproductive health needs of young people with disabilities.

#### **7.4. REFLECTIONS ON THE RESEARCH JOURNEY**

Reflections on the research journey are based on the research process that has been difficult but also rewarding. I reflect on the broad focus of the study, the research process and the personal learning curve.

#### **7.4.1. Broad Focus**

The focus of the current study was broad and difficult to contain. In considering disabled young people's experiences and perceptions of sexuality and HIV/AIDS, it was necessary to review the social constructions of disability and sexuality, both of which are broad and complex. Then, bringing the understanding of these two subjects on to the experience of HIV/AIDS, an equally broad and complex subject, was demanding. This approach involved an extensive review of literature on disability first, then disability and sexuality and lastly, disability and HIV/AIDS matters. The extensive literature review helped me generate relevant research questions that guided the current study.

Similarly, the interview process triangulated between three types of data collection methods, that is, document reviews, in-depth interviews and focus group discussions. Data were also collected from multiple sources, such as disabled young people, their parents, senior citizens and key informants. This exercise generated large amounts of data from all the sources. My biggest challenge was then to synthesize considerable volumes of literature and data in order to make sense of the process. Although it was a demanding task, the broad focus of the study helped to emphasise the importance of understanding the concept of disability and how it underpins every aspect of disabled young people's experiences of life. It is exactly the several aspects to do with disability, sexuality and HIV/AIDS that widened the focus of the study and made it intricate to manage.

Furthermore, the decision to use the Atlas.ti computer programme to analyse data was one of the exciting learning processes. Unlike packages for analysing quantitative data, such as the SPSS programme, which is designed to carry out the actual analysis, with Atlas.ti, the researcher does his/her own analysis. The computer package only assists with the process of data management and organisation. With basic skills in the use of the Atlas.ti computer package, I was able to organise, code the data and build my story as told by participants in the current study. I had no mentor, except for

information from literature and discovering things on my own. However, my discoveries paid off as I realised that I was the only PhD student that had ever used the Atlas.ti programme at UWC; and so by mid-2006, I began presenting seminars to colleagues and University staff who were interested in using the Atlas.ti programme for their own research. In the process, I improved my own skills.

#### **7.4.2. Personal Reflections**

As stated in Chapter 1, this study was motivated by my personal and professional experiences with HIV/AIDS. I felt very helpless after the death of my two sisters to HIV/AIDS in 2004. The feeling of helplessness as a general point, and as a particular understanding at a personal level, is not a very encouraging perception. We all like to think that we can 'make a difference' and one of the learning features of this process for me has been having to take in and appreciate the limitations of what I could have done for my sisters. On a broader front, I think of the limitations of existing strategies of HIV/AIDS intervention in the face of the extent of the problem and its interlinked human complexities.

The difficulty I have with existing HIV/AIDS prevention programmes is similar to the difficulty I had with health education, while growing up in a rural village with my grandmother. We were taught at school to boil drinking water to prevent water borne diseases. At that time, entire villages drew water from unprotected water wells, which were seriously unhygienic. But the reality is that we walked more than 15 to 20 kilometres to fetch firewood for cooking; therefore, boiling drinking water on such hard-earned fuel was a luxury we could not afford. For this reason, I only studied that aspect of hygiene in order to pass my exams, because boiling drinking water was simply not practical in my circumstances.

I liken the above experience to asking my sisters to be faithful to their husbands, which they were but got infected anyway, or asking disabled young people in Nyanga to abstain without protecting them from rape, teaching them

to use condoms when they cannot access any, or asking them to know their HIV status, when the VCT centres are inaccessible by public transport. What is the point? Widespread fatalism, however unwise, is hardly surprising when one sees the realities of the influences and constraints that act on the lives of disabled young people. Like my grandmother's, their life circumstances militate against their being able to do what they 'should'.

The fundamental conclusion, difficult to avoid, is that existing HIV/AIDS services are not relevant to many well-identified at-risk groups whose social circumstances are precarious. However, my assumption is that through this thesis, disabled young people's voice can now begin to be heard, and the contextual factors that make their situation so precarious begin to be understandable through, if not their eyes, then at least their own words. This understanding has been a rewarding and healing experience for me, as AIDS has changed my family and my own outlook on life forever.

On the professional level, I have been able to ascertain the need for physiotherapists to be involved in sexuality and HIV/AIDS education and counselling for people with disabilities with whom they work. All therapy professionals are particularly relevant because they spend more time with disabled people during rehabilitation sessions. Besides, as repeatedly shown in this thesis, people with disabilities consider sexuality one of the most important areas of their lives, and so therapists need to be knowledgeable, relevant, sensitive and responsive to such a need.

## **7.5. CONCLUSION**

The main findings discussed in this chapter point to environmental and cultural factors that influence disabled young people's experiences and perceptions of sexuality and HIV/AIDS. I have demonstrated that Nyanga's current socio-economic standing is a result of its historical apartheid past. As such, Nyanga is a risky environment on all fronts, that is, historically, culturally socially and economically. I have discussed the paradox that manifests in the fact that disabled young people are considered asexual and yet they are also

considered easy targets for sexual favours as well as sexual exploitation, which increases their risk to HIV.

I have highlighted the gap between social rights on paper and in practice. For example, policy documents advocate equal access to social services, yet disabled young people's lives are characterised by limited social amenities. In particular, disabled young people have no formal access to sexuality education HIV/AIDS prevention and support services. Similarly, I have offered a critique of the biomedical approach in the training of therapists. It is important that therapy professions re-examine their curriculums so as to be relevant to the pressing reality of sexuality and HIV/AIDS as it affects disabled young people. I have concluded the chapter with personal reflections. In the next chapter, the entire thesis is concluded with recommendations, and limitations of the study are outlined.



## CHAPTER 8

### CONCLUSION AND RECOMMENDATIONS

#### 8. INTRODUCTION

Throughout this thesis, I have dealt with the paradox of risk as it manifests in the way disabled young people are perceived by society and how they respond to their experience of sexuality and HIV/AIDS. In Chapter 1, I presented the problem of HIV/AIDS in South Africa, stating that young people between the ages of 15-24 are mostly affected, yet little is known about the pandemic as it affects physically disabled young people. As a result, this group is not accessing existing HIV/AIDS prevention services.

In chapter 2, a review of literature revealed the social construction of disability, and the varied ways in which disability is understood nationally and internationally. Of particular note, was the fact that all the stated ways of explaining disability are not comprehensive and they are silent about the sexuality of disabled people. In Chapter 3, a further review of literature demonstrated that the social construction of sexuality is characterised by cultural taboos and prohibitions, which exacerbate the stereotypes about disabled people's sexuality. It was revealed that the meaning given to sexuality and disability directly influences disabled young people's experiences and perceptions of sexuality and HIV/AIDS; as this group is not allowed to express their sexuality freely.

In Chapter 4, the methodological issues that guided the current study were explored and presented. A qualitative case study design helped to discuss the case of 'disabled young people' both in depth and breadth, using multiple data collection methods and sources. In Chapter 5, different and similar views from participants revealed the complexities involved in the way disabled young people experience growing up with a disability in Nyanga. I drew attention to the legacy of apartheid and its impact on township life that is characterised by poverty and crime, and that disabled young people experience the negative



consequences of poverty. Similarly, in Chapter 6, participants' views about disabled young people's experiences and perceptions of sexuality and HIV/AIDS in the context of disability were explored. It was revealed that environmental and cultural barriers prevent this group from expressing their sexuality and accessing existing sexuality education and HIV/AIDS prevention and support services. The main findings of the current study were discussed in Chapter 7. A number of factors that influence disabled young people's experiences of sexuality and HIV/AIDS, including contextual and individual responses were revisited. This chapter ended with my own reflections at professional and personal level, and how these influenced the current study.

In Chapter 8, I revisit the overarching research questions that I set out to investigate in the first place and these are: a) What are disabled young people's experiences of growing up with a disability? b) What are the contextual and individual factors in Nyanga, that impact on physically disabled young people's experience of disability, sexuality and HIV/AIDS? c) What are disabled young people's responses to the threat of HIV/AIDS? d) What is the level of disabled young people's participation in existing sexuality education and HIV/AIDS prevention and support services?

### **8.1. WHAT ARE DISABLED YOUNG PEOPLE'S EXPERIENCES OF GROWING UP WITH A DISABILITY?**

In spite of the many ways and models of explaining disability at national and international levels, historically and culturally, society continues to struggle with the concept of disability. It is clear that visible disabilities have a long history of provoking fear, repugnance and condemnation. Any marked differences in bodily form are primarily seen as deviations from a singular normal model rather than equally valid alternatives (Shildrick, 2002). Evidence of Shildrick's assertions was revealed in the current study as disabled young people's experiences of growing up in Nyanga are characterised by inconsistencies. Such inconsistencies are dependent upon cultural and religious beliefs about the causes of disability. Thus, disabled young people's experiences of growing up in Nyanga are characterised by discrimination,

acceptance and ambiguity. As stated in Chapter 5, such varied ways of perception and subsequent treatment of disabled young people deprive this group of a stable sense of identity. Consequently, I found that some disabled young people in the current study adopt a non-disabled identity in response to being accepted, which allows them to assert themselves and develop some resilience. However, the majority develop a disabled identity, which drives them to feel sorry for themselves and in the process they fall victims of society's prejudice and discrimination. I have also highlighted that disabled young people's experiences of growing up in Nyanga are marred by the poor socio-economic circumstances under which they live. Participants expressed regret that they have limited opportunities to education, skills training, gainful employment and recreational facilities.

## **8.2. WHAT ARE THE CONTEXTUAL AND INDIVIDUAL FACTORS IN NYANGA THAT IMPACT ON PHYSICALLY DISABLED YOUNG PEOPLE'S EXPERIENCES AND PERCEPTIONS OF SEXUALITY AND HIV/AIDS?**

There emerged from the current study, a picture of a complex interplay of contextual and individual factors, which combine and contrive, firstly, to increase disabled young people's vulnerability to HIV infection. Secondly, they affect access to sexuality education and HIV/AIDS information and prevention services by disabled young people. The third factor is the influence on this population's response to the threat of the HIV/AIDS pandemic in general and the threat of risk in particular. It is a paradox that material need has been reduced through development of human and technological productivity; as well as through legal and welfare protection regulations. Yet such change has created hazards and potential threats to the very human existence (Beck, 1992).

In this thesis, I have pointed at a number of contextual factors such as poverty, cultural beliefs/scripts, gender issues, crime, informal housing, inaccessible public transport, drug and alcohol abuse, lack of social amenities, disability grant, attitudinal and structural barriers, limited education, lack of recreational facilities and policies that are not translated into practical

realities to benefit disabled young people. All these factors were raised in Chapters 5 and 6 and discussed in Chapter 7. Factors such as inadequate policies, contribute to lack of provision of formal programmes for sexuality education and HIV/AIDS prevention and support services. Others, such as transport, prevent disabled young people from accessing existing services. However, none of the stated factors happens in isolation as each influences or is a result of the other. The combinations of these factors create complex conditions of risk for disabled young people and increase their vulnerability to HIV/AIDS risk.

Other contextual and individual factors include social rights that are documented in policy documents, but not applied in practice. Disabled young are expected to benefit from one-size-fit-all programmes instead of targeting them specifically with such services. For example, lack of HIV/AIDS services in Nyanga means that only those without mobility problems can travel to other townships for the same.

Furthermore, the manifestation of the paradox in question is the widespread belief that disabled people are asexual, are not at risk of HIV infection and therefore not including them in existing intervention strategies. This is in spite of the knowledge and evidence that this population is sexually active and likely to be at risk of contracting HIV. The other manifestation of the paradox is the large-scale mystery of why disabled and non-disabled people consistently place themselves at high risk of contracting a disease, which they know is likely to kill them.

Within the framework of the primary paradox, there are multiple levels of complexities and contradictions. The received perception of disabled people as essentially asexual (Groce, 2003; World Bank, 2004a), nonetheless contributes to their high vulnerability to sexual exploitation and rape. The asexual become a sort of ideal sex target. In the practice of such prejudices, disabled young people are denied their sexuality and also exploited for sex. They are assumed to be HIV-free, since they are asexual, and are of lesser importance anyway if infected with HIV because of their dehumanised status

(Shildrick, 2002). Exploitation of disabled people allows for sexual gratification without responsibility and without consequences.

### **8.3. WHAT ARE DISABLED YOUNG PEOPLE'S RESPONSES TO THE THREAT OF HIV/AIDS?**

As stated above, the nature of disabled young people's responses to the pandemic is clearly paradoxical in that their actions do not correspond with their knowledge of the pandemic. This group's fatalistic response to the threat of HIV/AIDS is a paradox that is influenced by the very difficult social circumstances under which they live, so that HIV is perceived in the same light as living in shacks and having inadequate food.

The majority of disabled young people in the current study appear so overwhelmed by the many social problems they face that they simply ignore the problem of HIV/AIDS risk. As pointed out in Chapter 6, most disabled young people feel unthreatened by the threat of HIV/AIDS risk; as a result they feel no need to take protective measures. Even the few who feel threatened adopt an equally fatalistic response towards the threat.

Disabled young people argue that if they are not able to change their situation of poverty, how can they be expected to change their situation in respect of HIV/AIDS? They liken contracting HIV infection to any other accident that cannot be avoided. Fatalistic responses to the problem of HIV/AIDS have also been recorded among non-disabled young people in South Africa (MacPhail and Campbell, 2001; James, Reddy, Taylor and Jinabai, 2004; and Hartel, 2005), who report that, in spite of their knowledge about HIV risk, this population is not using condoms consistently to protect themselves. This finding provides further evidence that HIV/AIDS intervention strategies need to look beyond individual risk and behaviour factors and focus, as well, on contextual factors that also compound the problem.

Consistent with the above interpretation, Parker (2001) notes that the problem of HIV/AIDS in most countries can be explained by a combination of inter-

related factors including migration and urbanisation, political and economic changes, cultural beliefs and racism. Such complex contextual factors cannot be solved by individual sexual behaviour change. Instead, HIV/AIDS programmes that engage disabled young people and their community in dialogue and debate on key issues need to be the way forward, if the failings currently observed are to be dealt with. This is one area of the need for a broad-based and disability-specific educational initiative on four fronts – the witchcraft aspect, the will of God aspect, the sickness aspect and the asexual aspect. There is also need for initiatives that focus on gender related vulnerabilities and general political and economic circumstances in which disabled young people live.

#### **8.4. WHAT IS THE LEVEL OF DISABLED YOUNG PEOPLE'S PARTICIPATION IN EXISTING SEXUALITY EDUCATION AND HIV/AIDS PREVENTION AND SUPPORT SERVICES?**

Apart from the DPSA peer educators, who had a one-off opportunity to participate in HIV/AIDS training activities, I found that disabled young people in Nyanga are not participating in any existing HIV/AIDS prevention activities. There are no community support groups to which they belong to deal with matters of common interest. In summary, it is apparent that this group is neither participating in nor accessing sexuality education or HIV/AIDS prevention and support services for the following reasons:

1. Nyanga is a historically impoverished setting that has limited social services and facilities, including education, employment, sexual and reproductive health and recreation for all people, but more so for disabled young people. Besides, Nyanga has a high crime rate, which makes movement around Nyanga for disabled young people, unsafe.
2. Disabled young people who participated in sexuality education classes in mainstream schools experienced condescending attitudes from their peers and presenters of such talks, which discouraged their participation. Those who went to special school were simply taught to stay away from boys or girls, and the girls even had contraceptives imposed on them.

3. There are no formal or effective sexuality education and HIV/AIDS prevention services specifically targeting disabled young people in Nyanga. The absence of such services means that this population is not participating in national efforts to contain the pandemic.
4. There is only one clinic and a VCT centre in Guguletu, inaccessible public transport, structural and attitudinal barriers hinder access by disabled young people.
5. There is an office near the Athlone suburb that is responsible for HIV/AIDS programmes in Nyanga, and obviously it is unknown to participants in the current study and it is inaccessible to disabled young people for the reasons cited above. Besides, the centre runs one-size-fits-all AIDS awareness programmes that do not cater for the special disability specific needs. As stated above, mobility by public transport is difficult for disabled young people and so they do not attend AIDS rallies that require them to travel. It is also clear that the belief that disabled young people are asexual therefore free from HIV risk, is another reason this group is not considered an at-risk group that may be in need of HIV/AIDS treatment and care.
6. Lastly, most HIV/AIDS prevention programmes have focused on awareness-raising through the abstain, be faithful and use condoms (ABC) message, which focuses on awareness raising and individual rather than collective responsibility. Parker (2001) has suggested that HIV/AIDS messages should go beyond individual behaviour and responsibility and focus on social, economic, political and cultural factors as well.

It is evident from the above summary, that disabled young people need to be viewed as a key group that requires special attention in the provision of sexuality education and HIV/AIDS prevention and support services. And if the foregoing demonstrates anything, it is that an essential component in any planning of future intervention strategies has to be the voice of the people who are not being reached at present. As such, the approach has to be guided by findings from research of the current nature that is informed by disabled young people themselves. The above summary raises two lines of thought:

a) What is not being done right at the moment? The absence of services for this group and the nature of existing services that are not tailored to include disabled young people specifically. Most programmes focus on individual factors of risk rather than on contextual factors as well.

b) What can be done to improve services where shortfalls or failings are identified? Firstly, there is a need to improve the living conditions of disabled young people in Nyanga in terms of provision of formal housing, creating jobs and reducing crime. There is also need to improve access to education, skills training, recreation, and transport facilities. There is equally a need for provision of community-based and inclusive sexuality and HIV/AIDS prevention services for disabled young people, which target the entire community instead of just individuals and can be used to address other contextual factors, such as crime and poverty, apart from HIV/AIDS. In addition, a guideline that can be used to adapt existing HIV/AIDS programmes into inclusive ones for disabled young people is also presented below.

## **8.5. RECOMMENDATIONS**

1. The current study has established that disabled young people are at risk of contracting HIV infection because they are exposed to a number of factors that place them at risk. However, the qualitative nature of the study was not able to establish how many are actually infected or free. Such information would not only complement the findings of the present study, but it would also confirm the stated vulnerability of disabled young people to HIV infection. Therefore, there is a need for more research of a quantitative nature to establish the HIV/AIDS prevalence rates among disabled young people in South Africa in general and Nyanga in particular. Such information would assist in the planning of holistic sexuality and HIV/AIDS intervention programmes for disabled young people in Nyanga, and more widely.
2. It is recommended that the approach to sexuality and HIV/AIDS intervention strategies for disabled young people should aim to engage

with whole communities instead of small groups or individuals. As stated above, such programmes should also focus on contextual and individual factors that impact on HIV/AIDS risk. Nyanga community needs to be helped to explore cultural and socio-economic factors that fuel the pandemic and seek ways to change those, at the same time identifying factors that reduce risk and encourage those. Existing HIV/AIDS intervention programmes need to be adapted to become inclusive of disabled young people's special circumstances.

3. Development programmes need to be an integral part of all sexuality and HIV/AIDS programmes. This is because conditions of poverty double the vulnerability of disabled young people to risk. Creating jobs for disabled young people might, therefore, reduce their need to sell sex for food, thereby reducing this population's vulnerability to HIV infection.
4. In view of the finding that health care professionals avoid the subject of sexuality and HIV/AIDS, and the likelihood that they are not trained to deal with such issues, it is recommended that curricula for medical and therapy professionals be reviewed with a view to broadening the biomedical approach to include a bio-psychosocial approach. In that way, medical and therapy professionals would be able provide holistic care to their clients. Such a move would prevent societies from turning to potentially harmful cultural traditions, such as witchcraft, that is believed to reduce the risk of HIV transmission, or cure it.

On the medical front, encouraging circumcision at an individual level, in isolation, is a double-edged sword – it provides protection in a man, statistically at least (Weiss *et al*, 2000), against contracting the virus, though it does little to reduce the risk of onward transmission. However, there is also the risk of it giving males a false sense of security, 'I'm circumcised so I'm safe', much of the consequences of which might well be borne by women at community level. This situation also illustrates the need for a holistic address to intervention methods – medical fact about circumcision needing to meet cultural belief and design a message that



can be understood in both ways, the two becoming complementary rather than being as mutually exclusive as stepping on a snake and catching a polio microbe.

5. It is further recommended that efforts be made for disability policy and services for disabled young people to be informed by the experiences and perceptions of the target population. This is in recognition of the fact that disabled young people are the best judges of their own needs. The voices of any group for whom services are intended can be key to successful planning and implementation of the same. This is the basis upon which the recommendations in this thesis have been formulated.

## **8.6. APPROPRIATE INTERVENTION STRATEGIES**

The fourth objective of the current study was to recommend intervention strategies that would be inclusive of disabled young people's needs. To this effect, disabled young people expressed specific concerns and needs for HIV prevention and support services. Among these, was their need to know more about HIV/AIDS, to be taught by fellow disabled people who understand them better, and to be included in mainstream HIV/AIDS programmes. There were others who expressed a need for separate HIV/AIDS programmes because they feel more comfortable in the company of fellow disabled people. Such a wish indicates the long-term effects of the prolonged social isolation of this population.

### **8.6.1. Community-Based HIV/AIDS Programme**

Based on disabled young people's recommendations above and the importance of including contextual factors in intervention programmes, a community-based HIV intervention programme is recommended. Airhihebuwa *et al* (1999) and Parker (2001) suggest that HIV/AIDS intervention programmes need to adopt horizontal and participatory approaches to communication. Such approaches incorporate a concept of enabling environments and a focus on contextual factors. For this reason, a programme known as Community Capacity Enhancement (CCE) is

recommended for disabled young people in Nyanga. The United Nations Development Programme (UNDP) developed this programme (Gueye *et al*, 2005). CCE is based on a methodology known as 'community conversations' (CC). A number of countries such as Senegal, Cambodia, Swaziland Cameroon and South Africa have adopted 'community conversations' methods and report satisfaction in how communities show capacity to discuss, identify problems and suggest their own course for change (Sharma, 2005).

The 'community conversations' method is aimed at dealing with some of the underlying causes of HIV/AIDS like power relations, gender issues, stigma and discrimination (Sharma, 2005). According to Sharma (2005), the main principle of 'community conversations' is to facilitate a process of decision-making and action within communities. While the importance of community-based systems that focus on awareness-raising and discussion is recognised, 'community conversations' focus on interactive dialogue on the pandemic's deeper causes. By implication, the social constructions of disability and sexuality constitute some of the deeper causes of HIV/AIDS as it affects young people with disabilities. For this reason, the 'community conversations', approach has capacity to assist the Nyanga community to uncover and deal with the deeper issues regarding sexuality and HIV/AIDS in the context of disability.

Furthermore, the 'community conversations' principle resonates with the argument presented by Snell *et al* (1993), where he suggests that, given the necessary support, communities have the capacity to exert normative and informational social influence supportive of AIDS-preventive behaviour. Based on this line of thought, 'community conversations' methods encourage the participation of all community members, disabled and non-disabled, young and old, male and female, family and religious members, employed and unemployed. Even stakeholders such as policy makers and custodians of culture can also participate in 'community conversations' (Gueye *et al*, 2005). In that way, a community such as Nyanga would be able to engage with issues such as cultural beliefs regarding disability and sexuality. Besides, and more importantly, young people with disabilities would participate in

'community conversations', in order for their own voices to be heard. When communities identify problems together, they are also able to explore possible solutions to the problems instead of handed-down solutions from outside or top-down approaches from the experts.

### **8.6.2. Steps in Facilitating Community Conversations**

#### **Relationship Building:**

In this phase, facilitators build a relationship of mutual trust, understanding and respect with the community, using skilful questioning, listening and observational skills as well as participatory activities. The facilitator develops an appreciation of community values and works from this understanding when helping communities to identify their own concerns. *This is a phase that would help communities to engage with disabled young people in ways that they normally and currently do not.*

**Identification of common concerns:** Community concerns are issues that worry or disturb communities, triggered by their own perceptions of the problem. *For example, sexual abuse is a concern for disabled young people which the Nyanga community seems helpless to do anything about.* Communities are capable of identifying their own concerns and needs, but the facilitator guides them using strategic questioning. The facilitator does not impose their views on the matter; otherwise the solutions that evolve from such an imposition may not work. The community takes on the responsibility for such identification of issues.

**Exploration of community concerns:** the identified concerns are put through a rigorous exploration process using community-sensitive language and techniques, guided by strategic listening and questioning. Exploration leads to a complex understanding of the underlying factors causing the identified concerns. *For example the reasons for the exclusion of disabled young people might be discussed at this level.* The community takes responsibility.

**Decision-making and planning:** In this phase, communities make specific decisions for action, based on the concerns they have identified and the findings of the exploration. This is a planning phase where communities are supported to apply the basic planning questions of ‘what, how, when, where and who’ to each decision taken.

**Action or implementation phase:** Decisions taken consist of changes that must be implemented and sustained for an effective response. Action on decisions must involve as many community members as possible, *including disabled young people*, so that the community assumes ownership of the process and ensures the sustainability of the solution.

**Reflection and review:** This is a facilitated reflection and review, not an evaluation. It is based on respect for the capacity of communities to identify their own changes and indicators of change. Reflection and review is also a practice linking all the various phases of the process. Each community session is concluded with a reflection and summary of the day, while the following session also begins with a recap of agreements of the previous session.

**Resonance:** In conclusion, the community conversations approach expands the ability of communities to transfer and share lessons with other communities. The process of transfer continues to share itself from community to community, as well as among the growing pool of implementers and facilitators, contributing to the scaled-up approach to HIV/AIDS. The proposed action often requires interface with other organisations and wider civil society, the changing of laws and enforcement of human rights, including *women’s rights* and *disability rights*. There are also changes that require financial resources that may not be readily available at community level, especially in the areas of care, support and mitigation of impact. This necessitates an interface of ‘community conversations’ with community documentation, community financing mechanisms and network development (Gueye *et al*, 2005: 5).

In the context of culture and through community conversations, the Nyanga community might decide to encourage the practice of male circumcision because it is associated with a reduced risk of HIV infection in sub-Saharan Africa (Weis, Quigley and Hayes, 2000). In the same breath, this community could find its own solutions for reducing rape of disabled young women. The same system and methods can be used to scrutinise disability policies, in terms of the effectiveness of implementation and monitoring processes. The flexibility of 'community conversations' is such that it can also be used to explore other developmental, social and health issues affecting the entire community.

An alternative to adopting the 'community conversations' method is to make existing HIV/AIDS prevention programmes inclusive of disabled young people's special circumstances. The World Bank (2004b) has proposed a guide that might be used to effect the stated modifications, as outlined below.

### **8.6.3. Inclusive HIV/AIDS Programmes**

The complex nature of disability leads to complex challenges that call for a diversity of responses, which are both inclusive and community-based (De Greeve, 2005). Specific actions to effect adaptations to existing HIV programmes have been proposed. These range from educational materials to issues of physical accessibility. As different groups of people with disabilities require different adaptations, the proposed guidelines can be used to meet the needs of all disability groups. According to the World Bank (2004b) and De Greeve (2005), the guide below provides three options from which existing HIV/AIDS programmes can choose. This choice depends on the type of disability group and the organisation's financial capacity to achieve inclusion of disabled young people in mainstream HIV/AIDS activities.

### 8.6.3.1. Types of Actions to Include Disabled People in HIV/AIDS Prevention and Care Services

There are three types of actions or approaches to HIV/AIDS prevention and care services that can include disabled people, as outlined below:

#### Type of action

**Type 1:** Individuals with disability are reached by the same AIDS education messages and services as members of the general public.

#### Methods:

1. Ensure that AIDS education outreach and services available to the general population include individuals with disability.
2. Use materials already available to the general public, incorporating simple adaptations to ensure accessibility by all.
3. Train AIDS educators, outreach workers, clinical and social service staff on disability issues. Train individuals with disability to be AIDS educators. Include outreach to the disability community to recruit into these programmes.

#### Cost:

Little or no additional cost (with the caveat that the cost will rise with the level of tailoring to individual disabilities).

#### Examples:

1. AIDS posters and billboards depict individuals with disability (that is, wheelchair users, blind and deaf individuals) as part of group scenes. Move AIDS education, testing and care service delivery programmes to accessible meeting places.
2. Make simple adaptations such as allowing blind individuals to feel a condom, rather than just talking to them about it.
3. Make simple and straightforward HIV/AIDS messages to allow intellectually-disabled individuals to understand and memorise the words

#### Type of action

**Type 2:** Adaptations are made to AIDS outreach campaigns to ensure that individuals with disability are included as members of the general public.

#### Methods:

1. Adapt already existing materials to ensure inclusion of disabled people.
2. Make simple alterations to facilities to increase inclusion.
3. During general training programmes, train HIV/AIDS educators and clinicians about disability in general, and that there are differences in

- the needs of individuals with different types of disabilities.
4. Train individuals with disabilities to be AIDS educators.

**Cost:**

Low to moderate additional cost

**Examples:**

1. Caption AIDS public service announcements on TV for deaf people.
2. Make AIDS materials available for blind people in inexpensive cassette formats and in Braille
3. Build ramps into meeting halls or clinics (ramps can be made of mud, bamboo, stone, wood and so on).
4. Ensure that HIV/AIDS information is disseminated in a variety of formats: radio, billboards, to ensure that specific groups (deaf, blind) do not miss out.

**Type of action**

**Type 3:** Disability-specific adaptations of existing materials and development of new materials to reach individuals with disability outside the bounds of the general public, targeting harder-to-reach individuals and populations.

**Methods:**

1. Develop disability-specific outreach efforts.
2. Develop new materials to use in outreach efforts.
3. Train AIDS educators, hire staff specialising in the issues related to serving the specific disabled population targeted; train disability advocates to be AIDS educators within the disability community as well as the overall community.

**Cost:**

Moderate to higher added cost

**Examples:**

1. Videos in Sign language for Deaf.
2. Target schools, institutions and organisations serving populations of disabled people for special programmes to ensure that students, residents or participating members have been informed.
3. Rewrite training materials in simpler language/easy-to-understand format for those with intellectual impairments, or for disabled individuals who are illiterate or low literacy.
4. Have a sign language interpreter at clinics/hospitals to explain complicated regimes of AIDS drugs and follow-up.
5. Train HIV/AIDS educators and service providers about disability issues.

*This information is based on a table that can be found in the Yale/World Bank Global Survey on HIV/AIDS and Disability report, 2004.*

## 8.7. CONSTRAINTS AND LIMITATIONS OF THE STUDY

Using the Atlas.ti package for the first time to analyse qualitative data was challenging. I supported such analysis with manual methods as well, which took a long time, but helped me to tease out as much relevant information as I needed to answer the research questions and meet the objectives of the study.

This study focused on physically disabled young people, thus it may not reflect the experiences of other disability groups, such as blind and intellectually disabled people, who are equally vulnerable to HIV/AIDS. Besides, there are other physically disabled young people in Nyanga who are not represented in this study because they could not be reached in the crime-ridden areas that are considered unsafe to visit.

The qualitative nature of this study does not claim that the results can be applied generally to all young people with different types of disabilities. However, readers bring to a case study their own experience and understanding, which lead to generalisations when new data for the case are added to existing data. Stake (1995) considers these generalisations to be part of the knowledge produced by case studies. Based on this argument, the current study can be replicated in other communities and the results can be generally be used to inform policy for the benefit of all disabled young people in South Africa. Although the present study was carried out in Nyanga only, the results are similar to those found in other studies in Uganda (Nganwa *et al*, 2002), worldwide (Groce, 2003), and among non-disabled young people in Ethiopia (Tadele, 2006). Therefore, the results of the current study can be fairly generalised, especially in sub-Saharan Africa, while drawing comparisons that would be specific to each country or townships in South Africa.

Not being able to speak Xhosa was a barrier to in-depth interviews of such a socially and culturally sensitive subject as sexuality and HIV/AIDS. Firstly, some mothers expressed reservations about discussing sexuality matters in



the presence of a male intermediary. In such situations I had to reschedule the interviews in order to identify female intermediaries to assist with translations. Secondly, the first interviews were shallower than later ones because initially, I did not understand any Xhosa and so could not question the translations. Subsequently, I picked up some of the language and could then understand much of what was being said. At this point, I was able to ask for further clarification if I did not understand the translation. In that way, the quality of the interviews improved.

Owing to limited research on disabled young people as a specific group, literature was extrapolated based on experiences of sexuality and HIV/AIDS of disabled people in general and also young people in general.

## **8.8. CONCLUSION**

I have come to the conclusion of this research journey, which set out to answer specific research questions, which I have done.

1. The paradox of risk lies in the belief that:

- a) Disabled young people are asexual, yet are considered 'easy targets' for sexual abuse that increases their vulnerability to HIV risk.
- b) In addition, disabled young people are challenged to prove that they are sexual beings, which leads them to engage in risk taking sexual behaviour.
- c) HIV/AIDS has been declared a health crisis that calls for all to participate in its prevention, yet disabled young people are not included in formal prevention efforts.

2. Another paradox is that disabled young people feel so overwhelmed by the many socio-economic challenges they face, so that both those who feel threatened and unthreatened by HIV risk, take no precautions against contracting HIV infection; they have to take risk as a way of life. For this reason, a community-based programme that views people and communities as agents of change and supports debate on key issues at local level has been recommended. An outline of steps that can be adopted to make existing HIV/AIDS programmes inclusive has also been presented. Thus, the current

study has not only answered the research questions, but it has also fulfilled the research objectives that were outlined in chapter one.



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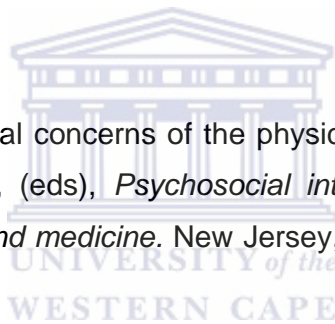
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## **Appendix A: SEMI-STRUCTURED INTERVIEW GUIDE**

### **Growing up with a disability**

- Tell me about yourself and your family
- How does it feel to grow up in Nyanga as physically disabled young person?
- What are cultural beliefs about disability?
- Tell me your experiences with schooling?
- Which school system do you prefer, special or mainstream?
- What other opportunities are available to disabled young people?

### **Facts about sexuality and HIV/AIDS**

- What do you know about sexuality?
- What are cultural beliefs about sexuality?
- What do you know about HIV/AIDS?
- What does the church say about sexuality and HIV/AIDS?
- Where did you get this information?
- Do you know any disabled young person who is infected or has died from HIV/AIDS?

### **Social relationships**

- What challenges do you face in making friends?
- Do you think society treats you differently because you are disabled?
- Do you have any challenges engaging in intimate relationships?
- Who taught you about matters of girlhood or boyhood?
- How about the role of society, school, church or social club

### **Perceived risk of HIV/AIDS**

- Do you think you are at risk of contracting HIV/AIDS? Why and why not?
- Do physically disabled young people perceive themselves to be at risk? Why and why not?
- What factors place you at risk of HIV infection?

### **Access to sexual health, HIV treatment and preventive care**

- What sexuality and HIV prevention services available in Nyanga?
- Have you had an HIV test? Explain
- If you were asked to choose between inclusive and separate sexuality and HIV/AIDS services, what would you prefer
- Who would you like to teach you about sexuality and HIV/AIDS matters? Explain



## Appendix B: PROFILE OF THE PARTICIPANTS

### I) YOUNG PEOPLE WITH PHYSICAL DISABILITIES

Name	Age	Sex	Disability	Appliance
Sibongile	19	F	Cerebral palsy	None
Nomthandazo	22	F	Left Hemiparesis	None
Xolani	24	M	Cerebral palsy	Wheelchair
Thandiwe	18	F	Cerebral palsy	None
Bongiwe	15	F	Right Hemiparesis	Walking stick
Mcumisa	17	F	Cerebral palsy	Crutches
Andiswa	20	F	Cerebral palsy	crutches
Bonginkosi	18	M	Post polio paralysis	Wheelchair
Ntokozo	19	F	Left Hemiparesis	None
Lindiwe	21	F	Contractures hips	None
Zandile	18	F	Right Hemiparesis	None
Vuyisela	17	F	Post polio paralysis	Crutches
Nontsikelelo	24	F	Fisted fingers	none
Nceba	24	M	Post polio paralysis	Crutches
Philisiwe	23	F	Post polio paralysis	none
Thembaletu	24	M	Post polio paralysis	Crutches

### ii) KEY INFORMANTS

Name	Age	Sex	Status	Position
Key 1	40	F	non-disabled	Coordinator – the elderly
Key 2	39	M	disabled	Coordinator – YPWD
Key 3	39	F	disabled	Workshop supervisor
Key 4	55	F	non-disabled	community member
Key 5	65	F	non-disabled	Retired schoolteacher
Key 6	35	F	non-disabled	DPSA head office
Key 7	29	F	disabled	DPSA member/Nyanga
Key 8	28	M	disabled	DPSA member

### iii) Focus group Discussion groups (FGD)

	#	M	F
1. Young people with Physical Disabilities	3	1	2
2. Young people with Physical Disabilities	8	3	5
3. Young people with Physical Disabilities	10	4	6
4. Parents of children with physical disabilities	6	0	6
5. Parents of children with physical disabilities	10	0	10
6. Parents of children with physical disabilities	7	0	7
7. Senior citizens	15	3	12
8. Councillors	4	4	0
9. Sangomas (traditional healers)	4	1	3
10. Association for Persons with Physical Disabilities	10	3	7

# Appendix C: PARENT INFORMATION SHEET AND CONSENT FORM

## UNIVERSITY OF THE WESTERN CAPE

### **PARADOX OF RISK: SEXUALITY AND HIV/AIDS AMONG YOUNG PEOPLE WITH PHYSICAL DISABILITIES IN NYANGA, SOUTH AFRICA**

**RESEARCHER:** MARGARET WAZAKILI (PHYSIOTHERAPY  
DEPARTMENT) TEL: 0826373453

The University of the Western Cape and those conducting this research subscribe to the ethical conduct of research and to the protection of the interests and comfort of participants. This form and the information in it are given to you for your own protection and full understanding of the procedures. Your signing of the form will mean that you are fully aware of the procedure of this research project and that you have received adequate opportunity to consider the information therein.

**Description:** I am a doctoral student at the University of the Western Cape in the Physiotherapy Department. I am currently doing research to explore the perceptions of physically disabled young people regarding sexuality and HIV/AIDS. I would like physically disabled young people between the ages of 15 to 24 to participate in focus group discussions with their peers with similar disabilities. Therefore, physically disabled young people in your child's age range have been selected as possible participants. I would like to ask permission from you for your child's participation in this research. Please be informed that all the governing bodies, including Disabled People South Africa were already approached to seek permission, and it was granted.

**Benefits of this research:** This study is the first comprehensive data gathering initiative in Nyanga regarding perceptions of the physically disabled young people themselves on issues of sexuality and HIV/AIDS. It will provide the basis for inclusion of physically disabled young people in mainstream programmes of sexuality and HIV/AIDS. I cannot guarantee that your child will benefit personally in any way from this study. However, your willingness to let your child take part, may in the future, help the disability sector and society as a whole to understand and be sensitive to the specific needs of the physically disabled young people on the subject.

**Risks, Stress and Discomfort:** There are no foreseeable risks in participating in this study. However, the topic of HIV/AIDS may make some physically disabled young people feel uncomfortable. Some direct questions will be asked about sex, but everything will be confidential. If your child may feel uncomfortable or upset at any stage, referrals will be made to appropriate services.

**Privacy:** Your child's privacy will be maintained, as any information obtained during this study will be kept confidential. Knowledge of their identity is not required and personal opinions will not be reflected in any of the results. Recorded material will be handled with utmost confidentiality and be stored in a secure location during and after completion of the research.

**Time involvement:** The research will be done during the school year at an appropriate time as negotiated with the different groups of disabled young people, depending on whether they go to school or not. Your child will therefore be involved at a time that will be suitable for you both or his/her school should that apply. Sessions will only be 1 to 2 hours per week and will involve interviews, which will be audio taped and transcribed. The transcriptions will be brought back to you and your child for verification.

**Payment:** Your child will receive no payment for his/her participation in this study.

**Participation rights:** If, after reading this form, you decide that your child should participate in this study, please understand that participation is voluntary and you and your child have the right to withdraw your consent or discontinue participation at any time without penalty. Your child has the right to refuse to answer particular questions should he/she feel uncomfortable. His/her rights will be respected at all times and your decision to prevent him/her from participating will have no effect on the quality of services he/she receives from any programme.

In the event that your child is dissatisfied or he/she wants to ask any questions about his/her rights as a participants in the research, you may register your concern with Prof R. Mpofu at (021)9592631, the researcher on 0826373453 or the Ethics Committee of the University of the Western Cape.

.....  
**I give consent for my child to participate in this study.**

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix D: CONSENT FORM

### RESEARCH ON THE EXPERIENCES AND PERCEPTIONS OF PHYSICALLY DISABLED YOUNG PEOPLE REGARDING SEXUALITY AND HIV/AIDS

I,.....freely and voluntarily consent to participate in a research project under the supervision of Ms Margaret Wazakili.

I understand that the purpose of the study is to explore physically disabled young people's perceptions on sexuality and HIV/AIDS and to find out if they have equal access to sexuality and HIV/AIDS information, treatment and care that is available to their non-disabled counterparts. I also understand that the researcher intends to solicit my views on how disabled young people can be included in mainstream sexuality and HIV/AIDS programmes that are available in my community.

I understand that the results of the study will inform policy makers, educators, and other service providers to make their sexuality and HIV/AIDS programmes inclusive of the special needs of physically disabled young people. The researcher hopes too that parents and communities would be informed by the results of the study so that they may be sensitive to the needs of disabled young people regarding sexuality and HIV/AIDS. The researcher hopes that disabled young people will not continue to be left out in efforts to prevent the spread of HIV/AIDS in the Western Cape and eventually in the whole country.

I understand that I might withdraw my consent and discontinue participation in this research at anytime without prejudice to me. I understand also that I have the right to ask any question and expect answers to my satisfaction. I have read the contents of this form and received a copy.

.....  
WITNESS

.....  
DATE

.....  
PARTICIPANT

.....  
DATE

**I HAVE EXPLAINED THE RESEARCH PROCEDURE TO WHICH THE PARTICIPANT HAS CONSENTED TO PARTICIPATE**

.....  
SIGNATURE

.....  
DATE

## Appendix E: SELECTED TRANSCRIPTS

The first two transcripts are from disabled young people, the next two from focus group discussions and the last two from key-informants

### Individual in-depth interview, doc-1

08.03.05

**Lindiwe** 21years. Severe hip flexion contractures, walks with a flexed spine almost 45 degrees.

Question: Tell me about yourself

Answer: I live with my grandmother, two brothers and two sisters. My mother died when I was young and I do not know my father, in fact, I never got to know any of my parents. My grandmother brought me up, my grandfather died. I went to school at Thembaletu up to grade 9. I could not go further with education because they told me I was old in 2002. I was the only one who went to school in my family, me the disabled one, my brothers and sisters are able and they did not go.

Question: When did you become disabled?

Answer: I was born like this, I was crawling, they did 3 operations on me, but I do not know what type of disability I have.

Question: Which hospital professional spent more time attending to you during the years that you were undergoing medical treatment?

Answer: The doctors (How about physiotherapists) yes there was PT. They exercised me.

Question: How do you feel about growing up as a disabled young person?

Answer: Nothing, I do not take myself as disabled, I am normal like everyone else.

Question: Do your friends treat you differently because you are disabled?

Answer: I have many friends, disabled and non-disabled. but yes, people just look at me so much when I am walking, they are not nice, others laugh at me

Question: How about the older people, how do they treat you?

Answer: they are very nice to me, no problem at all.

Question: As a growing up girl, were you taught anything about sexuality and sex

Answer: No, I just learnt from TV.

Question: Have you ever had a boyfriend?

Answer: Yes, I have one just now and he is here at this workshop.

Question: How about in the past

Answer: Yes, there were many guys who came to me. They were just using me. They wanted my money and to sleep with me. Then I realised that they did not love me, they were just using me. (*That's strange says me, I thought its girls who go after men for money, I did not know that the other way round was true*). Yes, it is true they just want my money. If a person does not like you, obviously they are going to do that, they are going to do that.

Question: Before Vuyo came to this workshop to talk about HIV/AIDS what did you know about the subject?

Answer: If someone has a hole in the hand and you touch it, you can get AIDS. If someone has a drop from the penis they can give you AIDS if you do not use a condom.

Question: Where did you get this information?

Answer: From the clinic.

Question: What additional information did Vuyo give you?

Answer: laughs...I cannot remember

Question: you got your first HIV information from the clinic, did you know there was going to be a talk on AIDS or it was coincidence?

Answer: I went for check up, I am 3 months pregnant.

Question: Do you intend to marry your boyfriend now that you are expecting his child.

Answer: No, I do not want to marry him although I am staying with him at the moment at his parent's house. I am not sure I want to marry him.

Question: Were you forced to live with him then?

Answer: No, I decided for myself and our parents agreed, but now I am not happy, I do not know why.

Question: Do you consider yourself at risk of contracting HIV/AIDS

Answer: No

Question: Why not?

Answer: I have only one boyfriend and I trust him

Question: Have you had an HIV test?

Answer: No, I am afraid

Question: Tell me who is best suited to give HIV/AIDS information to disabled young people.

Answer: Anyone can do it if they know what they are taking about

Question: Do you think disabled young people are more at risk of contracting HIV? Explain

Answer: Yes they are more at risk because the disabled girls like men, they sleep with many men. They go to the Shebeens and when they are drunk

the men take them to their house and sleep there the whole night. The parents do not know until morning because they are also busy drinking at night.

Question: How do you know this?

Answer: I know because I am one of them. I drink, but my boyfriend does not drink. It happened to me. I went to the Shebeen and got drunk. This man invited me to his house and raped me.

Question: Did you report this incident?

Answer: No, I was afraid, I just kept quiet.

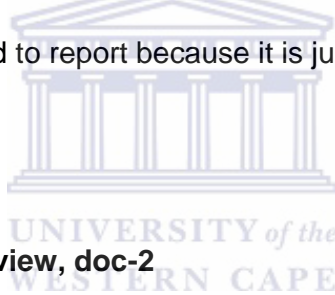
Question: Do you think there are many disabled girls who behave like you?

Answer: Yes, they are afraid to report when they are raped. Because if the parent know they will go to police and then their life is in danger. These men would also attack the disabled girl if she is walking alone in the street. So people are afraid.

Question: Having kept quiet about rape yourself, would you tell your friends to do the same.

Answer: No, it is good to report because it is just good to know...

Thanks for your time.



### **Individual in-depth interview, doc-2**

**06.07.05**

**Nceba:** 24 years post polio paralysis both legs (bilateral calipers/swing through gait)

Question: Tell us about your disability

Answer: I have got polio. I have been diagnosed in 1982. Since then I moved to Cape Town for Treatment as such. I was born in a rural area in Transkei in the Eastern Cape and treatment that side it wasn't like up to stretch. Since 1982 I was residing in Cape Town.

Question: Have you been disabled all your life as far as you can remember?

Answer: No, I remember being able to walk as a child but then I got sick and became disabled.

Question: At what age did you start using crutches?

Answer: I was about 4 or 5 years when I started using calipers and crutches.

Question: Tell us how it feels to be a disabled person in this society in this society.

Answer: Ok basically, according to my point of view...I went to a special school here in Montana, here in St Joseph's home, so where you have been isolated from society mainly so by the time I came out of the Institution, I felt like strand among able-bodied people. I saw myself different to them, but since I did that at a young age, I adapted very easily to the outside world. Ya...even to be honest, at that time, I wore like shorts but now, having my mentality, I see like myself in a nut shell, I wouldn't be able to wear shorts. To be honest, I feel embarrassed of how I look.

Question: Is this embarrassment because of how society treats you?

Answer: No, it's because of my own mentality state, because like I see other disabled people with the same disabilities on the sports ground when we used to play basket ball, most of them they wear shorts, three quarters, they wear like tights, you see they don't feel threatened about who they are. (*But you do?*) Only that mentality of mine that I look like this *uyabona* (*you see*). So I decided, I will be wearing long pants because this is who I am, other than that I have no problem.

Question: As you grew up, did you feel that friends treated you differently because you were disabled?

Answer: No, basically, my friends did not see me as disabled. It's like I remember at the High School that I went...I went at like a mainstream High school, the thing is like, when my friends were playing football and I was playing with them. I can remember one day, when we got our results even one of them, they forgot that I was disabled, they jumped upon me, yaah... so like I had to catch my balance (*What results were these?*) we won the football game.

Question: How about society in general, do you think society treats you differently because you are disabled?

Answer: No, I won't say that, because even people threaten to kill us (*What?*) You know, they see us as lover boys. (*What do you mean by lover boys?*) They feel threatened when they see us with a woman, like they told my friend here.. 'You if I see you with my girlfriend, I will shoot you' (*Do they really mean that?*) Absolutely, they think we love girls too much.

Question: Would you say that you have difficulties making friends?

Answer: No, it all depends on the mentality of the other person; people do not have problems making friends with me.

Question: How about members of the community in general, do you have challenges relating to them?

Answer: Some people are still full of stereotype, like seeing two people on crutches, being disabled together, its like an African ritual, like their luck day, should they play the lotto its like they will win because they have seen two disabled people together at the same time.



Question: Can you remember other rituals that are common in this community?

Answer: Sometimes they even like to ask, are you on strike? What is happening?...laughs...The other thing is what put you two together? Why are you walking together? Its like the mentality...the stereotype because it is unusual to see disabled people walking together. Once they see two able-bodied people walking together, they won't ask, but they will ask disabled people. By the way, even when two pregnant women are walking together, they will ask the same questions, why are they walking together? They are both pregnant (*Is pregnancy considered a disability as well?*) Not really, it is just state of society's mind.

Question: Tell us about sexuality, how are such issues handled among disabled young people?

Answer: To be honest, me I come from the old school type of arena, like people only became free to talk about this after the 1994 elections, before that you did not discuss sexuality issues, like that time when I was growing up, I had to surf for myself this information (*where from?*) from friends. But in this, there was one teacher, when I was in standard 4, talking about this like the 'birds and the bees' (*What is that?*) The 'birds and the bees' are like, especially when we grew up, its like when they tell us about reproduction, male-hood, female-hood, what is happening with your body, the change (*where was this done?*) All in school.

She said like you guys you like to make a girl pregnant, after that you run away saying that it's not your child (*Was she referring to disabled guys only or it was about all guys?*) In this school it was disabled guys only but I think she was talking about all guys. There and then I took a decision like, what this woman says might be true. But I was still young that time, but as I grew older, it keeps haunting me what she said, even up to today. (*So you are not going to run away from your baby?*) No, I am not going to run away from my responsibility because what I believe is that any man can make a baby, but not any man can be a father to a baby (*that's true*).

Question: What is your own family like?

Answer: I did not grow up with my mum and dad. I grew up here in Montana at school. But my parents are together. I have brothers and sisters and they are all younger than me (*Do you discuss sexuality issues in your family?*) Not with my parents, but sometimes I talk to my brothers and sisters.

Question: Who taught you about issues of boyhood (*sexuality*) apart from your teacher?

Answer: In a boarding school, we were always separated from girls. Then, when I grew up I like resented ladies, I didn't like them, I didn't play with a girl. So I grew up to be honest, like myself, I passed metric without having a girlfriend, having that mentality like it wasn't good for me. This was because of the school background that I have.

Question: Can you tell me about traditional ceremonies that teach young people about being male or female?

Answer: Aaah...for instance when you are a girl, there is intonjane like to say now you are a grown woman. You are ready now for the outside world (*What does that really mean?*) It's like to introduce her to female hood like who she really is. (*Do you know exactly what they teach them?*) To be honest, I haven't been to that school...laughter...

Question: What about ceremonies for boys?

Answer: Most of the time I am in Cape Town, by the time I went that side to the Eastern Cape it's either like they are coming out of the circumcision school, the bush, so when they come out its like celebration. That's the time like I know that this took place. they have come from initiation school. There you are being told like now what are men all about. (*Tell me exactly what it is to be man*) laughter...Its like the things you have been doing as a boy, you cut it out like for instance, you are not supposed to go and shout around in the street, boys do that but men don't do that. (*What else signifies you as a man?*) You report to your family, lets say you are visiting a friend, and it so happens that your friend asks you to sleep (*spend a night*). You have to report and say I am not coming back, otherwise I am safe I am with my friend, usually boys do not do that. In other words the dress code changes (*How?*) For instance like to show the difference between boyhood and men, there is stage you go in you have to wear like a dress code that they tell you like when you are a young man, in Xhosa they call you are a *kwala* (new initiate) then, when you are a *kwala* you have to wear a jacket, shoes and a hat, you are between being a man and a boy.

Question: I have seen a number of young men on campus with this kind of dress code that you are describing, are those the *kwalas*?

Answer: Yes, they have just been introduced to manhood.

Question: Ay what point did you start knowing about HIV/AIDS?

Answer: HIV/AIDS...it was at school. The teachers taught about HIV/AIDS some of the information I saw on TV programmes and through pamphlets given at school.

Question: Tell me what you know about HIV/AIDS.

Answer: Like when you as a person contract the virus, you contract HIV only, at that time its like a virus attacking your body. One it attacks your body it looks the same like white blood cells so like whit blood cells fail to counter it by the time they get aware that this cell inside the body s not the same as them, it is already too late for them, they (*virus*) have already multiplied so the virus are multiplying inside of you.

Question: How does one contract HIV/AIDS?

Answer: You contract HIV/AIDS in 3 different ways like unprotected sex, then you get like blood transfusion and then the 3<sup>rd</sup> one is like from mother to child.

Question: How can physically disabled young people protect themselves against HIV/AIDS?

Answer: Disabled young people can protect themselves from this virus by the three ABCs that is abstain, be faithful and condomise.

Question: Do you think physically disabled young people know as much about HIV/AIDS as non-disabled young people?

Answer: To be honest they know similar information.

Question: Are you talking about disabled young people who are in your position (educated and working) or those that are sitting in parents' homes in the community?

Answer: No, I would select disabled people who go to school, like those who sit at home they are like victims because they are like being isolated from everything. They feel sorry for themselves, they don't feel free to walk on the streets like they think society separates them.

Question: Do you think this is the problem of society or disabled young people themselves?

Answer: It's the problem of society, basically its like charity starts at home, its like how they were treated at home so if they are treated like that at home, they will think that society treats them like that.

Question: Talking about physically disabled young people who are sitting at home, do they have access to similar information about HIV/AIDS as their non-disable counterparts on the streets?

Answer: To be honest, they won't because like I would come back again to say like illiterate people, whether able-bodied or not, the information they have is just at partial level, like their information is the information of the young people who are disabled. So I do not distinguish differently, I say able-bodied people who are educated have the same information as disabled people who are educated and vice versa.

Question: Has HIV/AIDS affected your own sexual life?

Answer: Ya...big time because to be honest I have once been involved with a lady who is HIV+ so like to be with her, I always used safe sex (*What do you mean by safe sex?*) that is sex with protection, condomise.

Question: Did you know before you went out with her that she was HIV+?

Answer: The thing is when I go out with a girl for the first time, her I do use a condom. It's like I do not trust her yet. Once my friend knew that I was going out with her who told me that it was rumoured that this girl was HIV+. Every time I tried to ask her about this issue, I didn't like to come straight on that point of HIV+ because I know it's a sensitive issue, I did ask her like in a way but not to deny it. But she denied, so I said let me keep to my guts and try to be safe.

Question: Did it occur to you that you should get tested for HIV together with your girlfriend?

Answer: To be honest when I was going out with her, to be tested, I was a bit afraid because like I did not know whether I would be able to take the bomb, but say last year...I went out with her in 2003 and in 2004 April when I

was like teaching specifically disabled young people about HIV/AIDS like making them aware that they should know about their HIV status, I felt guilty, because I am preaching to them that they should know their HIV status while as I don't know my HIV/status and then like on day when I was like doing my preparation for tomorrow, like I went to a centre to be tested. I got my results I was free and I was happy.

Question: How can you describe the difference in your sexual life before you knew about HIV/AIDS and after?

Answer: Firstly like before I knew about HIV/AIDS, like you being a young man, I like to say I am a man, I am a man, I can score (sleep) with as many girls as possible so like just for sexual healing (*What do you mean?*) yaa...its like when you go out and you score with a girl for once, like sexual healing is just go out, have sex, the thing of having a relationship with that girl doesn't occur to your mind yet (*Did the girls not mind having sex without being in a relationship*) The only think when we come, we like come with camouflage like you see, you come with a big box, but the present inside is just a little...laughter....We enjoyed that because that's a stage of growing up like I said, I was like around able-bodied guys even they at that young stage, they would say to me, hey, there is a girl, take her. Like that time, I was still afraid of girls like girls are a lot of trouble.

Question: How many disabled girls have you gone out with compared to non-disabled girls?

Answer: Laughs...To be able to be possible, I will give you the number. With disabled, then I only went out with one and the able -bodied girls, the number, it's countless...laughter...(and you Dumo? To me I went out with a lot on both side, it's a draw I think...laughter...

Question: What drives you to ask a girl out, is it their attraction as human beings or their disability/non-disability status?

Answer: First of all you look at the attraction, physical attraction and you say, can she take me there (*What do you mean?*) I mean can she make me happy in bed...laughter...Secondly you look at the relationship issue and after that you are tired.

Question: You said earlier that you do not like to go out in shorts; do you think exposing your disability takes away your attractiveness as a young man?

Answer: No, as long as I wear long trouser on, I don't care.

Question: Do you consider a disabled girl unattractive when they expose their calipers?

Answer: To my point of view, what I said earlier is like first look like what she look like, is she physically attractive, ok basically like you will have a conscious like she is physically disabled, but then again, I look at the degree of the disability because for me having an affair with disabled people I would say it does not make sense because I am stereotype as well because before I went out with this girl, I used to say, I can't see myself going out with a

disabled girl since I am disabled as well. Lets say I am on crutches, if she is on crutches, how would she help me?

Question: Do you think HIV/AIDS affects physically disabled young people differently from non-disabled young people? Explain.

Answer: Ya, I would say it affects them differently, why would I say that? First of all they have this thing in their mind. I am already disabled, but now living with HIV as well as being disabled they might say it's a double curse on them.

Question: Do you think disabled young people in general are at risk of getting HIV/AIDS?

Answer: Yes, they are at risk

Question: In your opinion, what factors place physically disabled young people at risk of contracting HIV/AIDS?

Answer: Some of them are like illiterate, like the level of your education helps you to know what to do or not to do. Like some of them are abused at home by family members. Like their family member might have HIV and they are no longer accepted for relationship because people know their status so you they go to a disabled person, saying I won't die alone with this thing. (*Who is being abused mostly, boys or girls?*) Girls of course especially intellectually impaired children, they don't know what is wrong or right, their judgement is impaired and they actually take advantage of them.

Question: It's often said intellectually impaired young people are more at risk than physically disabled young people, what do you think?

Answer: You see, people who are in wheel chairs have been able bodied first. May be they were involved in a car accident. Before they were in a wheel chair they might have been sexually active and they might have contracted HIV/AIDS, so to accept the issue of AIDS and being in a wheel chair again might be very hard on them.

Question: How about young people who have been in wheel chairs all their lives like those with cerebral palsy?

Answer: The thing is like I would put it on your sexual drive. It all depends on your sexual drive. It all depends on how sexually active you are.

Question: Is it easy for such young people to form sexual relationships?

Answer: You get these disabled guys; it's just like any other human being. Like just for a one night stand so if they see this girl and she is beautiful and he sees this girl and she is like sex-wise he would not stop to give her that favour, the satisfaction and after that, say tomorrow there is nothing more, it's like what people are, always the same.

Question: Do you think disabled girls have the same opportunity for having sexual relationships as disabled girls?

Answer: Yaa..h..The rumours I heard, it's like girls who are disabled, they like men. (*What is your opinion of such rumours?*) Basically, I am not into that type of life, I could not tell like what is going on around me, that my concern.

Question: How feasible is it for a physically disabled young woman to negotiate for safe sex?

Answer: That's the thing; they must just say lets play safe here. Like the thing I have in mind, I won't put my life at risk just for sex. (*Let's talk about the disabled young women*) Not all of them can negotiate about safe sex (*why?*). It depends on that somebody, how aware is she? Does she like it, can she make it so as to feel the taste of the real thing...laughter...

Question: Do you then think disabled young women are more at risk of contracting HIV/AIDS than disabled young men?

Answer: That's a difficult question to answer because I am not a woman. It seems like my knowledge of HIV/AIDS, it is much. The chance of a woman getting HIV+ is much more than for men to get HIV (*why do you think so?*) The thing is like this, a woman has a vagina right, and a vagina is like a bowl that accepts something inside so a man has a penis, it goes inside of a bowl like the bowl is opened up like to catch water, it's like easy. So that's why I say it's easy for a woman to contract HIV than for men to get it. Like even you the guy you can be HIV- and the lady may be HIV+ but the whole thing is like the time that she actually get orgasm, by that time you the guy might have come already to a point of like ejaculation and get out because most of the African guys like they go for their own satisfaction not of the woman. So by the time he is getting out or releasing these fluids, the guy is already safe, he is out. (*Are you implying that when a woman is having an orgasm that is when she might infect a man?*). Basically yes, it's that time that body fluids get released from the body to outside, it's like the time when you feel free and relaxed that's the time the body fluids are released and that is the dangerous point.

#### WESTERN CAPE

Question: Do you know of programmes in Nyanga that address issues of HIV/AIDS for disabled young people in Nyanga

Answer: I do not know any thing like that in Nyanga, but I know in Khayelitsha there is TAC.

Question: It is my understanding that TAC deals with able-bodied young people mainly because most physically disabled young people cannot easily get to TAC activities because of mobility problems, what do you think?

Answer: It's like people with disabilities; they have their own mindset which they try to make themselves old like they are not the youth they feel themselves like important. The thing is like is they should not expect special invitation they like every body else.

Question: Do you think there is any merit in having special HIV/AIDS information sessions for disabled young people?

Answer: The way government is working now like having special schools. Special schools is a waste, it is not a necessity. Looking at government's point of view, I do not see the necessity for people with disability to have special attention about this because like, especially physically disabled people to me their functionality is like any other person out there.

Question: You have been to Thembaletu Protective Workshop. Who do you think is most suitable to give HIV/AIDS information to the physically disabled young people?

Answer: According to my knowledge disabled like it and feel calmer when disabled people are talking to them (*why do you think so?*) Because they see that these are people who like us who are teaching us these things. So these things happen to people like us too. Because most of the time able-bodied people are doing this teaching, disabled people might feel inferior like, they might not ask certain questions.

Question: What can be overcome to overcome stereotypes about disability issues in society, families etc?

Answer: Basically, we should have more disabled people on board as well because they are disabled themselves, they know what disability is all about so like their input in it, like the message to people with disability would be much positive as well. It's like if the party audience has disabled people the other disabled people would come to the party as well because the guy who is doing the ceremony is disabled as well and so they will come to the party.

Question: Earlier on you said there was no difference between disabled young people and the non-disabled young people, every one should be treated the same. Now you are saying disabled young people feel comfortable when addressed by fellow disabled young people, what are you actually saying?

Answer: Basically it all goes with the mindset of people like if you want more disabled people to come to the party you would rather get a disabled person also on board so they will also come. If you want a small group of disabled people then you can have any body up front. It all goes with the mind set of the people.

Question: According to belief systems in Nyanga, what really causes disability?

Answer: Most cases when you see people with polio, it's black South Africans. It's very rare to see white south Africans having polio because like most of us born in rural areas its like the medication for immunisation, you have to walk 15-20 km to the nearest clinic. So many mums can't afford that so most of the time like in this society, when you see a young person having polio; it's a black South African.

Question: But traditionally the Xhosa have their own beliefs about polio

Answer: Yes, there they say you have been witchcraft. When the cause of your disability or walking with crutches is like mysterious to them then you have been witchcraft. But if you have been in a car accident and then disabled, they know you have been in a car accident or if you have been hit by a gun and become disabled then it's a gun. It all depends on the mystery of the disability you have. Sometimes they think you were a thief, you stole things and got caught and you were bewitched.

Question: So does this mean that the two of you were bewitched according to traditional beliefs?

Answer: Yes, we stepped on a snake...laughter...

Thanks for your time.

Focus Group Discussion, doc-1

### 10.02.05

Physically disabled young people x 3. One male and two females.

Meeting place: Protective Workshop – Guguletu NY3

Question: I would like to know when each one of you became disabled

Answer: Nceda- was disabled when she was young but does not remember when exactly. Dumo was born with the disability and so was Jennifer.

Question: Tell me what type of disability each one of you has as you were told at the hospital or by your parents.

Answer: Nceda does not know, but she is hemiplegic with difficult speech; Dumo has cerebral palsy and moves around in a wheel chair. He has slurred speech. Jennifer does not know but presents as a diplegic cerebral palsy and uses crutches to move around, she stammers and has slurred speech as well.

Question: Tell us why you chose to work at this workshop.

Answer: (c) A social worker came to our house and told my parents that she was organising for me to come and work at this workshop. (a) Mpumelelo School, which I used to attend, referred me here because I know how to sew. (b) I chose to come to this workshop because it is cheaper than other workshops.

Question: Does he pay to come and work here?

Answer: Pays R4.00 for the shuttle called "Daily Ride" that takes them to and from work.

Question: Tell us your experience of growing up as a disabled person, for example positive and negative things.

Answer: (b) I was brought up by a single parent, my father died when I was 9 months old. The community discriminate against me. They see me as a useless person. Some people treat me like someone who does not know what they are doing. Others laugh at me. Yet others do not like talking to me. Sometimes I ask why God made me disabled.

I can work and clean the house very well sometimes my friends tease me about my disability, paralysis of left leg and left arm.

(c) I was referred for physio. I am one of a twin. I have an able-bodied twin brother. I have no friend in the neighbourhood; I stay in the house all the time. I have few friends, but they do not like me. Why? They laugh at me. I am a very sensitive person that is why I chose to spend time alone in the house.



Question: Do the two of you have a similar experience with friends like (c)?  
Answer: (b) Some friends are not right. Some others like me. They come to take me for a walk and they push my wheel chair for me. (a) I have no friends; I live in the house all the time.

Question: This feeling that friends do not like you; is this all about your friends or you also do not make an effort to visit your friends?  
Answer: (c) I am asthmatic and sometimes I use an inhaler. When my friends see that they laugh at me, they think I just like to use that. Sometimes when I trip and fall, they do not help me up, instead they run away from me. (a+b) Yes friends do not like to associate with us.

Question: You have told us how your friends treat you. Can you tell us how your family or older people in your community treat you?  
Answer: I have not heard any thing from older people. Some older people like others and me do not. (c) Me I am loved by all people, sometimes they give me money, sometimes they pay for my shopping when I have forgotten my money at the house and sometimes when they see me walking, they help me out. But the children are scared of me and they laugh and run away from me.

Question: Can you specify what the people who love you say and those who do not like you say?  
Answer: Those who love me say "never underestimate a disabled person's abilities" he is in a wheel chair now but you never know what tomorrow might bring for you. So you must love him for who he is.

Question: Are there any Xhosa proverbs or sayings that express what he has just said.  
Answer: Love yourself the way you are (Vuyo the translator did not know any proverbs either, to take this up with the elderly women).

Question: I would like to know if the three of you go to church.  
Answer: Yes, SDA, Apostolic Church for b +c

Question: What does the church say about disabled people?  
Answer: (b) I have only heard them talk and pray about HIV/AIDS. I have never heard them mention disabilities.

Question: Since you all go to church, does that help you in any way as disabled people?  
Answer: (b) Yes, The church helps me to accept myself as I am and to go on with life. (c) It helps me to be myself. (a) ...quiet...

Question: Now I would like us to discuss issues of sexuality. Tell who taught you issues of boyhood and girlhood? What did they say  
Answer: (a) my mother, she said I have grown up now and I must take care of myself (b) my three brothers, they said I must have only one girlfriend and I must condomise because there is a disease HIV out there. (c) My

grandmother, she said I am a grown up young woman now and I must look after myself.

Question: What exactly did your mother or grandmother say about looking after yourselves?

Answer: I must take care of myself when I have menses, the same with men, don't sleep with men (Anything else?). NO.

Question: Tell us how easy or difficult it is for you to form intimate relationships for example to have a girlfriend and a boyfriend?

Answer: (a) It is hard for me because I am afraid that most boys would want to sleep with me and leave, so I do not trust them. (b) It is easy for me; I have a girlfriend. (c) It is hard and I do not have a boyfriend, I do not want to have one.

Question: B talked about HIV/AIDS, do you all know about this disease? Yes. What exactly do you know?

Answer: Long silence... the girls cannot remember anything. (b) AIDS is a disease, which comes through sleeping with a person who is infected and by transfusion. Vuyo prompts the answer from (c) do not share teeth brushes. Do not share the same "refry"...laughter... this is a towel that is used to clean each other up after sex. Therefore do not use the same one on two people before it is washed.

Question: Where did you get this information about HIV/AIDS?

Answer: ...laughter and hesitation... then Vuyo says, they are afraid to reveal that I am the one who taught them about HIV/AIDS. (Why) because the girls have forgotten already. May be I did not do a good job.

Question: How about in your homes, who told you about HIV/AIDS?

Answer: (c) No body talked about AIDS at home, but when I go to the clinic I hear something about HIV/AIDS. (b) My mother and my brothers told me about it and they said you should condomise and be responsible, do not do it anyhow. (a) No body talks about that at home.

Question: Do you know any disabled young people who are suffering from HIV/AIDS?

Answer: I know one who used to leave in Philipi, but now I do not know where he is. The girls do not know anybody with HIV/AIDS.

Question: Do you think that you have been given the same opportunity as young non-disabled people to know about HIV/AIDS?

Answer: Yes, when we go to the clinic they tell us about HIV/AIDS.

Question: Would you rather information about HIV/AIDS is given to disabled young people alone or together with non-disabled?

Answer: This information should be given together; there should be no discrimination because the disease affects us all in the same way. The girls also reiterated the same, we should all be taught together.

Thank you all for your time. Would you accept that we come back to ask a few more questions? Yes

Focus Group Discussion, doc-2

12.05.05

**Parents of disabled children x 7. All females**

Meeting place: Home of rehabilitation worker

QUESTION: I would like this group to help me fill in the gaps from the other two discussions I have had with parents because it's been hard to get the same mothers again. I would like you to share with us the specific day to day challenges that you face in bringing up disabled children.

ANSWER: It is hard to bath your male child when he is older; it is difficult to carry him from one place to the next or to take him to the toilet, taking him to school on your back. For example my daughter when she was still young, I had to treat her like a baby because she could not do anything, I had to take her to the toilet, I had to change her, I had to bath her, she was always on my back, she couldn't do anything.

When I had to go and fetch wood at the bushes she was always on my back, when I had to do traditional beer she was on my back. She could not walk, but she was at an age when she was supposed to walk, up until I took her to some body (*sangoma*) that gave her medication (*amancedo*) until she got better. After I was given the traditional medicine, I gave it to her and she started talking and walking and after sometime, they told me that she had TB and then I took her to the clinic and she got better again.

I took her to the crèche, but she was always crying at the school and they suggested that I should take her to a crèche for people like her. I did not know what they meant by 'people like her'. Then I took her to '*Siyazama*' special school for the disabled, she stayed there for sometime and they said she is supposed to go to a different school now, which is *Nompumelelo* where she went up until now because she is old now, 22years.

QUESTION: What are the particular difficulties of a working mother bringing up a disabled child?

ANSWER: If you are working and you have a disabled child, you would not have many problems because you are working so you have to make sure that your child goes to school every day where he is taken care of. When you come back from work then you take care of your child. Sometimes if the child does not go to school, they you have to take care of the child at home.

QUESTION: At 22 years special schools seem to close their doors to disabled young people, what is there in Nyanga for these young people?

ANSWER: It would be better if they had something to do may be some handwork or some income generating activities. Because it is dangerous

when they are staying at home they can get raped. There is really nothing for that in Nyanga apart from the UWC project.

QUESTION: I heard in other discussions that talking about sex and sexuality with one's children is taboo in the Xhosa culture. What mechanisms are there then to teach about the subject?

ANSWER: In this day and age, kids are having kids with other kids. I say to my child (CP) that 'look here if you go out to have a baby its your own business. I am your mother and I have taken care of you so I cannot take care of another child, your child so if you have a baby you must know that you will take care of the baby yourself. My daughter laughs and goes ha, ha, ha, mama, I will never do that. I say to her, you are telling me that now, but when you go out there and meet a man, you will not come back to me to tell me that this is what you are doing. I am a real Xhosa woman, I say to her once you have a man on top of you and you are at the bottom, you must know that you will get pregnant.

QUESTION: What have the other mothers said to their children?

ANSWER: My son who is 15(CP) I can see he wants to go outside and see what is happening outside. Sometimes he has said to me, mama You must prepare that room for me, the outside room and I say to him, look if you get a girlfriend, you must know that you are going to take care of that child yourself. You must know that you are not going to maintain your child on the disability grant; the money must come out of your own body (You must work and earn extra money to look after your baby).

QUESTION: Another mother to share please?

ANSWER: My child is disabled (20yrs CP/hemi), when she comes back from school she eats and does her dishes then she goes to sleep, she doesn't go outside. (Is it because she has been told to stay in the house all the time or it's her own decision?). I have asked from God. I have said to him (God), you know that I have got this child, so she was laid on hands by the pastor. It's God who is doing the whole job to keep her in the house. So it's God that is controlling her so she doesn't do all these things.

QUESTION: I can understand that God has answered mama's prayer, is this prayer shared by the girl too; does she have a personal conviction that going out of the house is not good for her?

ANSWER: I suspect it's her disability in a way because even if a man comes in her room and shows interest in her she won't even answer him; she will continue doing what she is doing or continue sleeping. (Where does your daughter go to school?). She was attending at *Nompumelelo*, now because of age she is not attending anymore; she is at the community project run by UWC. This girl is actually my grandchild. When she was born, her mother said to me, mama, I cannot take care of this child because she is disabled, so can you take care of her? She took long to walk, she walked after 5 years. Now she can do almost everything, she can say that she wants to go to the toilet, but you never see her walking alone in the street.

QUESTION: Another mother?

ANSWER: I am also looking after my disabled grand child. My daughter got pregnant again from another boyfriend in Jo/burg and she decided to come and give me her disabled child to look after.

QUESTION: Do your daughters support their own children whom you are looking after?

ANSWER: No they do not support their children, we depend on the disability grant and my old age grant we put it together.

QUESTION: Were these girls given to you as the cultural norm or it was because they were disabled?

ANSWER: I think it's because they are disabled, so they think it is difficult to look after a disabled child. Also they want their men not to leave them because of a disabled child.

QUESTION: It is taboo to discuss sex and sexuality with your own child; do you think your disabled young people have sexual feelings?

ANSWER: When I look at my son (22 yrs) it seems he does not have the physical feelings or desires to have a wife that is why he does not have one

QUESTION: What do the other mothers say about the sexuality of their disabled young people?

ANSWER: Some disabled children have sexual feelings, you notice that they do. You see them walking up and down the street and you see they are looking for something like to sleep with a boy or girl.

QUESTION: Someone else to share on the subject?

ANSWER: My child has no sexual desires, when a man comes in she will be chicky and refuse to talk to him.

QUESTION: I have learnt from most disabled young women that their parents commenced them on contraceptives as soon as they had their first menses, is that what parents who are here today have done about their own daughters?

ANSWER: (Mother 1). If I start suspecting that my daughter has sexual desires now, I will take her to the clinic for contraceptives. (Mother 2) I have not seen anything unusual in my daughter, but once I see that she is getting sexual desires, then I will take her to the doctor.

QUESTION: I have learnt that rape is a big problem in Nyanga; can you elaborate this to me in relation to disabled young people?

ANSWER: I have heard a lot about children getting raped but it hasn't happened to my one. Sometimes I observe her talking to men on the streets and I clearly see her being cheeky and not showing any interest in the man, some girls will tease her and say her that one is not right intellectually, just leave her, she is not fine.

QUESTION: Maybe rape happens because these young women do not consent to sexual relationships, but you know they are going to be raped anyway so you give them contraceptives.

ANSWER: I certainly wait until I see signs that my daughter has sexual desires; that is when I will take her to the clinic, because I know that if she gets pregnant, she won't take care of the child. My daughter was put on contraceptives while at *Nompumelelo* School, after some time, all her blood finished to the extent that blood was coming out through the nose so I stopped giving her contraceptives and she is ok.

QUESTION: How about boys being raped, is that a problem in this community?

ANSWER: We do not know. (Mother 1). I once heard of a 4 year old boy who was raped, the man (rapist) said he just wanted to sleep with the boy because he was big and cute (5 parents said they had never heard about male rape).

QUESTION: Is it your experience that disabled young women are raped more frequently than non-disabled young people?

ANSWER: Yes, they do not have the mental capacity to reason with the rapists, the physically disabled do not have the power to fight or run. Like now I am worried as I am sitting here, my disabled girl is alone at home, anything can happen.

QUESTION: This is all a background to the problem of HIV/AIDS, is this a problem to your disabled young people?

ANSWER: We are very worried because our children are disabled and they can be raped by people they do not know.

QUESTION: Living in a community where rape seems to be an everyday occurrence, how do you protect your children from being infected with HIV?

ANSWER: It is hard. There is nothing I think of that can happen, the only thing I do is to watch over my child. When I am not there I must make sure of who goes into the house, because anything can happen. I know some people can come to rape her; I just have to stay close and watch over her. (Mother 2) In my case my child is not in my care she is wondering in the streets I do not know where. So she may get infected with HIV, how can I know because she is not in my house? (That is a special problem that I will throw back to the parents, what do you think?) She must go to the social worker. I have been to the social workers and to the police commander, they all told me, look here we do not deal with adults (22) we deal with children only.

QUESTION: Do I understand that in this community, there is no help for mothers with special problems like this mother has?

ANSWER: There is nothing, but the government must do something about this, we must shake them. They should send social workers and the police and people like you to come door to door and ask what our problems are and anything that we establish, must not be for now only, it must go further into the future. Like I have told you before that this woman who took my child, she is making money on her by claiming foster care grant and the social workers helped her to that, but they won't listen to me the real mother...

QUESTION: What are the churches saying about disability, sexuality and HIV?

ANSWER: My child in my church, they are taught about how to conduct yourself. They are told about all these things. That is why when my child comes back from school, she only washes her clothes and sits in the house all day because what she has been taught in church.

QUESTION: Are the non-disabled young people also taught to just stay in the house after church?

ANSWER: Yes (Gospel church), they are all taught the same thing, that they must not go around, they must not do all these things; but I have another boy, who does not listen, when he comes back from school, he goes around the streets in the dark. I think he wants girls...laughter...

QUESTION: Can we have stories from other churches?

ANSWER: In my Church (apostolic) nobody mentions about HIV/AIDS and sexuality issues because within the church, you end up seeing girls having babies. (Mum 2) In my church (converted). They don't talk about such things. Mother 3 (Zion) They warn the young people, that you must know how to conduct yourself, you must not do all these things. When they come back from the choir they must do house chore and not go out.

QUESTION: Most mothers today said that they do not think their disabled young people have sexual feelings. If that is the case, can we also say that these young people do not need sexuality and HIV/AIDS information because they do not have sexual desires?

ANSWER: If a disabled child walks around in the street, they will get HIV/AIDS. It all depends, those with sexual desires need to be educated, but may be even those with no sexual desire should also know. For example, my son who is 22 years, even though he has no desire but he can hear so he needs to be taught. The one who walks about at night will get the AIDS virus.

QUESTION: I will repeat this question, because I did not get a clear answer before. How you can as parents of disabled young people, protect them from getting HIV/AIDS?

ANSWER: The government should come to help, they should bring people to come and teach them. (*What is your role as parents?*) Parents should assist. The reason we want assistance from the government is that our children get used to us, they don't listen to what you tell them. So if the government sends people to do that, our children might listen if they see a new face. Besides that, parents must take care of their disabled children, they must not walk up and about at night because even the government will get fed up with us if we are just waiting for them to do things for us. The government should send people to our parents and grandparents who are not educated, they must stop focussing on people who are educated and come to the ground to our people who are not educated and teach them about HIV/AIDS.

QUESTION: Who has taught you parents what you know about HIV/AIDS?

ANSWER: I used to work for Health Services that is where I got information about HIV/AIDS; we used to have workshops and seminars on AIDS. (Other

mothers?) I do not know anything about AIDS, me also, me also, me also. I just heard from the clinic when I went for my high blood (hypertension).

QUESTION: Do you feel you have enough information to teach your disabled young people about HIV/AIDS?

ANSWER: Yes we do. I tell my child (22yrs) that because you are outside there, you might get things (rape). Sometimes when I tell my child about men she says, I don't want a man because I don't want to contract AIDS sometimes she says to me, I am protecting myself from all these things that are around (AIDS). Sometimes she gets worried when her friends on the streets tell men that no, you must not bother with that one because she is not intellectually well, so I tell her don't worry about those things, when you want a man and the time comes, you will get a man, sometimes she cries when people make fun of her.

*Our time is up. Thank you very much for your time and help. I am sure I will still be welcome should I have further questions?*

### **Key informant doc -1**

#### **08.06.05**

Key – 3, Sisi 39 years. Post polio paralysis, using a right caliper, in-charge of 'Protective Workshop'

Question: How long have you worked at this workshop

Answer: Since 1996, before this I was in Guguletu section 3 with Mrs Pamela, I was also doing the sewing. That was the first time I am on the machine, actually, I think I am too clever. They just teach me only for two days and me now it all. Then they said to me OK you are permanent...laughter...

Question: Tell me about your family.

Answer: I am Xhosa, professional Xhosa. I am from De Aar on the Jo/burg line. I have got my mum and my dad is passed away two years ago. I have got two sister and three brothers. Actually I am a twin. The one is at home, he is a guy and his name is Budi. (*What do your names mean?*) Sisi means the world and Budi means burden. I think really he follows his name because he doesn't do anything and he don't want to do nothing, he's got no vision. Every time when I am going home I am fighting... I am fighting with him...I said I mean in this world you are supposed to be strong and the time he said you want to kill yourself because you cannot make it and I said that is nonsense to me!

Question: So who are you staying with at home?

Answer: Actually here, I used to stay with my grand mum but she passed away and I decided to stay on my own so I am renting a shack. It is just around the corner from here. My bother is still staying with my mum in De Aar and I visit them once a year, in December only. My mum also comes once a



year. Like now in June she must come because on of my sister's child she is passed away and will be buried today or tomorrow. The mother was HIV+ and so the baby was also affected so she passed away. You know...I look at myself at my age, I am doing well; I am still thinking I am not destroying myself and its worse now after my experience, I said no I can't keep problems because problems make you not to think. You put yourself in a dark corner. I can't take it any more you know.

Question: Tell me, when did you become disabled?

Answer: When I was young, I was still crawling. Actually my mum, she was still drinking before she gave birth on us and then I was at the back and in her hand she had the boy, Budi. Then there was a man running after my mummy because he was proposing my mummy, you know drinking people, absolutely, and you know my mummy was running you know and I fell. And in those days there were not many doctors and I also think she was very slowly to take me to the doctor. At that stage I was beginning to stand on myself but after the fall, I was failing. So my grandmother said no, you must take Sisi to the doctor. She took me there and the doctor said, no, I won't be able to walk because now I have got polio and they took me to Kimberly. I was there until I was 9 years old. (*Which group of professionals was treating you that time?*) They treat me and they put me on calipers. I am not sure which group of professional was treating me.

Question: As a growing disabled girl, did you feel that friends treated you differently because you are disabled?

Answer: I don't think so because why, I am a strong woman. I have got always a challenge. I even challenge my sisters. Instead of being independent, they are always looking to me. They are always begging me, can you please do this for us and I am saying NO. I mean, I suppose as a disabled woman I don't feel sorry for myself. You have got two legs, what about me? That is why I am saying I am a strong woman. No matter you can say about me I don't care, you know. I think its because I went to the normal schools from the start I didn't go to the special schools for those things make me very strong.

Question: So do you think that going to special schools is not good

Answer: No ... no ... no ... no ... no ... because you always be with disabled people and then when you finish school you must meet with able people and it's so difficult because people they are always looking at you. You can't even address yourself because you are disabled. But when you learn with able people you are strong and you are not shy.

Question: Why do you think your mother took you to a normal school?

Answer: I think it is because the school was very near to me. The school did not have problems with me either.

Question: How about older people did they treat you differently?

Answer: Those days there were few disabled people so that house which have disabled, you will see that they ignore that house. There was a problem before. But now things are thanks God now its so broad now, each and every

house there is a disability, but before Uuuu...there was a big apartheid you know (*You mean apartheid against the disabled?*) Absolutely, I don't like that you know, that family that got disabled Uuuu. It was terrible before believe me. (*Do you think that was cultural?*) I don't think its culture, its people you know. I mean they are too much judge. I mean like now, people like to judge. Because now disabled people are high nowadays, I mean we are not down so we just don't care.....*tapering voice.*

Question: How about in Nyanga. Are disabled young people treated differently from their able bodied counterparts?

Answer: Yes, there is a problem here with parents. I always, when we have workshops, I speak very loud about that. Parents are still hiding their kids because they are very shy that they have got a disabled child of which to me is nonsense. You didn't apply to have a disabled baby, because it's a gift from God. So there is a big, big problem here. So the children (*young people are referred to as children as well for as long as they are under their parents' care*) still stay in the house in darkness instead of coming here to Thembaletu to meet others.

Question: Why do you think parents keep their disabled children/young people in the house?

Answer: It's because of the attitude out there. That's why I said people like to judge, people like to judge out there. When you have got a disabled baby at your house then you are down; but I think parents must be very strong.

Question: How can they be helped to be strong?

Answer: I think we must hold a workshop, call the parents and explain to them about the disability how they must treat their kids you know. They must not look at the neighbour and say that one is normal you know, I think we have to meet some where.

Question: What does DPSA do?

Answer: Aaa...DPSA is dealing with disabled people, physically disabled and all the others. They are sort of looking for a job for the disabled people. And whatever problems we've got. DPSA is there for us. (*Are all these people in the workshop members of DPSA?*) Absolutely, just now I had a call from Mr Victor because now I am a woman, on the 15<sup>th</sup> and 22<sup>nd</sup> I must go to the meeting for the women with disability and also on the 12<sup>th</sup> March, the Youth, they will meet at *Vukuwambe*.

Question: How about issues of sexuality for disabled young people, how are they handled?

Answer: Uuuu...I think that's a big problem, even to the disabled people. I think they challenge it wrong, the way I see it because I work with them here at Thembaletu. They fall in love because they want to show people, we can also, but they do it in a wrong way. I always call them, more especially the ladies, I say please, when you see a guy sometimes be very careful because we are disabled, they can also take chance. They just want to test us how we've got the same thing like them the able, we've got the same vagina. So

its where AIDS starts. There is no love; they are really abusing us, most of them you know. So that is why I say to them they must be very careful and don't go just because you want to show people. If you love that person, you have to sit down and be honest with your disability you know, don't say yes because you want sex. I said no ways.

Question: Do you think disabled girls say yes for the sake of saying yes?

Answer: Absolutely. I know why I am saying this because I see them aaa... Its worse because I am here with them you know. I said no, not to say that you can't have sex, you must but in a right way you know don't put yourself that because I am disabled the guys they won't sleep with me, I said no ways because now you say yes, yes, to everybody and they are using you and you ending AIDS. Just do it because you have to do it in a right way and you have to respect your disability. They don't understand when I say that.

Question: What do you mean by respecting your disability?

Answer: Don't show your disability to everyone. Like for instance I have got caliper, its taking time, I must take off my calipers so I have to be very careful I have to respect. If I have got a boyfriend I must stick to that one person and before I have to sleep with him, I have to show my disability. I have to be open because when they look at me, I am beautiful, but when its time to sleep, I must take time. Now I don't like this girl, she is beautiful but with disability you know (Do you think there are guys who would be put off because of your disability?) Absolutely, absolutely Margaret. When it comes to disability, its very sensitive and like it or not, you have to respect yourself.

Question: Do you know of reasons why parents of disabled young people do not speak to them about issues of sex and sexuality.

Answer: They are very shy. They now that their children have sex because its nature. There is words they like to say it outside, they say like this, disabled people like men, its like amahule, you know, and of which its not like that. Each and every person must have a partner, its natural

Question: My understanding of a Hule is that you must have multiple sexual partners

Answer: Its actually like you love men. You can't stay without a man.

Question: In your experience, would you say this allegation is true of most disabled young girls/women who are not as assertive and outspoken as you?

Answer: Absolutely *wena* (you) Margaret. I think at the same time its because of the back ground, the parents, they should sit down with them and explain every thing especially sexuality. They are shy, but at the end of the day they are getting problems with their children; because they have got friends who tell them, no you must have a boy friend you must have sex and now they do it wrong because of the friends and now the parents they find them and Oooo my goodness. I was supposed to sit down with my girl and just explain, and then its late.

Question: There are traditional practices like intonjane, circumcision do disabled young people go through these as well?

Answer: I don't think so Margaret (Why not?) I think *wena*...people are so, are so...I don't know how to explain this. We are in days and times when things go so quick, times are so terrible, no one don't want to listen to someone. At most the youngsters, they don't want to listen to the parents so the parents end up giving up.

Question: Would you say that your observation fits the non-disabled young people as well?

Answer: Absolutely.

Question: I have seen young men who are smartly dressed in suits and hats and I have been told that is a sign that they have just come back from being circumcised, is that true?

Answer: Absolutely, some of them they do circumcision, but I think also *wena* Margaret there is a problem, we do it because my friend is a man but at the back...when you see this smartly dressed man, after sometime he is going back to that time when he was *Amakwenkwe* (uncircumcised boy), I mean the ways he did now. He doesn't behave as a man you know. He is still the same person. When you go to the field you must be changed to be a man, a real man, dignified not doing funny things like before.

Question: Can you explain a bit more about the sort of change that one should expect to see in a dignified man?

Answer: If you go to the field and then you come back, when people look at you, they must see a change, you are a dignity, when you are not rude as before. The way you speak to the people and you must have a lot of respect, because you are coming from the field. I believe they say it's so strict there so I see no need to come from that bush and you are still as you were before as a person because the older men they talk so strictly with you. There are big rules but I don't know what's happening. They go to the field just only for two months they change, they are doing the robbing, beer drinking and all. We are questioning ourselves, but what's happening now, this day? You can't say this is a man (*indoda*) and this is boy, *pikinini* (*makwenkwe*), they are all looking the same; But shame, some of them, they are dignity, they still keep that dignity of the field.

Question: How about the girls, when they pass through intonjane, what sort of things are expected of them?

Answer: Oooo believe me, I am not good on that...Laughs... (So you are a *modern girl*?) I mean as I was saying before, it depends on how you handle this issue of respecting yourself. You have to love yourself not just respecting yourself these days.

Question: When a girl is growing up who has the responsibility of telling them issues about menses for example?

Answer: It's me as a mother; I have to sit down with her. Like now, I don't have my own children; I think it happened like that that God did not want to give me children...laughs ...I am not sad. I have got my sister's baby she is

12 years now. I decided to take her because her mother passed away in 2002. So I have got now a daughter. So she did not start her period yet; but always I sit down with her. If anything happens to you like me now I am wearing pads, you have to speak to me. She knows that I am wearing pads, even the question of sex, I am too open. I speak to her about sex and AIDS (*what do you say exactly?*) I say to her, please, first thing is education and sex before marriage is wrong. You have to finish your study and you have to respect your body and you must choose the friends. Don't listen to every friend. Friends are poison.

Question: I understand that Vuyo was here two years ago to talk to the employees here about AIDS. Before that did you have such programmes or do you have ongoing programmes on the same?

Answer: We had problems here at Thembaletu, the problem is that they like guys, they like sex, so they do it to everybody; and I chat with Grace (OT) and then we call one of the sisters at the Day Hospital to explain to them about sex, how must they do it or question of HIV before Vuyo came here you know.

Question: There is debate as to who should give HIV/AIDS information to disabled young people whether it should be the disabled themselves or the able bodied persons. What do you think?

Answer: I think every body should give information because AIDS affects every body the same. We must not be shy discussing to people about that, because the rate, it is very high.

Question: Do you think there is a difference in the way disabled young people would pay attention to a disabled person compared to an non-disabled person?

Answer: Yaa there is a difference. It happened when Vuyo was here...I was just laughing but I did not show because after that period of learning with Vuyo. Each and everybody said can I go to the clinic, why? I would ask, I want to test myself for HIV and I said thanks God. So almost all of them went for a test after Vuyo's talk so now everything is fine. (So there is some truth in the preference of a disabled person giving HIV information to disabled young people?) Absolutely, they learn and I think they take it very seriously.

Question: You told me that girls liked boys, was this something you saw or heard about?

Answer: No I heard about it from outside. Even some of them they come to me and say this lady, she behaves so bad. Then I saw one guy sick and another one, that's why I was chatting to Grace about this, we have to call somebody from the clinic to explain to them about sex.

Question: I have spoken to a few disabled young ladies who have told me that they do not want marriage, where do you think this is coming from?

Answer: I think it's a question of AIDS because the rate is very high and if you get that disease, you die. Me too, I am so scared. Guys they are stopping the cars and I say Uuuu no, I am so scared. I can't just say to every body, actually, I'd rather stay on my own and I am not worried. My prayer is that If I

must find a man I need to sit down with him and I think we have to be honest with each other and I think we have to go for a test.

Question: Do you realize that you are a different young person in the way you express yourself, the confidence and in being assertive?

Answer: Me? Yaa I know. The problem of many disabled young people is that they are very shy. They can't accept their disability. That is why when I speak to them, I say don't make competition, just accept yourself and just be happy. When you start making competition you find yourself in a situation that you can't even help yourself.

Question: How about sexual abuse, Is that a problem for disabled young girls?

Answer: Absolutely too much Margaret, its worse for those who are still at home (not in this protective workshop) The mother goes to work for the whole day and the daughter is alone and then the guys come in. Even the family, the uncles, the fathers, they are sleeping with them yaa.

Question: Do you think these girls report such incidences to their mothers?

Answer: No they are afraid they keep quiet.

Question: How do you think such girls can be helped?

Answer: That is why I am thinking people they need to be told about these things. To me its like we can have the whole week a workshop in a big hall to explain these things to our parents and to the disabled people you know.

Question: Most parents of the disabled young people I have spoken to are single, why do think that is so?

Answer: Absolutely. When a mother gives birth to a disabled child, the man walks away; he says he cannot give birth to a disabled child. It is the fault of the woman. I don't know what is happening to the fathers because it's like now they did make an application to have a disabled baby you know; but all these things God give us you know. You must love your child because you didn't make application; but they really left the wife saying I didn't expect that I must have a disabled baby. Its like now it's the end of the world, they run. So women are very strong, they bring up their disabled children alone.

Question: What are the factors in this area that put disabled young people at risk of contracting HIV AIDS?

Answer: I think also it's the carelessness of our parents, leaving disabled young people alone where they can be raped. Also sending them late hours to the shop is a real problem and the question of alcohol. Most disabled young people are drinking and their parents are drinking. It's where the problem of rape starts, the guy has a chance of grabbing the girl and putting her in a shack for the whole night, those things happen you know. Because they parents are drinking and the girl is drinking they don't know what is happening, they get shocked in the morning and say where is Sisi? I don't even know, Sisi is coming in the morning with other people, Sisi is bleeding and she is at the clinic. This is what happens.

Question: Do you think disabled young people are being targeted specifically with HIV/AIDS information or they are being left to access what is available for other young people?

Answer: No body has come to us; we are the ones who went to call the nurse. I think the organizations should come to us like Vuyo did. They are really not coming. We must think and ask them to come so that they can bring information to us.

Question: Do you think disabled young people have less information than their non-disabled counterparts?

Answer: No it's the same; because on the TV they teach about AIDS so its equal. As I say to you Vuyo was here and before Vuyo the nursing sister was here. For me I went to the workshop and I also bring information to them.

Question: How about the disabled young people who stay in the house all the time?

Answer: Uuu... that is a problem. I think they don't know anything what is happening. They know about AIDS but they don't know about AIDS exactly. Like if I ask what is AIDS; they cannot answer...I don't know.

Question: Do you have an idea how these can be reached with HIV/AIDS information?

Answer: Uuuu...my goodness God...I do not know. It's a lot of job you know. I think we must go to the radio and I think we must be specific to the parents at home. On this date, we are going to have this, this and that please can you bring your child with you? Or we can go to the newspapers like 'Uvukani' (local paper) just expressing ourselves about this problem, families must bring their disabled young people to us so they can learn. Or we can have a big car with a loudspeaker and we say, please, we are going to have a meeting can you please bring your child with disability, I think so.

Question: Do you think the stigma attached to HIV and that attached to disability are the same?

Answer: No I do not think say because if a person has got AIDS we can't judge, whatever you've got AIDS or you are disabled, you have to accept yourself. So I think to me its equal, it's up to you whether you accept or not.

Question: Tell me again why you are so different from other disabled young people

Answer: Its also because when I was very young I was shy girl and I was staying at home when I see many people I hide. Where I am coming from its not like Cape Town, there is no flexibility, there is no activity its just...I think Cape Town helped me. Ever since I was here in CT I learnt a lot of things. I went to the meeting of disabled people and they will always choose me. No don't keep quiet you must talk so it's where I learn. I have to stand up and talk. I learn I learn until I reach the stage now you know. They are always teaching us don't be shy because you are disabled; be proud of yourself. Thanks God I was staying with my granny, she always said you are not disabled, you are so strong. I think its because of that she really put power on

me because I grab it. I said, I am a woman, I am not disabled, I grab it. In my church I am also proud. I am not shy (what is your church?) It is apostolic faith, the gospel. I am preaching, singing, I am doing everything.

Question: What does the church say about disabilities?

Answer: To me, they treat me normal because it's me. I am proud of myself. When I stand in front of the church. I am just talking; I am singing I am leading the church song...laughs...

*Thanks for your time*

## **Key informant, doc-2**

### **17.05.05**

Key-informant 7 Manzi, Post polio paralysis both legs. Using crutches, swing through gait.

Question: Tell me about yourself and your family.

Answer: My name is Manzi. I was born in Eastern Cape. I grew up there as a disabled child...to be a disabled child there was difficult because children laugh at you and the distance to school is far...but I managed. I studied there at Eastern Cape until std. 10 then I moved to Western Cape to look for jobs and other things to make a person happy.

Question: When did you move?

Answer: I arrived here on 6<sup>th</sup> March 1999. When I arrived here I moved and met other disabled people. It was my first time to meet other disabled people and to work with them and to go to school with them. Because I grew up where I learnt that there was no special schools for disabled only

Question: Tell me about your educational achievements.

Answer: Ya...I've never gone to special schools. I was schooling in ordinary schools, which was a little bit far because I was crossing a river to get to the school...that was a problem when it comes to rainy days; it started to be a problem to me. It was those that I am a feeling disturbed...I am differ from other children. But my mother...she was coming to say she could help me cross the river. Because at that time all other students were running, running when it's raining...and then the thunderstorm...but out of that, I passed my standard 7 which is from junior to high school...then I moved from where I was schooling to another location now which is going to be a little closer to the school. After I've done that, I matriculated there, it was not a special school, it was an ordinary school.. To be the young person, I mean to be a different person to those people was not a problem.

Question: What was your experience of learning at a mainstream school?

Answer: Ya, it was a bad thing...on the other hand it was a good thing because PWD shouldn't be treated differently from the society; they must be inside with other people as well so that people will get familiar with them.



Because in those days what was happening was that if a person is disabled he must be locked inside and nobody should visit him or her and he will never socialize again. Even if you are trying to go to people to socialize...people will ask, 'Why are you here'? I know from my experience if there is a party like those parties that usually take place at night, people will ask, 'You disabled person, what are you doing here? Go, go and sleep'. They associate this person with abnormal personality...they don't see you as a person who can be among them, advise them or work with them. They just make you feel inferior if you just take as they give you.

Question: Do you have an explanation why a disabled young person would be asked to go and sleep while his friends are having a good time?

Answer: That is just what people are like...in the first place; people like them have wrong sympathy b looking at a person like you. As a person with a disability, they think that you are in pain. When they see a person with a disability, those movies, they may think that that person is in pain so it is difficult for that person ton do this and this...he must stay in one place and the person must be provided with everything. So since they see that it's difficult for you to do things or when you are moving or speaking, they think you must be treated differently. That is why people will do everything for you.

Question: How did your parents prepare you for adult life?

Answer: At home there is my mother and my father not taking me as a disabled person, they take me like any other child. As a result, at some stage they had to remind me and say you mustn't do this and that because you are disabled person. I was thinking and feeling bad...it was painful when they said that to me.

Question: Can you give an example of what they would stop you from doing?

Answer: For instance there is work that is being done in the village like sheering the sheep, I was really eager to do that and while I was at the stage, I was starting to drink beers, umqomboti you know? And they said no, you can't do this, you can't drink umqomboti because you are a disabled person. How are you going to walk when you are drunk? I just take that as a limit, that they are limiting me so that I don't drink like others at the same time they did not protect me from that. You see, just give me an overall instruction that you mustn't do ABCD because those things will harm you...you are not like your friends...so you must always understand that you are not like them. You can go with other things which are good, but when it comes to these things like drinking liquor and other things you mustn't join.

Question: Was sex and sexuality among the things they stopped you from doing?

Answer: No...no they were not saying anything around that. I was just challenging them with my own side of thinking. To be honest people were not interested in that regard to be in love and have sex because they telling me that how are you going to do certain things like...(sex). How am I going to go with my girlfriend on the road? How am I going to cross-rivers with her or how am I going to visit her if she lives in another location. You must know rural

areas; they are far apart from each other. But then when you grow up...they don't have to tell you. You reach a stage and you realize that ha...I am a man now I must have a girlfriend.

When I am trying to enter that department (love and sex life) really the world was pushing me away...it was like people were not interested. It's not that they were interested in me...actually, they were interested to be with me but they were not interested to be in love with me because I am disabled and I am not going to be able to get her home at night. You see there is that thing that the girl cannot go out because she has responsibilities at home during the day. She must hide to her parents that she has a boyfriend. So you can only see her at night time. So the others think that it will be difficult for me to travel to my girlfriend at that time...so that is why they were putting me aside.

I was feeling that they were chasing me because I am a disabled person, but God, I am a person like you. People ill think that I am ma when I am starting to be involved in such things (love life). It was painful, but I took it as a challenge and I didn't take it as a threat to my life. I just said no I must go on with my life. At school they know that when it comes to class, I will be the person that someone will come to ask me to help if I can. At the same time at school we were just sitting there with boys, boys didn't have any problems. They were just staying there smoking...hey, I have experienced many things as I am growing.

Question: Growing up in a rural area, did you think that all disabled young people were treated differently?

Answer: I would put time to this because in the past years people would expect to treat disabled young people differently...but as time goes on, people are getting aware that these are not animals, they are people. PWD are people and they must be amongst us, they play a major role in society and they can be fathers like us and have a family you know. So I would say to grow up in the rural areas and the townships, its better in the townships because it's easy to move from one place to another because it is modernized and the availability of transport and all the stuff. But there in the rural areas, they might feel that you are unable to walk...because of the long distances that have to be covered. The mode of transport there is absolutely poor especially where I am coming from, only one car to the town.

Question: Can you tell me what you think are the positive and negative aspects of circumcision?

Answer: According to the way I think, you are getting to another point, you were at that level and now you are at this level. Then you get respect because you are now a man. The negative side is that everybody is interested to know how things are going to happen, like in my case people were interested to know how I am going to wear my suit...they also want to know that did this really happen to a disabled person?

Another negative side of this is that there are many things that need to be omitted due to disability. You must be omitted because you can't run. For example they won't chase you to the water so things like that. After you've

done that culture you might think that people are respecting you, but know they just regard you as disabled not able to do many things or to run.

Question: Are issues of sex and sexuality taught at circumcision?

Answer: There is some of that...but most times it's observing circumcision. Observing the rules, which you have now passed. You should respect yourself in the first place and you don't sleep with certain girls as a result of your circumcision. But then they say after you have done circumcision there is nothing to stop you from...(sex) but then you respect yourself as a person. At the same time sexuality, there is nothing specifically that is going to be taught there, nothing, nothing. What they do when you come back, they give the code of conduct, what a good person is looking like and what you should be...a lot about respecting another person, a person older than you and society as a whole because respect is giving you every thing. If you don't respect people they will not like you. That attitude is going to break society. Once the society has a problem with you, obviously you are going to die or you re going to jail...those are the lessons.

Question: Do you think disabled young people are at risk of contracting HIV/AIDS?

Answer: I would say yes because disabled people are exposed to the new world now which is also aware that disabled people are also people with same feelings. But more society is coming to us with different opinions. Others may come to us because they want to get money; I am talking about the girls now. They also think that if they get a disabled person, he or she is not so much socially active so he or she won't be going out with other boys and girls. So they think that they're just coming to us to get a rest on relationships. We as disabled people we don't like that side of life; we are trusting. If for instance I am looking at a young beautiful lady and she shows some interest, I will fall in love without knowing what exactly is in her mind, do you understand? But that person might be looking at my money, not loving me. She can also be a polluter (HIV/AIDS carrier). She looks at me and she says she is not going to die alone; she is going to die with me. So these are the things that will lead disabled young people to HIV/AIDS.

Question: Do you know any myths that are said about sexuality and HIV/AIDS for disabled people?

Answer: They say that if you sleep with a baby or a virgin that will mean it will cure your HIV/AIDS. So it's a myth again. According to my understanding, so far there is no cure. It is just the reduction or the stopping of multiplication of HIV virus in the blood. That is why we are using ARVs.

Question: Do you know disabled young people who are infected, affected or have died of HIV/AIDS?

Answer: I heard about one girl in Khayelitsha. They say she was positive but she denied and she was in a wheel chair.

Question: Can this be a true reflection of the problem of HIV among disabled people that you have only heard about one disabled person who is infected?

Answer: No...I think there are many who might be infected. It's just that they are not tested.

Question: Can you think of an explanation why they are not tested?

Answer: The reason why they are not tested is that most of them do not have stable relationships. I mean a stable relationship to know that this is my wife and this is my girlfriend...they don't have such kind of situation because the girls and boys are still exploring this freedom of being in the society, that's my opinion.

Question: In the light of what you have just said, how can the problem of HIV/AIDS be solved in this community?

Answer: I think they (programmes) must visit them (disabled) and discuss their sexuality and from that we will see how much sexually active they are and from there we discuss these issues.

Question: Although disabled young people are sexually active, they have told me that they cannot contract HIV because they trust their partners.. What do you think?

Answer: To be most cautious, I think we shouldn't be looking to sex only. There are so many other ways of contracting the disease.

Question: What are those other ways of contracting the disease?

Answer: It can be that you go to the saloon to cut your hair there and they use the same clipper that another person used. I can't remember the other things now...may be later.

Question: Do you not think that focusing on other ways of HIV transmission is avoiding the subject of sex?

Answer: I think we can change the pattern of talking about this HIV/AIDS because people have been told don't do this and don't do this for a very long time. What is left now is to talk to people...to be realistic and to be faithful to them.

Question: What do you mean when you say to be realistic?

Answer: To be realistic, I mean a person must understand that if you condomise...you won't get HIV. This person, however beautiful she is and however beautiful...he might be positive at some stage and so he must be realistic...and to be faithful to yourself not to your partner. Making them aware that if you are faithful to yourself it will reflect to your partner. At the same time if your partner is faithful it will reflect to you as well. So I think we need to conscientise people...otherwise education around this has been done already.

We have been having peer education around this issue of HIV/AIDS where we were involved with people who are HIV+, normal people...I mean who don't have it. So these peer educators gave information on HIV/AIDS, how it is transmitted, how one can contract it and so many other things, I was one of the peer educators. We shared this kind of information. Now we need to come up with new information whereby people are encouraged to go and have a

test so we can have the statistics, how many people are infected and how many are still negative.

Question: I understand that the peer educators trained by DPSA went to institutions only, how can those who are not in institutions be reached with such information?

Answer: You are touching on a problem that we as young people are trying to avoid so we are planning. Organisations like DPSA specifically targeted groups of disabled associations like the physically disabled and schools...they are on the grass root level. Disabled individuals need to join DPSA first, we need to campaign for people to join their various disability groups, so that it can be easy for them to access information like this.

Question: Are you implying that HIV issues are a responsibility of the disability groups?

Answer: Yes, it is the responsibility of the disability organisations not government. Because government cannot access these individuals. Even the government of today, says people must be in groups or organisations or certain structures so that the government might know that at such and such a place there is a structure called bla, bla, bla. Then if there is need or a gap that needs to be filled by the organisation or its people, you can go to the organisation and get the information to fill the gap.

Question: I have been told that disabled young people find it hard to be employed, what is your experience?

Answer: Coming to that, it's difficult really to be disabled because in the first place, companies in this country are not interested to adapt their situation to suit people with disabilities. I mean accessibility of their buildings and tables for people with wheel chairs, accessibility in terms of making availability of certain things for people with disability. Making a central point may be for accessibility like if that company has got one printer, they can also buy a second hand printer for this person so that he can access instead of to go up and down stairs looking for a printer. So because they don't want to do that thing to accommodate disabled people, they decided to employ normal people. Last of last year, I can't remember when the minister in the department of Labour Mr... find out that only 0.04% instead of 4% of disabled people are currently employed in this country generally so really it is difficult.

Question: Do you think that the risk of HIV/AIDS is higher or the same amongst the poor and the rich?

Answer: What is happening is that those that those who are poor are worse... Ya, the disabled are not worthwhile, they have no jobs, no money and so most of them will sleep around to make money, especially the girls. Also the rich men will sleep with many girls because they have money to give.

Question: Is there something you would like to share with me around the subject of HIV/AIDS?

Answer: In general I would like to say HIV is something that is there... but we are not taking it as something that might happen to ourselves or to me. You just take it as something that is for certain people. People used to treat in

background (secretive). The background is what you did in the past, now you must carry on with the struggle against it. That's the only thing.

Question: How about issues of rape amongst disabled young people, what can you tell me about that?

Answer: Ya, those are things that are happening on a daily basis but they are not reported.

Question: Do you know why they may not be reported?

Answer: First of all people are using the opportunities and they take chances in terms of finding the disabled girl alone in the house when the mother has gone to work or to look for food for the family... and other thing they take chances that that person cannot run or report about the rape because she is afraid to be killed. On the other hand people are using the opportunity that since they have power, so in most cases the victims they will not report because nobody will believe them, sometimes she cannot remember who was doing this thing or she may think that sometimes she is wrong, on the other hand that person will just use her.

Question: Do you know of any disabled boys who have been raped?

Answer: Not at the moment I do not have any idea... I do not have any case study in my mind whereby the boy was raped ... it might be happening but it is not reported. Especially to those young men...there are other women that are using them to fulfil their need. That is why it is a special case.

Question: How easy is it for disabled young people to find marriage partners?

Answer: Well...it is not very easy. Girls think that a disabled boy cannot perform (sex). So they don't take you serious when you propose, hey think you are dead. Men want a woman to work hard in the house, fetch water, clean...a disabled girl cannot do all those things so they don't want her.

Question: Do you have a family of your own?

Answer: No, but I have a son...he is staying with his mother at her parent's house. I am planning when I am ready I am going to buy a house that she is going to call it her house and stay there for the rest of our lives.

Question: Most disabled young people told me that they do not want to get married, is there a special reason for this wish?

Answer: It's like it's depending on where your love is....when you first meet a person with disabilities it's like that, you marry him and if you met with a normal person you'll just marry. But I don't appreciate to marry a non-disabled young person for the following reasons. Firstly that person, she might have hidden agenda because she can think that she's doing you a favour of loving you because nobody is going to love you. There is a number of normal people I have spoken with, they are playing those games saying that I was thinking that when am being in love with this disabled person I am taking myself out of trouble I didn't notice that this person is going to betray me like this because now she has a lot of boyfriends and whatever.

When I am dealing with that I can see why disable people don't want to marry...they may think that the girl can just run away from the relationship, she will come and make all that vandalism, taking advantage of that particular person. If she started to have another relationship she will make a show off to this disabled guy like, I was just eating your money you were thinking that I can be in love with a disabled person? Look at this kind of things... as a result I would just look at the situation and I said to myself no I don't want to enter in marriage.. .I want to go to the person who is going to love me, to a person who is not going to think she is doing a favour of loving me. I don't need someone to lie to me. I need a person who is going to love me.

*Thank you very much for your time.*

*I wish you good luck*



## Appendix F: LETTER TO UWC SENATE

The UWC Senate  
The University of the Western Cape  
Physiotherapy Department  
P/B X 17  
Bellville 7535

05.10.2004

Dear Sir/Madam

**Re: RESEARCH ON THE EXPERIENCES AND PERCEPTIONS OF  
PHYSICALLY DISABLED YOUNG PEOPLE REGARDING SEXUALITY,  
AND HIV/AIDS**

I am a doctoral student of physiotherapy at the University of the Western Cape. I plan to carry out a research study on the above subject in fulfilment of a doctoral degree in physiotherapy. I write to ask the Senate of the University of the Western Cape to grant me permission to carry out the proposed study.

The purpose of the study is to explore physically disabled young people's perceptions on sexuality and HIV/AIDS and to find out if they have equal access to sexuality and HIV/AIDS information, treatment and care that is available to their non-disabled counterparts. I also intend to solicit their views on how they can be included in mainstream sexuality and HIV/AIDS programmes that are available in their community.

I hope that the results of the study will inform policy makers, educators, and other service providers to make their sexuality and HIV/AIDS programmes inclusive of the special needs of physically disabled young people. I hope too that parents and communities would be informed by the results of the study so that they may be sensitive to the needs of disabled young people regarding sexuality and HIV/AIDS. Finally, I hope that disabled young people will not continue to be left out in efforts to prevent the spread of HIV/AIDS in the Western Cape and eventually in the whole country.

I look forward to your consideration in this matter.

Yours sincerely

Margaret Wazakili (Doctoral student)

Supervisors: Professor R. Mpofu  
Professor P. Devlieger



## Appendix G: LETTER TO KEY INFORMANTS

The University of the Western Cape  
Physiotherapy Department  
P/B X 17  
Bellville 7535

05.10.2004

Dear Sir or Madam

**Re: RESEARCH ON THE EXPERIENCES AND PERCEPTIONS OF  
PHYSICALLY DISABLED YOUNG PEOPLE REGARDING SEXUALITY,  
AND HIV/AIDS**

I am a doctoral student of physiotherapy at the University of the Western Cape. I plan to carry out a research study on the above subject in fulfilment of a doctoral degree in physiotherapy. I write to ask if you would please consent to participate in this study as one of the key-informants. The present study would benefit from your experience and expertise on issues of disability, sexuality and HIV/AIDS.

The purpose of the study is to explore physically disabled young people's perceptions on sexuality and HIV/AIDS and to find out if they have equal access to sexuality and HIV/AIDS information, treatment and care that is available to their non-disabled counterparts. I also intend to solicit their views on how they can be included in mainstream sexuality and HIV/AIDS programmes that are available in their community.

I hope that the results of the study will inform policy makers, educators, and other service providers to make their sexuality and HIV/AIDS programmes inclusive of the special needs of physically disabled young people. I hope too that parents and communities would be informed by the results of the study so that they may be sensitive to the needs of disabled young people regarding sexuality and HIV/AIDS. Finally, I hope that disabled young people will not continue to be left out in efforts to prevent the spread of HIV/AIDS in the Western Cape and eventually in the whole country.

Thank you in advance for your consideration in this matter

Yours sincerely

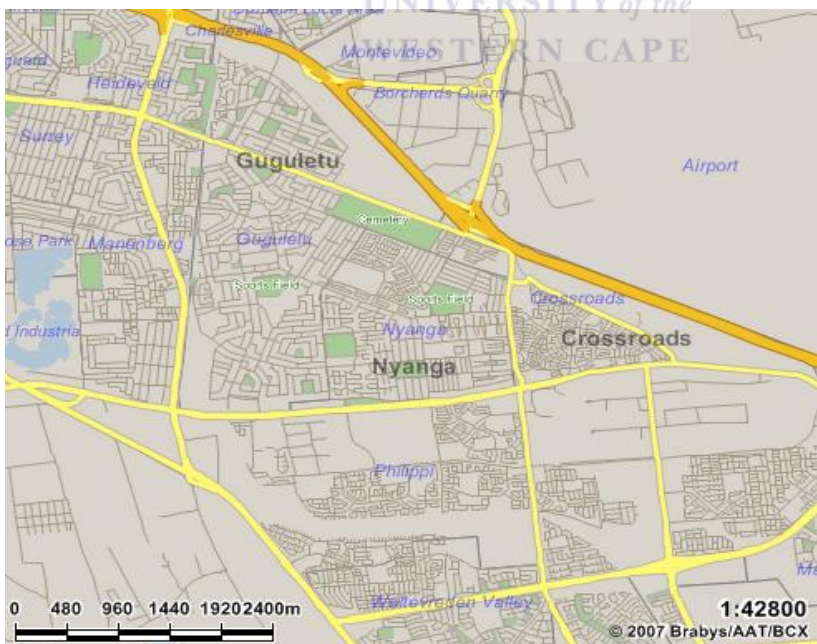
Margaret Wazakili

Supervisors: Prof. R. Mpofu  
Pro. P. Devlieger

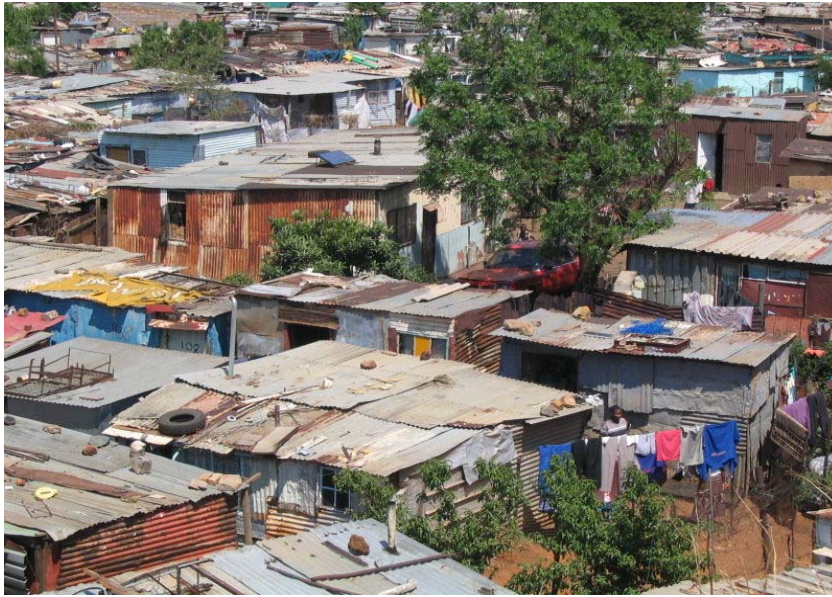
## Appendix H: SELECTED PHOTOGRAPHS



Picture 1: The Western Cape



Picture 2: Nyanga and neighbouring townships



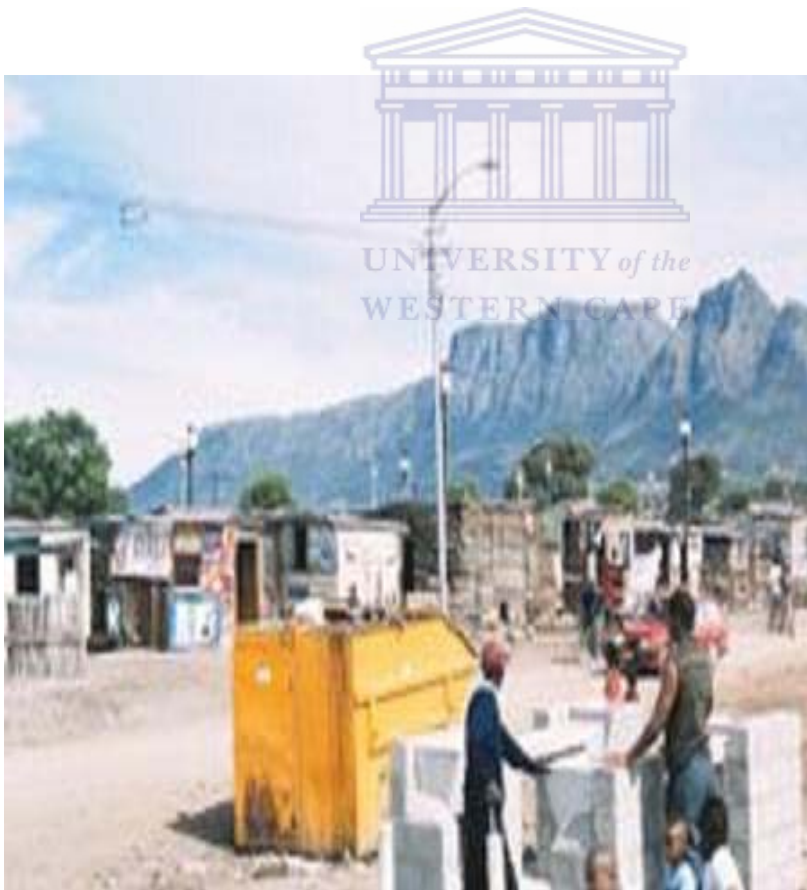
Picture 3: Shack scene i



Picture 4: Shack scene ii



Picture 5: Shack scene iii



Picture 6: Shack scene iv



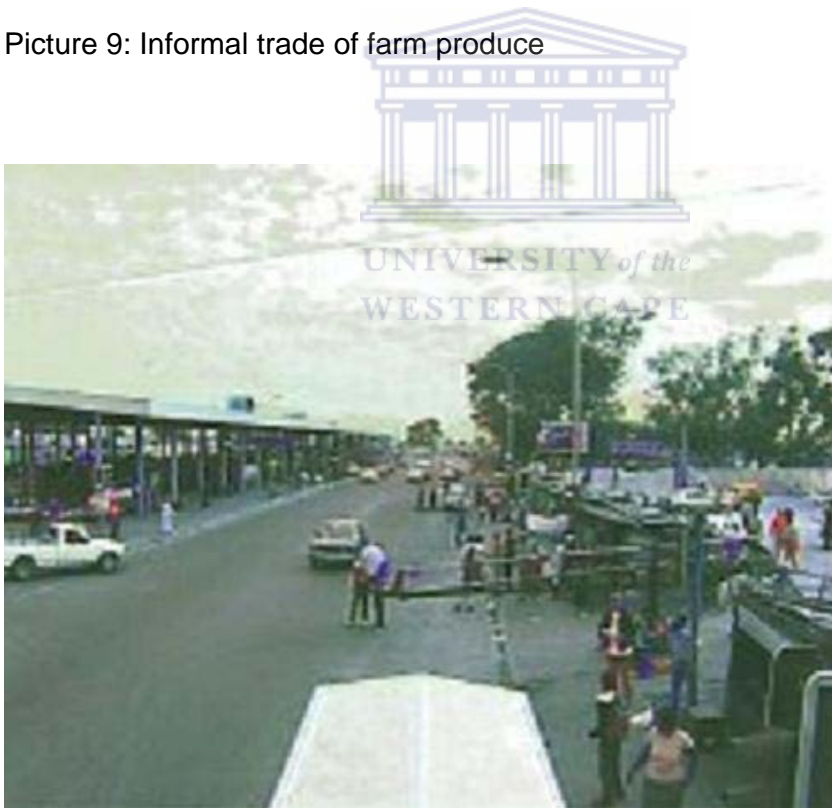
Picture 7: Shack scene v



Picture 8: Refuse disposal at the door step of a shack



Picture 9: Informal trade of farm produce



Picture 10: Mini-bus/taxi station (left). Informal businesses (right).



Picture 11: One of the shebeen situation



Picture 12: Public bucket system toilets