

**AN INVESTIGATION OF DISABLED WOMEN'S PERCEPTIONS OF HIV AND
AIDS AND ASPECTS OF SEX AND SEXUALITY IN THREE SOUTH AFRICAN
PROVINCES**

MELANIE BASSON



**Thesis presented in fulfilment of the requirements for the degree of
Master of Arts (Psychology) at the University of Stellenbosch.**

Supervisor: Prof Leslie Swartz

December 2010

STATEMENT

I, the undersigned, hereby declare that the work contained in this thesis is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

.....

Signature

.....

Date

ABSTRACT

A lack of research on disabled women and HIV and AIDS within the South African context has been identified by various authors. The present research is a qualitative investigation into the lived experience of seventeen disabled South African women. Their knowledge of and attitudes towards HIV and AIDS and sex and sexuality, their lived experience with regards to these issues, as well as to sexual abuse, rape and violence, and their access to HIV related health care services is explored in the present study. Semi-structured questionnaires were employed. Content analysis revealed that most participants knew of HIV and of ways of HIV transmission, and slightly fewer of them knew where to access HIV and AIDS related health services. The vast majority of participants reported that they saw no difference between sexual practices and sexuality of disabled- compared to non-disabled people. Misperceptions of others' with regard to the sexuality and sexual practices of disabled people were identified as the main barriers to disabled women's equal access to HIV and AIDS related health services, and to their freedom of choice and expression in terms of sex and sexuality. Almost all of the women had been subjected to rape, sexual abuse and violence.

OPSOMMING

‘n Tekort aan navorsing oor gestremde vroue en HIV en VIGS binne die Suid-Afrikaanse konteks is deur verskeie outeurs geïdentifiseer. Die huidige navorsing is ‘n kwalitatiewe ondersoek na die lewenservarings van sewentien gestremde Suid-Afrikaanse vroue. Hulle kennis van, ervarings rondom en houdings teenoor HIV en VIGS, seks en seksualiteit, seksuele mishandeling, verkragting en geweld, en kwaliteit van toegang tot HIV en VIGS- verwante gesondheidsdienste word in hierdie studie ondersoek. Semi-gestruktureerde onderhoude is met die vroue gevoer, en inhoudsanalise is toegepas. Bevindinge sluit in dat die meeste vroue van HIV en van oordragsmetodes bewus was. ‘n Effe kleiner groep van deelnemers was bewus van presies waar om toegang tot HIV en VIGS- verwante gesondheidsdienste te verkry. Die oorgrote meerderheid van die vroue het geen verskil gesien tussen die seksuele praktyke en seksualiteit van gestremde en nie-gestremde persone nie. Die wanopvattinge van ander (nie-gestremdes) rakende seksuele praktyke en seksualiteit van gestremde persone is aangedui as die grootste struikelblok tot die vroue se gelyke toegang tot HIV en VIGS- verwante gesondheidsdienste, asook tot hulle vryheid van keuse en uitdrukking in terme van seksuele praktyke en seksualiteit. Bykans al die vroue in hierdie studie is al blootgestel aan verkragting, seksuele mishandeling en geweld.

ACKNOWLEDGEMENTS

For his patience, encouragement and his faith in my ability to complete this work, my heartfelt thanks goes to Leslie Swartz. This thesis is dedicated to the seventeen women on whose stories this work is based. It has been my privilege to document their experiences. I am also grateful to SINTEF Health Research, Norway, and Stellenbosch University for funding the research.

LIST OF CONTENT

Statement	I
Abstract	II
Opsomming	III
Acknowledgements	IV
List of Content	V
List of Figures	IX
List of Tables	X
List of Appendages	XI
Chapter 1 - Introduction	1
1.1 HIV and AIDS and Disability in Southern Africa	1
1.2 Research Approach	2
Chapter 2 – Literature review	7
2.1 Introduction	7
2.2 The Not So Modern Myths: Cultural Misrepresentations of Disability	8

2.3	Sexuality and Disability: Common Myths and Stereotypes	9
2.4	Effects of Societal Misrepresentation of the Sexuality of Disabled Women	11
2.4.1	Internalisation of Negative Societal Perceptions	11
2.4.2	Exclusion of Disabled People from HIV and AIDS Education, Prevention and Intervention Services and from Sex Education Programmes	13
2.4.3	Victimisation of Disabled Women: Violence, Sexual Abuse and Rape	20
	Chapter 3 – Methodology	25
3.1	Positioning of the Present Study	25
3.2	Purpose and Research Questions	27
3.3	Rationale of Qualitative Research Approach	28
3.4	Overview: Process of Appointing Data Collectors	29
3.5	Data Collection Instrument	31
3.6	Research Sample	32
3.7	Data Analysis	35
3.8	Ethics	41

Chapter 4 – Findings	43
4.1 Knowledge of HIV and AIDS	43
4.1.1 Sources of Information	43
4.1.2 Knowledge HIV Infection Prevention Strategies	44
4.1.3 Knowledge and Perceptions of Consequences of HIV Infection	44
4.2 Participants’ estimations of risk faced by disabled people compared to non-Disabled people for HIV infection	46
4.3 Disabled people’s Perceptions Regarding the Sufficiency of their Knowledge of HIV and AIDS	48
4.4 Experiences of Access to HIV and AIDS related health services	49
4.4.1 Physical Accessibility	50
4.4.2 Format Accessibility	50
4.4.3 Attitudes of Health Care Staff	51
4.4.4 Attitudes of Others	52
4.5 Attitudes Relating to Sexuality and Sexual Practices of Disabled People	53
4.5.1 Participants’ Perspectives of Similarities and Differences in Sexuality and Sexual Practices of Disabled and Non-Disabled People	53
4.5.2 Participants’ Perspectives of Non-Disabled People’s Attitudes	

towards Sexuality and Sexual Practices of Disabled People	54
4.6 Sexual Abuse, Rape and Violence against Disabled Women	56
4.6.1 Participants' Own Experiences	56
4.6.2 Participants' Knowledge of Other Disabled People's Experiences	57
4.6.3 After the Ordeal: Experiences related to the reporting of Incidents to the Police	59
4.7 Individual Narratives	60
4.7.1 Rachel	60
4.7.2 Nolutando	65
4.7.3 Sibonisiwe	67
Chapter 5 – Discussion	72
Chapter 6 – Conclusion	81
References	85
LIST OF APPENDAGES	
• Appendage A: Semi-Structured Interview Guide	94
• Appendage B: Note about the author	97

LIST OF FIGURES

- Figure 3.1: Positioning of present research 25
- Figure 3.2: Map of South Africa 33

LIST OF TABLES

- Table 3.1: Content analysis framework 37
- Table 3.2: Final framework for writing up results 40

Chapter 1 – Introduction

1.1 HIV and AIDS and Disability in Southern Africa

Southern Africa remains the most severely affected region by HIV and AIDS in both Sub-Saharan Africa, and indeed the world. Currently, an estimated population of 5.7 million (4.9 million – 6.6 million) HIV positive people live in South Africa (UNAIDS, 2008). Adults (age 16 and up) are reported to number around 5.4 million people, with an estimated 3.2 million of this number being women. These figures reveal that there are about 2.2 million more women living with HIV/AIDS than there are men.

Disabled people have been largely overlooked in terms of HIV and AIDS in South Africa. Given the above figures, and the fact that disabled females are recognised as a particularly vulnerable group, the paucity of research and literature on the impact of HIV and AIDS in the lives of disabled women is particularly worrisome. Currently very little is known about the day to day lived experience of South African disabled women in relation to HIV and AIDS.

As a response to this situation, the present qualitative research explores the experiences of disabled women in South Africa in relation to factors that may increase their risk of HIV infection. The supposition is that if some understanding could be gained of these disabled women's experiences of, attitudes towards and knowledge of sex and sexuality, access to Government Provided Health Care Services (GPHCS), and sexual violence, abuse and rape, it could lead to a better understanding of the needs of and challenges faced by this population.

1.2 Research Approach

The present study has been conceptualised and executed from a social model perspective, but to appreciate the significance of this, it is important to understand how the interpretation of the concept of disability has undergone significant changes since the 1970's. Disability has historically been defined according to a medical model, which regards and associates disability with disease and deformity.

The medical model focuses on the dysfunction or impairment of the individual, and views impairment as being the significant factor which excludes or limits the disabled person from attaining normative ideals of health and functioning. In short, the medical model understands and constructs the concept of disability as the outcome of an impairment of the individual.

As the medical model views disabled people as people with impaired and malfunctioning bodies, it comes as no surprise that the response of the medical model to the issue of disability is to make attempts at curing the impairment. The medical model's reduction of disability to a physical construct has held a range of consequences for disabled people.

One of the consequences of the medical model was that disabled people had diminished agency in their own lives, since the medical and academic experts were making the decisions based on what they regarded to be the disabled person's medical condition.

The emergence of a social model, which views disability from a human rights perspective, has been developed and refined by disability activists over the course of the past three decades. Swartz and Watermeyer (2006) explains how the social model adopts a broader view of disability. It reveals the medical model to be oppressive in that it places the cause of inequality and oppression squarely in the bodily difference of disabled person when compared to a supposedly 'normative' body.

Interestingly enough the impetus for change from the medical model to the social model in the United Kingdom came partly from South Africa. Vic Finkelstein, a disabled, white South African opposed to the apartheid system, lived in exile in the UK after the apartheid government banned him from his home country during the 1960's (Finkelstein, 2001).

Finkelstein demonstrated connections between the discourse of apartheid in South Africa and to what disabled people were experiencing in the UK and further afield. The UK system of the welfare state, along with the role played by 'caring' professionals within this system, combined in the form of institutionalised living, separate schools, transport and employment, to systematically classify and segregate disabled people, thus relegating them to a position of otherness and abnormality, and ultimately of being 'socially dead'.

A social model of disability proposes that the impairment itself is not the disabling agent for the disabled individual, but that disability is rather a socially constructed phenomenon and that it requires a social and political reaction. Within this model, physical barriers, personal attitudes and other features of the social environment are the impairments that disable people,

rather than physical characteristics of the latter. Therefore, it follows that inaccessibility of buildings and difficulties faced in using transportation are but some of the challenges that limit disabled people to participate fully in society. Environmental changes should be made, and in this regard it is society which should be 'cured' rather than the individual who is disabled by it.

Swartz and Watermeyer (2006) also point out that social model theorists adopt the perspective of disability which resists definitions such as disability not being 'random' or 'natural', but rather a construct created and maintained by a disablist society. The fact of the matter is that there is no golden standard for a normative body, and impairment is as natural or normal as the absence of it.

Society in effect needs to acknowledge that there always has been and always will be a wider range of people or bodies which need to fully participate in it, and that society has to be structured in such a way as to accommodate not only what the medical model views as a normal person or a normative body, but that society has to be structured in such a way as to allow for full participation of everybody, regardless of in- or out-group status, or of being regarded by society itself as normal or abnormal. In this regard, the social model views disability as a purely social construct. A disablist society is therefore a society structured in such a way as to keep disabled people in a position of exclusion.

South African legislation identifies disabled people under the constitution as a vulnerable group, and explicitly protects the rights of disabled people. The present study does however echo the findings of other research, which reveal South African society to be disablist, in that

the practical implementation of the constitution is insufficient concerning the rights and needs of disabled people.

In addition to the present study being firmly rooted in the social model of disability, both the directive and participation of disabled people within this study has been critically important. Mmatli (2009) has argued for the importance of disabled people playing key roles at every stage of the research process. Mmatli (2009) has also emphasised the importance of disability research to negotiate changes for the better in the lives of disabled people.

In order to achieve this, disabled people need to play a fundamental role in every aspect of the research process, including the decisions around dissemination strategies and use of research findings. If adhered to, these guidelines may serve to facilitate that research results play an instrumental and relevant role in the development and implementation of policy and programmes designed to serve the human rights and needs of disabled people.

The disability sector in South Africa also propagates the crucial need for the involvement of disabled people in research on issues of disability. The critical importance of research created and executed in partnership between disabled and non-disabled counterparts has been a central consideration throughout the course of this study, in order to establish findings that could stand the best possible chance of being relevant and instrumental for disabled people in policy and programme design.

In order to facilitate the involvement and empowerment of the disability sector in South Africa, the present research employed a participatory research approach. The slogan of one of the research collaborators, which specifically represents the disability sector in South Africa, Disabled People South Africa (DPSA), is *Nothing about us without us*. Disabled People South Africa (DPSA) represented the disability sector of South Africa. It served an important function in facilitating an understanding and directive of how the potential participants could be reached through networks of Disabled People's Organisations (DPOs). It also served to illuminate the protocols were for engagement with the South African disability movement, and guided the process of including disabled people in every aspect of the research in the hope of creating research by and in the interest of disabled people.

Chapter 2 – Literature Review

2.1 Introduction

Over the past twenty years, disabled women from countries in the northern hemisphere have published a significant amount of literature around their experiences of living with disability (Kristiansen and Traustadóttir 2004; Morris 1993; 1996; Thomas 1999). Since the lived experience of human beings, disabled women included, is shaped within the societal context within which they live, it is to be expected that the experiences of disability for women within an African context will differ greatly from their northern counterparts (Kvam & Braathen, 2008).

A dearth exists in the literature around how HIV/AIDS affect both disabled people in general, and disabled women in particular. This is especially the case for the developing world, and even more so for the Southern African region (Rohleder, Braathen, Swartz & Eide, 2009). Disabled people, as a vulnerable group (Loeb & Eide, 2004), have also largely been overlooked in terms of HIV and AIDS education, prevention and intervention (Rohleder et al., 2009). Disabled people have also commonly been excluded from education on sex and sexuality, and as a result, it is understandable that their knowledge of HIV preventative measures is limited (Rohleder, 2009).

The literature review investigates firstly at the common cultural representations of disabled people and disabled women in particular, and proceeds to illustrate how myths about

disability affects the sexuality and sexual practices of disabled women, the exclusion of disabled people from HIV related health services as well as from sex education programmes. Lastly, the relationship between societal misperceptions and violence, sexual abuse and rape of disabled women is explored.

2.2 The Not So Modern Myths: Cultural Misrepresentations of Disability

Both women and physically disabled people are devalued in many cultures globally (Nosek, 2001). It has been established that within an African setting, stigma plays a significant role in the status afforded to disabled women (Sentumbwe, 1995). Cultural myths and stereotyping attitudes and behaviours are often the sources which result in the low status awarded to disabled people within society, and that these myths and attitudes are mostly very challenging to undergo change (Milligan & Neufeldt, 2001). Devaluing, oppressive and patronising preconceived societal notions about disabled women, as well as a range of misperceptions held about disabled women, set the stage for the violation of their human rights.

Within the African context, lower living conditions – indicated by factors such as education-, employment- and economic status, and levels of access to information – has been reported for disabled people when compared to their non-disabled peers (Eide & Kamaleri, 2009). In addition, a systematic difference between genders has been revealed by Eide & Kamaleri (2009), with disabled women scoring lower on all the main indicators used for measuring living conditions.

Cultural ideologies position disabled people as abnormal, and as an out-group, in a varied and comprehensive range of ways. When a society views disabled people as psychologically, behaviourally, socially, intellectually and physically deviant and undesirable, an unequal split in power between disabled and non-disabled people is created and maintained. This renders disabled people to be regarded as deviant, abnormal, incapable, an Other kind of human which is positioned as an outsider in every regard mentioned.

This in turn of course significantly inhibits the freedom of disabled people in terms of the personal and political. In this regard, it is clear that discriminatory practices and attitudes by society towards disabled people are legitimized by employing stigmatised cultural representations of these people. It can therefore be said that the phenomenon of discrimination based on disability status influences the access of disabled people to full participation in society and thus creates and sustains conditions of living of a lower quality of life than of those who are non-disabled.

2.3 Sexuality and Disability: Common Myths and Stereotypes

For the majority of people, whether disabled or not, sexuality and sexual practices constitute a significant part of identity, well-being and quality of life (Felce & Perry, 1997). Wazakili, Mpofu & Devlieger (2006) have pointed out that the subject of disability in relation to sexuality and HIV/AIDS is particularly prone to misperceptions and stereotyping.

As one considers the literature on societal misperceptions of disability, it seems that disability and sexuality may very well be some of the most misunderstood aspects of the lives of disabled people, and disabled women in particular, and may therefore also hold the most far reaching and severe consequences for this population.

Societal expectations very often embrace the notion that disabled women are asexual (Milligan & Neufeldt, 2001) and/or sexually inactive, despite that disabled people - and disabled women in particular - are more likely to have more sexual partners in a series of unstable relationships than their non-disabled peers (Economic and Social Commission for Asia and the Pacific, 1995).

Misperceptions of disabled women also include that they passive, dependent, childlike and incapable of contributing significantly to society (Hanna & Rogovsky, 1991), and that they are helpless, useless and sick (Sentumbwe, 1995). It has also been shown that disabled women are regarded by society as being incapable of credibly testifying about being victimised (Chenoweth, 1996; Nosek, 2001). Milligan and Neufeld (2001) have found that intellectually and psychiatrically disabled individuals are regarded as possessing diminished social judgement and that they therefore they are thought to be incapable of having responsible sexual relationships.

Howland & Rintala (2001) noted that disabled women have been deemed unsuitable to engage in romantic relationships or dating behaviours. Sentumbwe (1995) found that in

Uganda it is commonly believed that blind women were incapable of fulfilling traditional female roles – such as being a mother and/or 'housewife'. These societal misperceptions have also been shown to include that disabled women should be grateful for sexual or romantic affection of any kind that come their way, regardless of who is making the advance and the manner in which it is made.

Disabled women were shown to be thought of as unacceptable choices in marriage, yet acceptable partners for purely sexual relationships. In the light of these misperceptions, it is clearly a misperception that disabled women are thought to be at a decreased risk for violence or rape when compared to non-disabled women (Groce, 2003).

2.4 Effects of Societal Misrepresentation of the Sexuality of Disabled Women

2.4.1 Internalisation of Negative Societal Perceptions

Prejudice and negative stereotyping of the sexuality and sexual practices of disabled women may dramatically affect the way they see themselves and experience their lives. The literature on the topic reveals that both actual and perceived limitations of sexual functioning may contribute to disabled women negating, denying or suppressing their sexuality.

Nosek, Howland, Rintala, Young & Chanpong (2001) have stated that the journey of discovery which disabled women go through in acknowledging their value and womanhood,

is long and complicated by onslaughts from all directions. It has been found that disabled women may find that to escape the internalisation of negative, devaluing or mythical social attitudes, which negate their sexuality, to be extremely challenging (Milligan & Neufeldt, 2001). These findings also indicated that disabled women may hold the view – as society does - that they have to regard themselves lucky merely to be on the receiving end of romantic and/or sexual propositions, irrespective of whether the men in question are abusive or ill suited to them (Phillips, 1990).

Disabled women have reported in a study conducted by Yoshida (1999), that actual or perceived rejection from others have lead them to refrain from romantic or intimate relationships, resulting in the denial of their sexual nature. Potgieter (in Rohleder et al., 2009) established that physically disabled adolescents viewed themselves as potentially sexually unattractive to others, and that if others did show an attraction towards them, it would be the result of pity, and not due to romantic motivations. The findings of De Klerk and Ampousah (in Rohleder et al., 2009) included that disabled people, despite having internalised a sense of self-worth, had an awareness of being perceived by others as abnormal and being regarded with pity.

Another important aspect to take into account is that low self-worth and feelings of being sexually unattractive or undesirable has the potential to lead to risky sexual behaviour. For example, in a US study conducted by Becker, Stuijberger and Tinkle (in Rohleder et al., 2009), it was found that sexually promiscuous behaviour amongst physically disabled women resulted from indiscriminate acceptance of whatever sexual propositions they received.

As one considers that disabled women may accept sexual propositions even if the potential sexual partner is a bad match for them because they themselves might think that they are undeserving of responsible, loving and respectful relationships, it inevitable raises the issue of their facing an increased risk of contracting HIV.

2.4.2 Exclusion of Disabled People from HIV and AIDS Education, Prevention and Intervention Services and from Sex Education Programmes

Various studies have drawn attention to the exclusion of disabled people from HIV- and sex education campaigns (Blanchett, 2000; Groce, 2003; Morrow, Arunkumar, Pearce & Dawson, 2007; Yousafzai, Edwards, D'Allesandro & Lindström, 2005). The reasons for the lack of non-discriminatory services related to sex education, as well as the poor access to information on HIV and AIDS for disabled people, present as complex and interwoven sets of factors, and in the light of the HIV pandemic, these clearly need to be addressed. Non-discriminatory service provision, in the context of this study, constitutes service provision that is inclusive in all aspects of its functioning, and that welcomes the participation of disabled people. This definition also includes that service provision in all its aspects be non-judgemental towards disabled people.

An article from Southern Africa confirmed that the prevalence of HIV is higher among vulnerable groups, but called attention to the lack of statistics available for disabled people (Groce, 2003; Janssen, 2005). Various studies have emphasized the need to develop strategies

in HIV prevention programmes which include disabled people and which take into account their experiences and perceptions (Groce, 2003; Groce & Wirz, 2004; Wazakili et al., 2006; Yousafzai et al., 2005).

In various Southern African countries, the knowledge of disabled people about the transmission of HIV was limited. In a comparative study conducted in Swaziland, Yousafzai, Dlamini, Groce & Wirz (2004) found that disabled people in both rural and urban settings were exposed to more limited range of HIV and AIDS information sources than their non-disabled peers, that their knowledge of HIV and AIDS were not as extensive as their non-disabled peers – only three out of 36 disabled participants knew facts about HIV rather than just having heard about it. In addition, information they had about modes of HIV transmission had largely been inaccurate.

Examples of inaccurate factual knowledge of HIV transmission were also encountered in a study conducted in Nigeria by Groce, Yousafzai & Van Der Maas (2007), with deaf participants being more likely than their non-disabled peers to believe that HIV could be transmitted through mosquito bites, kissing, touching and hugging, germs in the air and dirty places. In South Africa, Wazakili et al. (2006) also found low levels of accurate knowledge on HIV and AIDS among disabled youths in an urban informal area of Cape Town.

It is important to take into account some of the factors identified in the developing world as barriers to disabled people's access to general health services. This lack has been shown to stem from a combination of factors (Wazakili et al., 2006). Some of these have been described as restrictive cultural norms (Smith, Murray, Yousafzai, Kasonka, 2004), service

limitations (Ubido & Huntington, 2002), poverty (Elwan, 1999), lack of mobility aids (May-Teerink, 1999), lack of communication skills by staff (Ubido & Huntington, 2002), inaccessible buildings (Kitchin, 1998), marginalization in the community (Beresford, 1996), illiteracy (Helander, 1998), lack of education (Helander, 1998) and gender inequality (DFID, 2000).

A study conducted in Uganda found that disabled people prevented from accessing general health services due to an array of factors, including the physical inaccessibility of these services, negative attitudes from health care staff, poverty and lack of awareness of HIV and AIDS (Mulindwa, 2003). Smith (2004) have reported that barriers to access of health care services by disabled people included physical distance to health care facilities and lack of transport to get there.

Reasons for lack of access to HIV and AIDS related information and services have been identified in various African countries. A low level of general education has proven to be one of these barriers. Groce et al. (2007) found in Nigeria that due to insufficient education of disabled people, they experienced a limited capacity to comprehend information and processes of HIV education campaigns. This was also one of the findings of a Malawian study by Munthali, Mvula & Ali (2004). Low literacy rates among disabled individuals and disadvantages faced by deaf people in accessing radio and/or television messages present challenges to HIV prevention efforts.

The need for HIV and sex education strategies to be contextually relevant to their target audience has been addressed by Chilisa (2005) in a study that commented on HIV and AIDS campaigns in Botswana. The findings indicated that these campaigns employed culturally and contextually insensitive information, education and communication materials. Findings also included that vulnerable groups were not targeted, and that the information was largely not communicated in local languages, but in English. The findings of the study emphasize the importance of incorporating the frame of reference of local communities by conducting research within a community centred approach. As an alternative to cultural and contextual insensitivity of these campaigns, the research highlighted the usefulness of contextually relevant modes of communicating information on HIV and AIDS, and in this case, the use of stories, poems and songs in HIV education strategies was suggested.

The modes of sex education have also been shown to present restrictions to the quality of knowledge for intellectually disabled persons. In Australia, McCabe (1999) found that media sources or formal sex education classes were the most common modes of information on sex for people with intellectual disabilities. Among the findings were that these two sources were unlikely to enable intellectually disabled people to verify the accuracy of the received information, and that it also served to decrease the likelihood of them discussing their thoughts, feelings and experiences around sexuality with others.

Another barrier has been identified as information and services not being available to disabled people in formats that are accessible to them. Philander and Swartz (2006) conducted a key informant study on the needs, barriers and concerns concerning HIV among visually disabled people, and in doing so revealed the lack of information on HIV and AIDS

in Braille for visually impaired people. In Uganda, a lack of information on HIV in Braille has also been found (Yousafzai et al., 2005). Groce (2004) has also reported on the inaccessibility of billboards, which are commonly used mediums in HIV prevention campaigns, to blind and partially sighted people.

Other examples of inaccessible formats, which resulted in disabled people having decreased access to HIV and AIDS related information, were of radio messages that were inaccessible to deaf people. In addition, intellectually disabled people were not reached due to information communicated being too complex or vague. In addition, clinics and health services proved to be inaccessible to disabled service users (Groce, 2004).

The World Bank (2005) has reported that disabled people may face an increased risk of being socially excluded in various ways, and included both family and community affairs. These findings are illustrated in a Ugandan study (Yousafzai et al., 2005) which reported that deaf adolescent sign language users were unable to access information on HIV at community meetings due to a lack of interpreters – indeed, their parents could not communicate with them either.

The recognition of disabled adolescents' sexuality and therefore risk of HIV infection is a fairly new development (Digiulio, 2003), and in this regard, stigmatising misconceptions abound (Wazakili, 2006). Swart-Kruger and Richter (1997) have found that South African youths' awareness and knowledge of HIV and AIDS does not prevent them from engaging in unsafe sex, as also indicated by the high rate of HIV prevalence among this population. Shisana and Simbayi (2002) found that the desire for acceptance among physically disabled

South African youth outweighed for them the need to practice safe sex. Shisana and Simbayi (2002) have also reported that adolescents, including disabled adolescents, engage with multiple sex partners, transactional sex, and fail to use condoms.

Condom use among disabled people has been reported by Mulindwa (2003) to be extremely low. Reasons produced for this phenomenon are a dislike of condoms by both disabled males and females, failure by disabled women to negotiate safe sex, and the difficulties that are encountered in trying to acquire condoms. In light of the various myths regarding disability and sexuality that have been discussed, it is not surprising that something as seemingly simple as getting condoms from a clinic may likely prove for disabled people to be a particularly challenging process.

Depending on the nature and severity of disability, some disabled people have been shown to be more likely to receive sex education and access to HIV and AIDS information and services than others are. Philander & Swartz (2006) highlight the fact that sex education programmes for disabled people are rare, and that they are even rarer for mentally disabled people. Birch (2002) found that students who are mildly intellectually disabled were more likely than moderately or severely intellectually disabled students to receive education on HIV and AIDS were. In Rwanda and Uganda, disabled youths' level of knowledge of HIV and HIV testing facilities were influenced by both the nature and severity of their disabilities (Yousafzai et al., 2005; Yousafzai et al., 2004).

Rohleder and Swartz (2009) draw attention to the implications of the common societal misperception that sexual relationships of people with learning disabilities are inappropriate or dangerous. These implications include restrictions that are often imposed on their sexual lives by those who are non-disabled. An example from this South African study revealed that sex education of people with learning disabilities, rather than a tool of empowerment, was used as an instrument to discourage sexuality. The discourse employed to achieve this took various forms, such as demonization of sex, characterising sex as dangerous, and linking sex to abuse and disease, and risks excluding discourses that may serve to empower people with learning disabilities from leading fully sexual lives.

McCabe (1999) has highlighted the need for a general knowledge of sex and sexuality among disabled people. The low levels of knowledge are of major concern since this has been shown to be associated with high levels of sexual abuse (McCabe, Cummins & Reid, 1994). Smith et al. (2004) have pointed out that the large-scale exclusion of disabled women from health education programmes, which include HIV education and prevention services, lead to a lack of knowledge on their part, which in turn influences their ability to negotiate safe sex successfully. Nosek et al. (1994) and Sandowski (1993) have emphasized the importance of sexual information and experience for life satisfaction and wellness among disabled people.

2.4.3 *Victimisation of Disabled Women: Violence, Sexual Abuse and Rape*

Outlaw (2009) points out that sexual abuse and sexual violence are inherently gendered across cultures globally. Beck-Massey (1999) has highlighted the fact that although powerlessness may be well known to women in general, it is even more so for disabled women, whose lived experience have been shown to include disablist societies as well as physical or mental powerlessness in the face of biological or biochemical disabilities.

When disabled women are abused, they face many of the same problems that non-disabled women do, but with complications. Nosek et. al (2001) and Fine & Ash (1985) are among a host of authors who have produced studies that provide examples of the double burden faced by those who are both female and disabled. Social stigma and isolation which is associated with disability have also been shown to lower self-esteem and to act as a barrier to emotional and instrumental support from others, leading to a decrease in the emotional defences of disabled women (Nosek et. al, 2001).

Bearing in mind that most often the perpetrators of sexual abuse and rape of disabled women are reported to be current and former intimate partners, it is warranted that attention be given to the phenomenon and dynamics of intimate partner violence against women (IPVAW). It is important to consider the impact of violence against women in the broadest sense of the term (Smith, 2008).

Uthman, Lawoko & Moradi (2010), in looking at IPWAV in Sub-Saharan Africa, point out that it is inherently connected with male superiority over women, and that this type of violence is instrumental in an array of regards, of which the enforcement of gender hierarchy and the seeking of a resolution to a crisis of masculinity by providing a sense of power is of particular interest to the present study.

Jewkes (2002) elaborates on the latter point by referring to a study by Bourgois (1996), in which men grew up in urban slums of New York, without employment and with no hope of attaining masculine success as proposed by modern contemporary social expectations, due to poverty. The research described how in these circumstances, the goals of masculinity were moulded into a new shape, which emphasized, amongst other aspects, misogyny.

In this example, it becomes clear how violence against women is both a result of the need for male superiority and dominance over women, but also as being grounded in male vulnerability. In an attempt to protect their masculine identity, which is in crisis because of their inability to attain masculine success – they try to save face by exerting power where it comes easily – namely by perpetrating violence against women. Given the levels of poverty and the high incidence of violence and rape against women in South Africa (Rohleder & Swartz, 2009), these findings seem particularly important.

In a sample of 177 physically disabled women (Milberger, 2003) a positive relationship has been indicated between abuse history and being unemployed. At the time of the study,

participants who were abused were also more likely to be divorced and less likely to be single than participants who had not experienced abuse.

Both male and female disabled individuals around the world are more likely than their non-disabled peers to be victims of sexual abuse and rape (Nosek, 2001). This increased likelihood contributes to their exposure to the increased risk of HIV infection (Groce, 2003). Disabled women, compared to men, face an even more disadvantaged position (Beck-Massey, 1999; Hanna & Rogovsky, 1991). Outcomes of this disadvantage may include a greater likelihood of an increased vulnerability for disabled women to a range of risk factors for HIV infection (Groce, 2004).

Brownridge (2006) found in Canada that disabled women were 40% more likely to be the victims of violence than non-disabled women, and that disabled women faced a significant risk of encountering severe violence when compared to their non-disabled peers, as well as being at an increased risk of experiencing violence and abuse over longer periods of time than their non-disabled peers.

Disabled women have also been shown to experience all forms of violence – including threats, attempts at actual physical violence and unwanted sex – more frequently than non-disabled women do (Smith, 2008). These findings are concerning on various levels, including the fact that prolonged exposure to abuse have been shown to increase the risk that women face of negative health outcomes, which include injury, chronic pain, depression, post-traumatic stress disorder, substance abuse, homicide and suicide (Campbell et al., 2004).

Disabled women may choose to stay in abusive intimate relationships due to fear of being alone and also because they may anticipate difficulties in replacing the abusive partner - disabled women tolerated abuse in exchange for companionship and intimacy (Hassouneh-Phillips & McNeff, 2005).

Mulindwa (2003) identified factors that predisposed disabled women to both contracting sexually transmitted diseases (STIs) and HIV. These included include poverty, rape, and failure to use condoms, traditional practices and reliance on traditional medicine, lack of awareness, polygamy and wife sharing. The South African context is at present characterised by high rates of sexual abuse and rape (Moffet, 2006; Rohleder & Swartz, 2009). If one takes into account that South Africa has a high rate of HIV infection, a large population of HIV+ persons, and that the South African context is one where disabled people are marginalised, it is to be expected that the lived experience of disabled people and disabled women in particular will present with unique challenges.

A stigmatic cultural belief held within some traditional African cultures (including in South Africa), namely that of virgin cleansing, is directly resulting in the rape of disabled people. This belief holds that by having sex with a virgin, a diseased person may be cured (Groce, 2003; UNICEF, 1999). The high rate of HIV infection in South Africa, coupled with the misperception that disabled people are sexually inactive and therefore incorrectly assumed to be virgins, leads not only to an increased risk of disabled women to be victims of sexual abuse and rape, but also to an increases their risk of HIV infection (Groce, 2003). This stands in stark contrast to societal perceptions of disabled women being less likely to experience rape, sexual violence and abuse.

In taking into account the limited resources available in South Africa, coupled with the multitude of challenges – when compared to northern countries - it is likely that the lived experience of South African disabled women may put them at an even greater risk for HIV and AIDS than their northern counterparts.

Chapter 3 – Methodology

3.1 Positioning of the Present Study

The present research forms part of a national study on HIV and Disability conducted in South Africa by Disabled People South Africa (DPSA), The Human Sciences Research Council of South Africa (HSRC), SINTEF Health Research (Living Conditions and Service Delivery), Oslo, Norway, and the Department of Psychology at the University of Stellenbosch (SUN), South Africa. This study was subdivided into two main phases, with a quantitative study preceding a smaller qualitative study, the present research being an offshoot of this qualitative component. The positioning of the present study is illustrated in Figure 3.1 below.

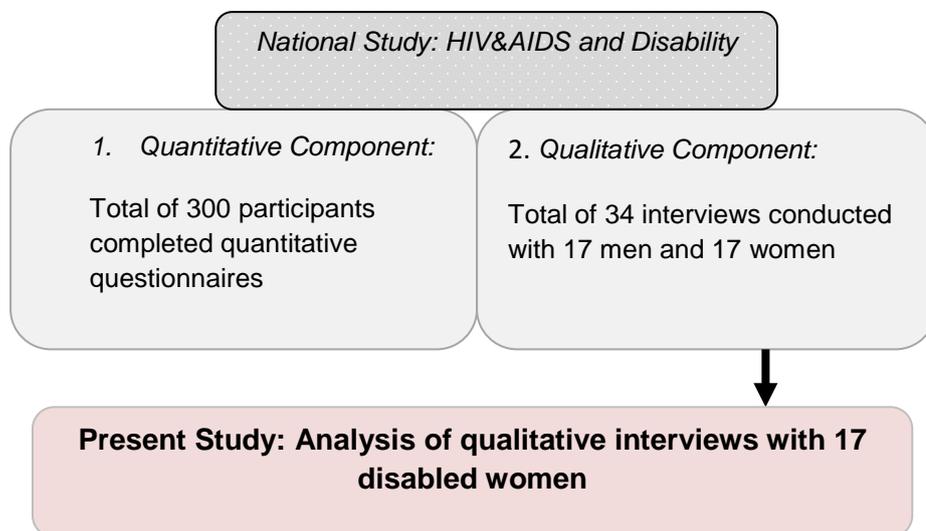


Figure 3.1 Positioning of the present research

The aim of the quantitative study (Component 1) was to gather data on disability types, demographic-, employment-, household-, and health status information, as well as information about the level of education of participants. The quantitative study also gathered data on disabled people's access to Voluntary Counselling and Testing (VCT) services, their access to general information on sex and sexuality, as well as their HIV status – participants were only asked whether they knew what their HIV status was, since HIV is a non-notifiable disease in South Africa. They were however free to disclose their status if they so desired.

The quantitative study was also instrumental in paving the way for the subsequent qualitative part (Component 2) of the study, in that data collectors could inform potential participants about the opportunity to participate in the in-depth interviews that would follow. These interviews employed semi-structured interview guides and data was gathered on levels and quality of access to and actual knowledge of disabled people concerning HIV and AIDS, sex and sexuality. The qualitative interviews also looked at the awareness and experiences of disabled people concerning issues of violence, sexual abuse and rape of disabled people.

In light of the content of the topics in the qualitative interviews, the preceding quantitative study presented the opportunity to introduce the potentially sensitive and challenging topics of disability, HIV and AIDS and sexuality to potential participants. This introduction was also instrumental in building a trust relationship between data collectors and participants. Qualitative interviews were conducted with 34 participants, with women and men being equally represented. The qualitative interviews with the 17 female participants form the basis for the present study.

3.2 Purpose and Research Questions

The purpose of the present research is to explore the lived experience of disabled women in South Africa concerning HIV and AIDS, sex and sexuality as well as access to VCT services. The research question is informed by four main components of inquiry that aim to facilitate a better understanding of the impact of HIV/AIDS on disabled people within the South African context. These are:

- 1) What are the perceptions of disabled people of the status that they are afforded by others concerning both HIV&AIDS and sex and sexuality?
- 2) What are the attitudes towards and practices of sex and sexuality of disabled women in South Africa; and
- 3) In terms knowledge, attitudes and behaviours of disabled women with regards to HIV and AIDS:
 - 3.1) What knowledge do they have about HIV and AIDS?
 - 3.2) What are their attitudes towards HIV and AIDS and disability?
 - 3.3) Do they access HIV and AIDS prevention programmes?
 - 3.4) What is their experience around access to these programmes?
- 4) What are the experiences of disabled women concerning rape, abuse and violence?

These components illustrate how the study attempted to explore disability and HIV/AIDS through issues that were revealed in the literature review.

3.3 Rationale of Qualitative Research Approach

The rationale for using a qualitative research approach in this study is to allow the experiences and daily reality of disabled people to be described as it is subjectively experienced by themselves. Brinkmann & Kvale (in Willig & Stainton-Rogers *eds.*, 2008) point out that qualitative research enables the exploration of human existence in detail, and it allows for researchers to describe intimate aspects of people's life worlds, which is an apt rationale for employing a qualitative approach to gain an understanding of the research question at hand.

Qualitative methods also allow for an acknowledgement, as Pujol and Stainton Rogers (1997) put it, that 'something is always un-understood'. The aim of the study is certainly not attempting to make absolute conclusions, produce definitive knowledge, concrete facts or last words on the subject at hand. Rather it is an attempt to understand the lived experience – which for the purpose of this study consists of their knowledge, attitudes and practices - of disabled people concerning HIV and AIDS, sexuality and access to VCT services.

3.4 Overview: Process of Appointing Data Collectors

The very first step, before carrying out the data collection, was to put out a call through DPSA for disabled people to apply for positions as data collectors. Since the consensus amongst the partners collaborating on this project was that disabled people had to be a large as possible part of the research team in order to build capacity amongst disabled people and also to have as much input from them as possible, non-disabled people were not invited to apply for the positions of data collectors in this study. Another factor, which was considered in this regard, was that of participants likely being more comfortable, forthcoming and at ease in talking to other disabled people, given that both stigma and exclusion is features of the dynamic between disabled and non-disabled sectors in South Africa.

Selection criteria included that they had to live in the sites where the study was to take place, proficiency in reading and writing in a language widely spoken in the area, as well as being fairly proficient in English was more important than having obtained a specific level of education. Though it was not explicitly stated in the call for applications, there was a general consensus that an education level of some secondary grade would be more appropriate.

Another criterion that the partners in the project wanted to adhere to was to select a group of data collectors that was as far as possible representative and inclusive of gender and disability type, and applicants who were unemployed at the time were favoured above those already in employment. The reason for this is simple and twofold: those already employed would invariably be challenged in terms of availability to work on the project, since their flexibility

would almost certainly be limited. It would also, albeit in a small way, contribute to the enhancement of skills of the successful applicants, and in that way contribute to capacity building.

Twelve data collectors – six men and six women – were selected from a group of 45 applicants. They were to work together in the six research areas in pairs of one male and one female. The rationale behind this was perhaps first and foremost that since the research engages with issues of a very personal and often sensitive and/or stigmatised nature (sexuality, HIV/AIDS, disability) that it would be most relevant for male data collectors to interview men and female data collectors to interview women. As it has been pointed out in the literature review, the status afforded to men and women often differ, and anticipation of the quality of the data gathered being influenced, the data collectors were gender-matched to participants.

For one week data collectors gathered in Pretoria to participate in a training process, and to familiarise themselves with the study, and with both a questionnaire as well as the semi-structured interview guide. I co-facilitated this training. Much of this week was spent on the interviewing process and the skills required to successfully conducting interviews.

A research team manager was assigned to each province (in two cases not data collectors themselves, and in the third instance an experienced data collector who also interviewed participants), who would oversee the process and support the data collectors in logistical and any other matters that could come up during the course of the project. All the partners were

also available to both the team managers and the data collectors for any form of support or information they were to require during the course of the project.

After training was completed, the data collectors set out to collect the data. Through their membership organisations, DPSA coordinated disabled people gathered at various types of venues (community halls, church halls etc.) where information about the purpose and methods of the study was communicated to potential participants. Participation was voluntary and anonymous. Interviews were conducted in a one on one setting, in a place where there was privacy to the greatest possible extent within the often-limited range of options available.

3.5 Data Collection Instrument

A semi-structured interview guide, which was informed by an extensive literature review conducted by the Lead Academic Partner (SUN), as well as being guided by the risk factors which increase disabled people's risk of HIV infection, as identified by Groce (2004), was developed for use in the overall qualitative component of the study. This interview guide was constructed in such a way that it could facilitate the gathering of qualitative data – employing open questions and inviting participants to speak of their personal experiences with regard to the topics at hand. Interviews were conducted in the home languages of the participants, and captured on audio recording devices, for which permission was first obtained from each participant. Data collectors then transcribed the interviews verbatim, and translated the transcriptions to English. Both men and women were interviewed using the semi-structured

interview guide, but only the interviews with the female participants were used for the purpose of the present study.

3.6 Research Sample

The research sample consists of disabled females aged between the ages of 25 to 45 years old. Women younger than 18 years were excluded from the study due to the added logistical and legal implications of the participation of minors, which could not be accommodated within the scope and resources of the study. The research team did however not want to ignore the vulnerability of this population; therefore, the questions in the semi-structured interview were open to the extent that participants could respond about their experiences over the course of their life, thus not relegating participants to respond only about experiences after the age of 18 years old.

The sample was drawn from people with a range of disabilities, in an attempt to have a sample that is as inclusive and representative as possible. The aim therefore set out was to draw a sample on a convenience basis from a population of physically, sensory, psychosocially, communication and intellectually disabled people, or any combination thereof. The final sample of 17 seventeen women was limited in that it comprised of only two disability types, namely physically (13) and visually disabled (4).

Another criterion for sampling was that participants had to reside in the three provinces identified for the purpose of this study. These were Gauteng, KwaZulu Natal and the Western Cape. Within these three provinces, samples were drawn from deep rural, rural, informal peri-urban and urban areas. The provinces are highlighted on the map shown in Figure 3.2 below.

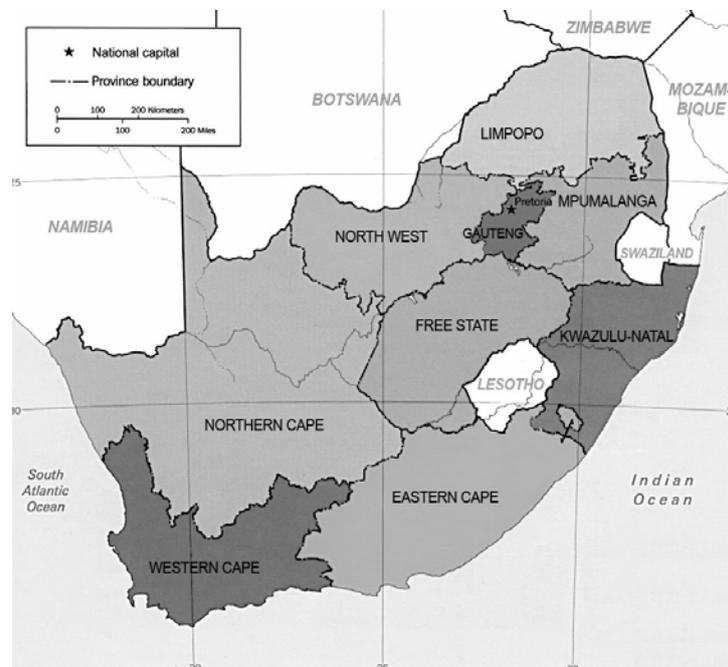


Figure 3.2 Map of South Africa

These areas for sampling and data collection were identified after taking into consideration the rates of in the HIV infection and people living with AIDS in the nine South African provinces, the measure of research done on HIV and AIDS in the various provinces, and scope, resources and limitations of both the project and DPSA, which has as its affiliates DPOs in various provinces and who also directed the project in terms of the expressed need

of research in relevant areas. DPSA played an instrumental role in facilitating access to the disability sector through its network of member DPOs.

A total of 9 participants live in the following areas of Gauteng:

- Soweto (includes urban and informal peri-urban areas) and
- Diepsloot & Tembisa (informal peri-urban township),

A total of 5 participants live in the following areas of KwaZulu-Natal:

- Pietermaritzburg (urban & informal peri-urban) and
- Mahlabatini (deep rural) , and

The remaining 3 participants live in the following areas of the Western Cape:

- Mitchell's Plain (urban) and Phillipi (informal peri-urban township) as well as
- Ceres and Tulbach (rural).

After potential participants were alerted to the opportunity to participate in the study, they were invited to attend meetings in community halls and various other venues. These meetings were set up by data collectors in collaboration with local community leaders, chiefs and social workers. Data collectors also moved through the specified area and with the permission of community leaders and chiefs, enquired about where disabled people were living in the area, and then sought them out in that manner.

At the beginning of the interviews, participants were also asked about their level of education, employment status and marital status. They were also asked whether or not they had children. Even though these aspects did not constitute criteria in establishing the parameters of the sample, it was deemed to be important sources of demographic and contextual information to the study, given the relationship between these factors and the lived experience of participants as illustrated in the literature review.

The level of formal education of the sample ranged from one person with no education, to one person with a tertiary certificate. The rest of the sample consisted of slightly more participants with some level of secondary than primary school education. At the time of data collection, nine participants were unemployed, three were employed and two worked as unpaid volunteers. Three participants' employment status was unknown. In terms of relationship status, 12 women are single, two married, two in relationships and one participant's relationship status is unknown. Between the seventeen participants, they have a total of 23 children, with seven single women having a total of eleven children between them, and five of the single women having none. Amongst the two married women, there were three children, and one woman in a relationship had one child, whilst the other had none. The woman who has the most children (5) is the one whose relationship status is unknown.

3.7 Data Analysis

Data analysis was done by studying at the transcribed and translated interviews and performing qualitative content analysis according to the guidelines suggested by

Krippendorff & Block (2009) and categories into which responses were allocated, were HIV and AIDS, sexuality, and access to VCT services. Concerning each of these three components, participant responses were classified as they related to knowledge, attitudes and practices. Responses were coded, and the details of categorical allocation of responses are indicated in Table 3.1, which follows on the next page.

Table 3.1

Qualitative Content Analysis Framework

KNOWLEDGE OF HIV AND AIDS	
1.	Information sources
2.	Detailed knowledge of HIV and AIDS
3.	Knowledge of HIV transmission
4.	Knowledge of consequences of infection
5.	Estimation of vulnerability to HIV: comparison between disabled and non-disabled people
6.	Level of access to knowledge
KNOWLEDGE & ACCESS TO HIV TESTING AND TREATMENT	
1.	Knowledge of the term 'VCT'
2.	Knowledge of HIV and AIDS related health care services
3.	Yes / No to ever having had an HIV test
4.	Description of access to HIV and AIDS related health services
4.1	Distance to clinic/hospital
4.2	Physical accessibility of facilities
4.3	Information format accessibility
4.4	Health care staff attitudes
4.5	Attitudes of others
ATTITUDES OF SELF AND OTHERS WHICH RELATE TO SEXUALITY & SEXUAL PRACTICES OF DISABLED PEOPLE	
1.	Own attitudes: similarities & differences between sexuality of disabled people compared to non-disabled peers
2.	Attitudes of others as perceived/experienced by participants
3.	Knowledge & experiences of rape, sexual abuse and violence
3.1	Own experience of rape, sexual abuse and violence
3.2	Knowledge of other disabled people experiencing rape, sexual abuse and violence
3.3	After the rape/abuse: Reports to police and consequences thereof

After responses were allocated to and organised with reference to these categories, further qualitative content analysis enabled a refinement of these categories and the inclusion of emergent categories formed the framework, which then emerged, was used to write up the findings. The outline of the second and framework is illustrated in Table 3.2, which follows on the next page.

The approach to data analysis follows that suggested by Bless, Higson-Smith and Kagee (2006).

Qualitative content analysis was performed without electronic qualitative data analysis packages. The author manually studied the transcripts of the interviews and organised the data according to key issues. The process was guided by the data itself. Three things in particular necessitated this method, the first being the nature of the semi-structured interview guide, as well as the relative inexperience of the data collectors. A third aspect which influenced the need to follow this process was that often participants seemed to interpret the questions put to them in a different way than expected by those who designed the questions.

To make sense of the data as a whole, it was therefore decided that emergent aspects were grouped in terms of content. The qualitative method of data collection and analysis certainly proved to surprise and challenge those involved in these aspects – there were few answers that could be fitted neatly into one category and be done with. In three sentences, a participant could sometimes address as many as five issues under discussion, and sometimes the participants would answer questions as though the question put to them were something entirely different from what had been asked. The data naturally had to be untangled and classified according to the qualitative content analysis framework. This in turn had to be

reworked and modified to build a systematic and meaningful structure through which the information that came from participants could be presented.

This process entailed that the author engaged robustly with the data, and after repeatedly classifying the data and in the process always finding weaknesses and coming to understand why and how the particular classification could be refined, developed the final framework for writing up the results (Table 3.2). The data therefore provided the framework, and the framework was then used to glean the data repeatedly, until every bit of information was slotted into the final framework, and until the framework could provide a place for every single piece of information that participants provided.

It was also decided that three individual narratives would be employed to provide not only a description of collective experiences, but to enrich and illustrate the collective findings with the stories of three women telling in their own words of their own experiences.

Table 3.2

Final Framework for Writing up Results

COMPONENT 1: HIV and AIDS
1.1 Knowledge of HIV and AIDS <ul style="list-style-type: none"> ➤ Sources of Information ➤ Knowledge HIV Infection Prevention Strategies ➤ Knowledge and Perceptions of Consequences of HIV Infection
1.2 Participants' estimations of risk faced by disabled people compared to non-disabled people for HIV infection
1.3 Disabled people's Perceptions Regarding the Sufficiency of their Knowledge of HIV and AIDS
COMPONENT 2: ACCESS TO HIV RELATED HEALTH SERVICES
2.1 Experiences of Access to HIV and AIDS related health services <ul style="list-style-type: none"> ➤ Physical Accessibility ➤ Format Accessibility ➤ Attitudes of Health Care Staff ➤ Attitudes of Others
COMPONENT 3: SEXUAL PRACTICES, SEXUALITY AND STIGMA
3.1 Attitudes Relating to Sexuality and Sexual Practices of Disabled People <ul style="list-style-type: none"> ➤ Participants' Perspectives of Similarities and Differences in Sexuality and Sexual Practices of Disabled and Non-Disabled ➤ Participants' Perspectives of Non-Disabled People's Attitudes Towards Sexuality and Sexual Practices of Disabled People
COMPONENT 4: RAPE AND ABUSE
4.1 Sexual Abuse, Rape and Violence Against Disabled Women <ul style="list-style-type: none"> ➤ Participants' Own Experiences in the form of three individual narratives ➤ Participants' Knowledge of Other Disabled People's Experiences ➤ After the Ordeal: Experiences related to the reporting of Incidents to the Police

3.8 Ethics

Ethical review for the present research was obtained from the ethical review committee at the Faculty of health Sciences, Stellenbosch University.

Informed consent forms were designed by the research team, and when prospective participants were briefed on the nature, process and purpose of the study, they were informed about their ethical rights if they were to participate. These included that their names would be kept confidential – only the research team would ever have access to these. They were also informed that their participation would be voluntary, they could discontinue their participation at any stage, and that they were free to decide not to answer any of the questions if they were uncomfortable, or for any other reason. They were also informed that there would be no financial reward for participation, but that they would be provided with either transport, or an amount of money to cover their taxi travel expenses in order to have access to the various local venues where interviews were conducted.

Regarding follow-up counselling services for those participants who could be emotionally upset by participating in the study, in the initial project plan the university budgeted for counselling services. The DPSA representatives on the study however suggested that a better and more culturally sensitive way of providing follow-up would be through the auspices of DPSA itself, and DPSA therefore took on this responsibility. Participants were also informed of facilities for HIV counselling and testing services that they could seek out if they needed it.

A further important ethical issue was the impact of the process on data collectors. We created a supportive training group through which the data collectors could depend on one another for emotional support. They reported that they found the process stressful and the support helpful.

Chapter 4 – Findings

4.1 Knowledge of HIV Prevention Strategies

4.1.1 Sources of Information

Information about HIV and AIDS was reported to come from a range of sources, and often from multiple sources. Thirteen participants indicated that information on HIV and AIDS reached them via the media, making it the most commonly reported source. Media sources were reported as radio (5), television (4), newspapers (3), whilst Braille books and information leaflets (1). One respondent reported having obtained information from books in Braille.

The second largest source of information on HIV and AIDS was clinics and/or hospitals, with 9 participants, followed by workshops and/or community meetings (5) and schools (2). One respondent obtained information while she attended classes in nursing, and another respondent said that though she had heard of HIV and AIDS, she had no detailed knowledge of it.

4.1.2 Knowledge HIV Infection Prevention Strategies

Twelve participants indicated that condom use can avoid HIV infection, making it the most commonly reported HIV prevention strategy. Avoiding contact with HIV infected blood was reported by 10 participants to be a way of avoiding HIV infection. Seven participants indicated that keeping to one sexual partner and avoiding sex with multiple partners to be an effective strategy. Five participants indicated sexual abstinence, rendering it the least commonly reported HIV prevention strategy.

4.1.3 Knowledge and Perceptions of Consequences of HIV Infection

Participants' knowledge and perceptions regarding the consequences of becoming HIV infected are categorised into three main components, namely physical suffering and death, treatment and lifestyle implications, and consequences related to attitudes of others towards HIV+ persons.

Physical changes as a result of HIV infection, such as the HIV positive person's hair becoming fluffy and losing weight, were reported. All the respondents said that HIV and AIDS is an incurable disease, and a common response was that the person infected with HIV would die. Some respondents said that to die of AIDS is a very slow and painful process.

Three participants referred to the use of medication for the treatment and management of HIV. Of the three, two referred specifically to antiretroviral (ARV) treatment. Three participants indicated that by following a healthy diet, doing exercise, adhering to the regulations given by the counsellors at the clinics and taking good care of yourself, you will delay the onset of AIDS. The possibility of living a long life despite being HIV+ was expressed by two participants.

Three of the four women, who relayed their experiences of others' attitudes towards those who are HIV+, are HIV+ themselves. Disbelief among family members of the HIV+ person, who discloses his /her status to them, was reported. One respondent said that most people infected with HIV do not talk about it – they just keep quiet and keep spreading the virus.

Fear and anxiety around the responses of both family and community members were said to be influential in the decision not to disclose HIV+ status. Another respondent told of how her mother was the first person to whom she disclosed her HIV+ status. Her mother's response was "very, very aggressive" and riddled with "vulgar language".

The same woman has not disclosed her HIV+ status to her husband. She fears disclosure because they have only been married for one year. To the question of whether she thinks her husband will react badly if she were to disclose her status, she replied that they have discussed the topic of HIV status, but only after they were already married. During this conversation her husband expressed the sentiment that if one of them should ever become infected, it would be "a bad reaction", but that they would still keep on living together and

lead a happy life. Despite this, she is too anxious about his response to disclose her status to him.

Another HIV+ participant said that she wants very much to go to the clinic to get more information on HIV and AIDS and to access treatment, but she is unwilling to take the risk of being seen when she goes there. She fears that if people in her community see her going to the clinic, they will find out that she is HIV+, or at the very least, suspect it.

4.2 Participants' estimations of risk faced by disabled people compared to non-disabled people for HIV infection

The issue of perceived risk of HIV infection of disabled people compared to non-disabled people came up in 13 out of the 17 interviews conducted. Of these, seven respondents estimated that the risk of HIV infection is higher for disabled people than for non-disabled people. The latter responses were motivated by references to the inability of disabled women to defend themselves when faced with rape or sexual abuse.

“Women are the one who get easy to be infected by non-disabled. They take advantage of them. Using them as if they love them after they get what they want they dump them.”

It is important to note that the term *rape* was used across all the interviews to describe an incident of a woman being forced to have sex against their will *by a stranger*, and in only one instance was the *rapist* known to the victim and it was still called *rape*. All the other incidents of sexual abuse, which under the Constitution of South Africa is defined as *rape*, were euphemistically called *being forced*. Usually forced to have sex without a condom, and being unable to defend themselves physically, were reasons provided for their increased risk of HIV infection for disabled women. One woman's response describes the situation:

“You are disabled you can't fight for yourself. If you fall in love with a person he always want to force him upon you and have sex with you without a condom. This put your life at risks, when you insist they must use a condom they don't understand but always want to have sex without a condom.”

Other reasons given for the increased risk is a lack of knowledge of HIV and AIDS amongst disabled people, alcohol abuse amongst those who are mobility impaired, and not being able to see (blind respondent) whether a male sexual partner “opens up a hole in the condom”.

The remaining six out of thirteen respondents who were asked this question perceived no difference between the risk of HIV infection for disabled people and non-disabled persons. Respondents said that the risk of being infected with HIV is high for everybody – regardless of disability status, and that disabled and non-disabled people are all the same, and need to

take the same precautions to avoid infection. Two of the women's responses capture all the elements expressed by those that held this view:

“The risks are the same as non-disabled ... actually we are all the same. HIV infect us the same, there is no difference. It doesn't even check whether you are disabled or not.”

“Anyone who does not take care of him- or herself can be in the same situation of HIV. I can say for disabled and non-disabled people if we don't protect ourselves by using condoms, HIV cannot leave us because we are disabled, or that one can survive because he or she is disabled. All of us if we don't protect ourselves we can be infected.”

4.3 Disabled people's Perceptions Regarding the Sufficiency of their Knowledge of HIV and AIDS

One third of respondents said that disabled people have enough knowledge about HIV and AIDS. Views expressed included that disabled people do not use this knowledge to the maximum extent possible, or that although some disabled people do know enough of HIV and AIDS, that most disabled people do not.

Two thirds of respondents held the opinion that disabled people' knowledge and understanding of HIV and AIDS is insufficient. One of the respondents noted that even though the choice of contributing or not contributing to the topic of HIV and AIDS is a personal matter, she is concerned over some disabled people who choose not to attend community meetings where information about HIV and AIDS is disseminated. She said, "These people end up knowing nothing", and that the reason they stay away is because they are "scared (that) people will look at (them)". Another respondent said that many disabled people also do not go to health service centres to get information on HIV, since they think that as disabled people they cannot be infected with HIV.

Even though the respondent set included no deaf persons, the lack of sign language interpreters at clinics and VCT centres frequently came up as a pitfall to disabled people knowing enough about HIV and AIDS. One woman said that she lives with deaf people, and that in her experience any attempts to try and explain the concept of "HIV" to them is virtually impossible. They do not understand, they say that they disagree, that what she is saying to them does not exist.

4.4 Experiences of Access to HIV and AIDS related health services

Fifteen of the 17 respondents were asked whether they know the term 'VCT'. 60% said yes, and 40% no. All the respondents were asked whether they know where to go to get tested for HIV, and all of them did. Whilst 2 of the respondents were not asked whether they have been tested for HIV, of the remaining 15 respondents, 86.7% had been tested for HIV at some

point, and 13.3% had not. Reasons indicated for not testing were that (it is) “not necessary, since I am not in love” and another respondent said that “I don’t go anywhere, I spend time at home and plus I don’t have a boyfriend, never had one, and don’t need one”.

4.4.1 Physical Accessibility

To the question of whether there are any difficulties in getting to the venue where HIV and AIDS related health services are available, one respondent said that the clinic is close by and that she can get there by herself. Another respondent said that health workers come into the communities, making it accessible to disabled people in her area. Three participants spoke of difficulties when needing transport to access health services: for disabled people in rural areas, transport is not readily available, and when wheelchair users use transport, they pay double the fare, since the wheelchair is also charged for. Regarding physical accessibility of clinics/hospitals and VCT centres itself, respondents found the facilities easy to use and did not report challenges in this respect.

4.4.2 Format Accessibility

Thirteen of the 17 participants gave information about their experience of the accessibility of information at HIV and AIDS related health service centres. More than half of this group found the format of the information very accessible. Some provided specific reasons for this, which ranged from information being in respondent’s first language and in Braille, and user-

friendly. Two respondents (of the 10 which found information to be accessible) indicated that the way that health workers explained the information was very clear and accessible to them.

The range of negative aspects in relation to the accessibility of information included that deaf service users were not provided with Sign language interpreters, that people with visual disabilities are not sufficiently catered for, and that information given is very difficult to understand.

4.3.3 Attitudes of Health Care Staff

Negative experiences regarding the attitudes of staff at HIV and AIDS related health services were encountered by 3 of 9 participants who touched on the topic during the interview. One woman reported that “we face that problem every day at the clinic ... people (health workers) will say ‘How can a disabled person get HIV?’ Another woman said that she encountered very poor service delivery at her local clinic where she went to get tested for HIV. At the clinic, she was asked by staff how a person in a wheelchair could get HIV. She described the experience as hurtful and stressful. She was transferred to a large regional hospital where “everything went smoothly, no problems”. A third respondent expressed her frustration after feeling that she was treated unprofessionally by a health worker by saying: “I have no powers to sort that nurse”.

The majority of respondents (6 out of 9) did however indicate that health care workers treated them the same way as they would any non-disabled person, that “they don’t discriminate, they show a lot of care”, that service is good, and that no negative attitudes had ever been encountered at the health care centres in question.

4.4.4 Attitudes of Others

The attitudes of others often seemed to be experienced by respondents as a barrier to accessing services. One woman, who is HIV+, said that she wants to go to the clinic to find out more about HIV and AIDS, but she is ashamed of her positive status, and afraid of what people in her community will say when they hear about her status. She feels that by just going there, people will know that she is HIV+.

Another respondent said on this issue, that when people find out you are HIV+, “they think you are close to death”. Respondents also spoke of positive experiences of others (friends, community members and HIV positive people living openly) attitudes, which did nothing to inhibit them from accessing health care services that relate to HIV and AIDS.

Another interesting point made was that the attitudes of disabled people themselves often hindered their access to information and services relating to HIV and AIDS. One respondent reported that disabled people stay away from community meetings because they think “people will look at me”, and consequently “they end up knowing nothing”.

4.5 Attitudes Relating to Sexuality and Sexual Practices of Disabled People

4.5.1 *Participants' Perspectives of Similarities and Differences in Sexuality and Sexual Practices of Disabled and Non-Disabled*

The overwhelming majority (15 of 17) of respondents indicated no perceived difference in the sexuality and sexual practices of disabled people compared to non-disabled people. Sentiments that were commonly expressed include that physical disability has no bearing on one's ability to have sex, and that in terms of sex and sexuality, disabled people experience the same range of feelings and desires as non-disabled people. One respondent's view is representative of the collective response when she says:

“I don't see any difference. The fact is we are all the same, we have the same feelings. I can do whatever a non-disabled can do. I have feelings as well, I have just lost part of my body. When it comes to love life and sexuality, I feel it as well.”

Of these respondents, five indicated that, though they don't see any significant differences, there are some elements which are not the same. A blind respondent said that though there is no difference in sexuality, sexual practice is different in that blind people cannot see everything that is going on during sex. One respondent said that the difference “is in the way you do it”, but without elaborating on her point. Another respondent said that the difference

came in for her when she sometimes “feel pains, then I don’t even want to be touched or used. Immediately when pains stop, I can have sex”.

Only two respondents perceived a clear difference in sexuality of disabled and non-disabled people, and they indicated that this perception is informed by their experiences of the attitude of non-disabled men towards disabled women. The first of the two said that it is different, because non-disabled people don’t want to have sex with disabled people. The second woman said that in her experience, men will say to her that they can only be her friend, but not sleep with her or love her.

4.5.2 Participants’ Perspectives of Non-Disabled People’s Attitudes towards Sexuality and Sexual Practices of Disabled People

Women in this study perceived the attitudes of non-disabled people to be predominantly negative toward and ignorant about disabled people’s sexuality. They felt that non-disabled people “undermine” disabled people. This was motivated by their experiences of non-disabled people who think that disabled people are not “full people”, that disabled people know nothing relating to sex, that they cannot have sex with others, or that they are unable to do certain “sexual things”.

Respondents also said that in their experience, non-disabled people think that disabled people should not be involved in relationships or marriage, but that disabled people are merely

“snacks”. One woman explained about disabled women falling in love (with able-bodied men), saying: “You fall in love with a guy he is only after your grant and he does not love you”.

Another respondent also felt that when a non-disabled man wants to have sex with a disabled woman, his desire to do so may be less motivated by sexual desire and more by sexual curiosity about what it would be like to have sex with a disabled person. Some respondents expressed the view that some non-disabled people find it completely unfathomable that anybody would want to have sex with a disabled person, by saying that non-disabled people do not believe that anybody will make a sexual proposition to a disabled woman. One participant said:

“The fact that I can also have blood just like them, they don’t think of that. They don’t even believe that we can also be proposed and have sex. They just undermine us by saying that we don’t know anything related to sex. “

One respondent pointed out that even when non-disabled men are having sex with disabled women, they are unwilling to acknowledge this: “Boys come to have sex in secret with disabled people and do it quickly so that they are not seen by people”. This was echoed by another woman when she said that “non-disabled are playing with us and making (a) fool of us. They also hide us, but with non-disabled, anytime, anywhere”.

4.6 Sexual Abuse, Rape and Violence against Disabled Women

4.6.1 *Participants' Own Experiences*

Thirteen of the seventeen women who participated in this study were asked whether they had ever been raped or forced to have sex against their will. Out of these thirteen, nine responded affirmatively. The term 'rape' was only used by 3 women, twice about being raped and once about being the victim of an attempted rape. The remaining women all reported of having been, or repeatedly being forced to have sex by either their partners, brothers or acquaintances.

Bearing in mind that of the 17 participants in this study, all are physically disabled apart from 3 women who are blind, and one who has a psychosocial disability, it is perhaps not surprising that it was almost always reported by the women that they cannot defend themselves when they are confronted with abuse and/or rape.

Another element which was frequently mentioned is the challenge of negotiating condom use. Participants frequently reported that they cannot defend themselves against rape and abuse, and also that the men who force them to have sex against their will, do not use condoms, and that there is nothing they can do to convince them to do so. The vulnerability that disabled women speak of in this study is reflected in the following response by a woman who is physically disabled, and also HIV+:

“They beat us up before ... sleeping with you when you don’t want to. They don’t want to use condoms when they sleep with me. I was living with four guys including my boyfriend. The guys would come in and do with me as they pleased. I am forced to have sex in front of my child. I think it is because they know I cannot defend myself. I was forced to have sex, and that is how I learnt of it being abuse.”

One respondent said that since she is unable to walk, she drinks alcohol to pass the time, and someone, under the pretext of helping her, raped her without using a condom. The only respondent with a psychosocial disability, reported that she was raped by two of her aunt’s boyfriends, when she was 8 months old, and again by a second boyfriend when she was twelve years old. “They took advantage of me and I ended up losing my virginity when I was not ready.”

4.6.2 Participants’ Knowledge of Other Disabled People’s Experiences

Many of the women who indicated that they themselves been victims of rape, abuse and violence, also spoke about “us” and “we” encountering these abuses. Apart from these responses, women were also asked whether they knew of other disabled people who were victim to these crimes. Two of the five respondents who were asked this question, said that they knew of many instances of disabled people being sexually abused. Between the five respondents 8 examples of rape and abuse – all of which were perpetrated against females -

were reported. Amongst these stories, 4 told of the rape of young girls with disabilities: one was on the way to school when she was raped by her grandfather, one was taken to an abandoned house and gang raped by 4 boys, a third girl – who is a wheelchair user – was found where she was being raped by an unknown person in the toilets at her school, and another girl was the victim of sexual abuse by her brother (incest).

Other examples include an attempted rape, and three adult disabled women who were raped. One of them is a mentally disabled woman who routinely went into the bush to collect wood. Unbeknownst to her family or community, men went into the bush after her and “forced her to have sex with them”. She was not telling anybody of what was happening. Only after she was pregnant, and questioned by a nurse about how she got pregnant, did she break her silence about what was happening. The sentiment that disabled women cannot defend themselves against rape and abuse was voiced again:

“Many disabled people are sexually abused. People are using these people and forcing them to have sex. It happens for someone who is HIV+ to go and force these people to have sex and they will be infected. Non-disabled people take advantage because they know that they are not okay.”

4.6.3 After the Ordeal: Experiences related to the reporting of Incidents to the Police

Of all the women who told of being raped or forced, or of knowing of someone who was raped, there were only four instances where it was reported to the police. A disabled girl, who was raped by four boys in an abandoned house, succeeded in recognising them after the case was reported to the Police, and they were arrested. The woman who was raped at the age of 12 also identified the rapist and this led to his arrest.

Another respondent told of how her statement was taken by a female police officer in a private room, and how the police sent her to hospital for a check up, where it was confirmed that she had indeed been raped. The men who raped her were arrested. Despite the fact that the perpetrators were positively identified by the victims, none of the cases ever made it to court and therefore no convictions were ever obtained.

One respondent said: “The disabled person is threatened with death if they report such incidents”, and another woman spoke of the extremely discriminatory and derogatory treatment by police officials, who were unwilling to help her when she wanted to lay charges after being raped. They said that since she was “also enjoying herself”, and therefore they could not do anything for her, and sent her away.

4.7 Individual Narratives

The names used in these narratives are fictional and not the names of the actual participants.

4.7.1 *Rachel*

Rachel is a 26 year old physically disabled, single woman from Soweto in Gauteng. She lives with her child in a predominantly informal township. She is currently single, unemployed, has completed secondary school, and is HIV positive. She has also been a victim of rape, physical and emotional abuse on multiple occasions and over an extended period of time.

HIV/AIDS

The first time Rachel had ever heard of HIV/AIDS was when she visited a clinic because she fell pregnant. She reported that she was tested for HIV without her explicit knowledge or consent. When she was informed at the clinic about HIV/AIDS, and that she had tested positive, she understandably found it difficult for various reasons. She was under the impression (and it seems that she was still under this impression even at the time of the interview) that her and her child could die at any time, and she reported that she did not make any attempts to find out more about HIV/AIDS, but rather 'moved on like it was not happening'.

Less than one year before the present study, she visited a clinic with her child, where the nurse told her that the child did not have to be on ARV treatment, since “one could see a sick child”, and that her child was not ill. The child was re-tested and the results were negative. The nurse subsequently asked Rachel whether she received a pill just before she gave birth, which she did not.

The nurse asked Rachel to return for another HIV test, but she never did. The reasons she provided for this was that she was not sick, that she had never been sick, and that she had a lot to deal with and therefore did not pay attention to it. She was surprised to find out later that her child was also HIV positive, and the child initially received ARV treatment.

Rachel seemed indifferent about obtaining more information on HIV/AIDS, stating ‘I never went to find more information about the virus, I just couldn’t be bothered’. Upon further questioning about why she did not attempt to find out more about HIV/AIDS, she indicated that she would in fact like to find out more, but that she was afraid not only of people finding out that she is HIV positive, but also of people finding out about any attempts from her side to do so, fearing that it may make her a target.

This fear was so extensive that she reported extreme hesitance to the reaction of even a taxi driver to her request of wanting to go to a VCT centre. She stated that she was ashamed about her status, and that the majority of people in her community were unaware that she was HIV positive.

In this regard, her fear of their reactions to her status, as well as being unaware of the confidential nature of HIV testing and counselling, has prevented her from disclosing. She was surprised when, during the course of the interview, she learnt that she would not have to talk about HIV related issues in front of other clinic users, but that it would only be her and the nurse in a private setting. It would be fair to say that at the time of the interview, the extent of Rachel's knowledge of HIV/AIDS was limited, and her only reported sources of information was the time she went to the clinic during her pregnancy, and television.

Sex and Sexuality

Rachel indicated that she 'didn't know much about sex', and she "learnt about sex" when she was painfully 'forced' into having sex with somebody. When asked about perceived differences between the sexuality of disabled and non-disabled people, she reported feelings of hurt 'because people don't view us as full people' and also commented that disabled people are often measured by what they cannot do, rather by what they can do.

She indicated that disabled people encountered problems with regards to sex, since they some people 'want to sleep with you without consideration, which is not right', and since others don't always understand the need for using a condom during sex.

Sexual Abuse and Rape

Rachel was infected with HIV when she was raped. She pointedly equates sex with abuse as a result of the rape. She indicated that she is unhappy about her personal experiences of sex, and said ‘they abuse us’ when asked about the relationship between disabled and non-disabled people with regards to sex. She reported that non-disabled people ‘beat us up before sleeping with us’, and that disabled people were victims of emotional abuse by non-disabled people, since the latter know that ‘we (disabled people) can’t stand up for ourselves’.

She indicated that she has always been raped by people she knew, and identified the main perpetrators as being her brothers and her boyfriend. Rachel was first raped when her mother was alive, and she was a live-in member of her family home. She was raped by her brothers. As a result of this rape, she fell pregnant, and was subsequently kicked out by her family. She moved to Meadowlands, and stayed in a house with no doors, windows or sanitation facilities. She shared the house with her boyfriend at the time and four other men. They would all “come in and do as they pleased on me”.

“Sleeping with you when you don’t want to, beating you and blackmailing you with money. There are days when you don’t have money to buy food, you have a child to feed, and then people make offers to you which you later have to pay back in kind.”

She went to the police and reported it when she was first raped, and she was satisfied with the way she was treated at the police station. A female officer took her statement in a private

room, and afterwards sent her to a large government hospital for medical verification of her statement. It was indeed confirmed that she was raped by multiple perpetrators, and yet the case never made it to court. Without her ever being notified about it, the case was eventually dropped, and she “never bothered again”, thinking that the officers may have been bribed, since the docketed all disappeared.

It comes as no surprise that Rachel reported being unhappy most of the time, and only being capable of being happy for “a few moments”, before feeling sad again and crying. From the following extract, it seems that as a result of repeated abuse and rape, she finds herself in a situation where she feels hurt, powerless and hopeless.

“I don’t want to see myself in this situation that I am being beaten up which I dint like and to be forced to have sex in front of my child. It hurts me because I can’t say anything about it as I am always viewed as the one in the wrong and get shouted at. So I don’t say anything.”

When asked about her views on the notion of an increased risk faced by disabled people to contract HIV compared to non-disabled people, she responded affirmatively, and provided reasons. These were that disabled people are often less able to go about their business independently, and therefore also more vulnerable to abuse. Rachel also indicated her inability to successfully negotiate condom use, as well as her dislike for staying with one man for a long time, as factors that increase the likelihood of HIV infection. In addition, she

expressed the view that she was being abused specifically because she was physically disabled, and therefore the perpetrators knew "... I cannot defend myself".

4.7.2 Noluthando

Noluthando is a 31 year old resident of Mitchell's Plain, an urban community of Cape Town in the Western Cape. She is physically disabled and has completed grade 6, which is one year short of completing a primary school education. She is single and has one child.

HIV/AIDS

She was unacquainted with the term VCT, but knows that HIV testing is done at a large government hospital in Cape Town. When she fell pregnant, she visited her local clinic to get tested for HIV. At her local clinic she was ridiculed and refused an HIV test, but despite this attitude from staff, they transferred her to the large government hospital in Cape Town. Upon arriving at the hospital "everything ran smoothly", and this was also where she delivered her baby without problems or abuse of any kind. She tested positive for HIV.

In terms of knowledge of HIV/AIDS and related prevention programmes and strategies, Noluthando reported that HIV can be prevented by using condoms, being faithful to one's partner and by sticking to one partner. She has learnt of HIV/AIDS from nurses at the hospital in Cape Town, and from workshops which she attended, and also pointed out that

these was the sources of information on HIV/AIDS that she found accessible. When these workshops are held in Cape Town as opposed to Mitchell's Plain, she finds it difficult to attend, since transport is not provided for those who want to attend. She points out that wheelchair users often have to pay extra for their wheelchairs when accessing transport.

Noluthando said that disabled people could easily be infected with HIV/AIDS, since "we drink liquor while we can't walk", and end up being raped by someone pretending to assist them. She thinks that too few disabled people have sufficient knowledge of HIV/AIDS.

Sex and Sexuality

Her knowledge of sex stems from her relationship with her current partner, and she reported that she feels "very comfortable about it, especially when I'm with my partner". In what seems like a contradiction, Noluthando spoke about not liking sex when she was diagnosed with HIV, since it was during intercourse that she contracted the virus. She went on to say that now she has sex because it is "human nature" and that after she found out about her HIV positive status, she told herself "it's not the end of the road ... it's just a challenge".

So even though she is comfortable with sex now, she said that the only problem with sex stemmed from her being sad when her partner "forces" her. She deemed her own knowledge and experience of sex too limited to comment on any possible differences between the sexuality of disabled people compared to those who are non-disabled.

Sexual Abuse and Rape

Noluthando reported that she had not been a victim of rape or sexual abuse – even though she did express sadness about when her partner “forces” her. She did know of a wheelchair user who was discovered whilst being raped by an unknown person in school toilets. She also knew of a young disabled girl who was victim to sexual abuse by a sibling.

4.7.3 Sibonisiwe

Sibonisiwe is 45 year old blind woman who lives in an informal urban township located in Soweto. She holds a secondary school certificate, but despite this, she is unemployed. She is married, has two children and is HIV positive.

HIV & AIDS

At the time of the interview, Sibonisiwe had never heard the term VCT. When she needs to access HIV and AIDS related health care services, she goes to a clinic outside of Soweto, which requires extensive travel by public transport, but which is the only clinic that she knows of where she can access these services. She knows of two clinics in Soweto, and

though she was aware of the fact that HIV education services available at government clinics, she said that these services are not provided at the two local clinics known to her.

Sibonisiwe was unable to identify HIV prevention and education campaigns, and indicated that she had learnt about HIV from her work where she was previously employed, and that she had read a book in Braille about HIV and AIDS. Unfortunately the interviewer did not ask her where she accessed this book. Her knowledge of prevention methods included avoidance of multiple sexual partners, and abstinence from sex until marriage, and using condoms.

When asked about how a person could become infected with HIV, she said that HIV could be transmitted by sleeping around with people, and by getting your blood mixed, which she suggested may happen if one has a cut and assists an infected person at the scene of an car accident.

Sibonisiwe said that before she went to get tested for HIV, she just felt 'something wrong.' When her family commented on the fact that she was rapidly losing weight, and that they suspected that she may be HIV positive or have AIDS, she went for the test. She said that there were no access problems at the clinic, and that the staff 'treated (her) just like any individual.' At the time of the interview she was not on ARV treatment, but she was on TB medication.

After she tested positively, she told her mother of her status. Sibonisiwe said that upon hearing about her being HIV positive, her mother became ‘very, very aggressive’ and proceeded to abuse her verbally. At the time of the study, she had already been married for one year, but had still not told her husband about her HIV positive status. She said this was because of fear of his reaction, even though they were using condoms anyway. They had also spoken about HIV after getting married, and her husband said that ‘(they) will still continue living together because in the first place both of us did not think of going out and test to see if any of us is positive and we will still live a happy life.’

In response to the issue of vulnerability of disabled and non-disabled people to HIV infection, Sibonisiwe said that she perceives the risk of HIV infection for these two populations are the same. When asked whether disabled people have enough knowledge of HIV, she said ‘I would not say I know all the information ... (but) I feel like we should go out and speak to them (disabled people) about HIV and AIDS.’

Sex and Sexuality

She indicated that she had learnt about sex from school and also from books, and that she had no problem with discussing about sexual intercourse. When asked about her own attitude to sex and sexuality, she replied:

“At certain times, I don’t know about every woman but for me I sometimes have a problem with sex and sometimes when my body feel like it I will do it but when my husband ask for it and my body does not

feel good, I will say no and he really does not force me into it, he knows when I am tired or not feeling good, he does not touch me but when I am feeling good and ready he knows that that is the time we go for it and have a sexual intercourse.”

When asked about disabled people and sex in general, she replied by asking the interviewer what it was that she wanted to know, since it was her view that disabled and non-disabled people all have sex. Upon further questioning about the sexuality of disabled people compared to non-disabled people, she again asserted her view that there is no difference, and in addition she expressed her view that power does not always only lie with the non-disabled person when it comes to having sex:

“No, they are the same, I believe so ... a normal person will have an edge over a disabled person, but sometimes a disabled person might have the edge over a normal person during sexual intercourse.”

She said that she is happy with her sex life, and that the only thing that could be regarded as a problem is that in being blind, she obviously cannot see anything. When asked about the reasons for disabled and non-disabled people not being different from each other in terms of sex and sexuality, she replied as follows:

“They are the same. The reason why I say they are the same is because I feel if a normal person has an intercourse with another normal person and a disabled with another disabled, there is nothing wrong they are the same, I see no difference in many things as long there is penetration.”

Sexual Abuse and Rape

Sibonisiwe said that she had never been sexually abused or raped. In addition to this however, in what seems a blatant contradiction, she said in response to a question about her satisfaction with her sex life, that ‘, I do not have a problem with it but the problem is that I do not like to be forced into it as it causes a lot of pains and stuff.’

In response to the question of whether she knew of other disabled people who had been sexually abused or raped, she seemed hesitant to provide examples, indicating that it is up to the person who experienced it to talk about it – ‘it is left to the person.’ She did however tell of a blind woman who was supposedly sexually abused, and then proceeded to almost negate her statement by saying that she does not know the ‘character’ of the woman in question.

Chapter 5 – Discussion

Firstly, it is of importance to note that given the wealth of research which suggests that disabled people (and women even more so than men) are more vulnerable to HIV infection compared to their non-disabled peers (Chilisa, 2005; Groce, 2004; Rohleder et. al, 2009), Only slightly more than half of participants held this view.

This is an interesting and somewhat unexpected finding if one regards the landscape of experiences related by participants in the present study. The way that the question of estimated risk was approached by participants were not integrated with the rest of their experiences as related by them, in that risk was seemingly approached mainly from a very narrow perspective, namely the physical effect of HIV entering the body of a disabled person compared to a non-disabled person. It can be said that in this regard, disability with regards to vulnerability of HIV infection were estimated by disabled people themselves from the medical model perspective of disability. The issue of risk was interpreted within a medical frame of reference which only looks at the difference in the body of a disabled person from those who are not disabled.

Though they were in the minority, there were some participants who motivated their estimation of disabled women facing a higher risk of HIV infection with increased physical vulnerability to rape and sexual abuse, poverty, social isolation, stigma relating both HIV and sexuality of disabled people and insufficient knowledge of HIV and AIDS. In this regard, it may be argued that these participants, though unwittingly, argued the issue of disabled people's vulnerability to HIV infection from a social model perspective. In pointing out

issues such as societal attitudes and a lack of knowledge and access to knowledge, the disabling effect is located within society rather than in the bodily 'difference' of the disabled person.

With regards to the latter, two thirds of participants expressed the view that disabled people do not have enough knowledge of HIV and AIDS, affirming the importance for the needs of vulnerable groups to be considered (Yousafzai et. al, 2005; Yousafzai et. al, 2004) when HIV and AIDS prevention campaigns are designed and executed. Despite the exclusion of disabled people as a target audience of HIV and AIDS prevention campaigns (Rohleder et. al, 2009), it is interesting to note that media sources were the most frequently reported source of information.

This finding may in part be explained by participant responses which indicated that their access to HIV and AIDS related information is inhibited by the social nature of access to and the setting of clinics, hospitals and community meetings. The reason provided for this is that stigmatising views amongst communities with regards to HIV and AIDS present major challenges by generating fear in prospective health care service users, thus inhibiting them from obtaining information from social settings where their privacy may be compromised, whether this compromise is actual or perceived. Therefore unwillingness to access HIV and AIDS related health care services may in some respect be attributed to judgmental attitudes held by community members who may know or suspect service users to be HIV positive if they should be seen to attend these facilities.

Stigma surrounding HIV is not the only complicating factor to disabled people's access to HIV and AIDS related health care services. The attitudes and perceptions of non-disabled peers regarding sexuality and sexual practices of disabled women also influence the experiences of the latter population's of access to HIV and AIDS related health services. Anderson & Kitchin's (2000) deconstructive analysis of the marginalisation of disabled people, and the subsequent unequal division of power between disabled and non-disabled people, is confirmed and illustrated in the findings of the present study. The effects of the adoption of a medical model perspective of disability, which locates difference within the body of the disabled person can be seen in this result. In viewing disability as non-normative rather than seeing it for what it is – a 'normal' and ever present feature of humanity which has been around for as long as human beings have – facilitates the stigmatising and discriminating treatment of disabled women when they try to access HIV and AIDS related health services.

Stigmatising cultural ideologies are reported in the present study to misrepresent the nature of the sexuality of disabled women, and are created and sustained in the communities where participants live. Participant responses indicated that they are often incorrectly viewed as sexually non-normative or abnormal. These negative views were expressed in a range of participant responses, and can loosely be categorised as their being regarded as asexual, not fully human, unable to have sex, sexual novelties, sexual 'snacks', sexually fragile, and as being without knowledge or authority regarding sex.

As Anderson & Kitchin (2000) proceed to point out, a consequence of these negative and mythical views regarding disabled women positions them as an out-group, and in turn

legitimises discriminatory practices against them. Discriminatory practices were reported in the present study in various forms. Aggressive, violent and abusive attitudes were indeed prevalent themes in the participant responses of the present study. An example of this is that women reported they often had no power in negotiating condom use, which echoes findings from previous studies (Mulindwa, 2003; Smith et. al, 2004).

Physical vulnerability compounds the vulnerability of disabled women to defend themselves against aggressive behaviour of others toward them. When these aggressive behaviours are of a sexual nature, it compounds their risk of contracting HIV. Physical vulnerability of disabled women place them in a position in that they often have no power over their own financial matters, since non-disabled partners and/or family members simply take their disability grant. Theft of their grant is facilitated for perpetrators by the threat of or actual physical and/or sexual violence against them. This effectively disables the women from attempting any efforts to defend themselves against crimes of this nature perpetrated against them.

It should be taken into account that the sample of the present study is composed of 13 physically disabled and four visually disabled participants. Considering that the likelihood of disabled people obtaining information on sex and HIV and AIDS have been shown to be influenced by the nature of their disability (Birch, 2002; Yousafzai et. al, 2005; 2004), the information gathered in this regard is limited in terms of representivity across disability types with regard to access of information on HIV and AIDS. The discriminatory power of a medical model view of disability is harshly illustrated in this finding. The difference which a medical model locates in the body of a disabled person is used to distinguish and

discriminate, and the type and measure of difference relates directly to the quality of access to information on HIV and AIDS. From a social model perspective this is a gross denial of human rights of disabled people. A social model argues that access to information and services should cater for all people, rather only to those who have a very specific, narrowly defined type of body.

The accessibility of the formats of available information was reported to be very satisfactory by all participants. Reasons provided were that materials were available in participants' mother tongue, that it was in some instances available in Braille, and that health care staff explained information in a very clear way.

The limitation in this regard is that intellectually and learning disabled people were not represented in this study and psychosocially disabled people were underrepresented, since only one multiply disabled participant reported being disabled in this regard. Given findings that they have been identified as populations that may find information difficult to understand due to low levels of education (Groce et al., 2007; Munthali et al., 2004), their absence from the sample is both lamentable and restrictive to the scope of the experiences reflected within the present study.

The level of formal education of participants ranged from one participant with none whatsoever to one participant with a tertiary certificate. Of the 17 participants, only one had obtained education on a tertiary level, and seven participants had obtained some level of secondary education. It is therefore particularly encouraging that only two participants

reported to find HIV and AIDS information extremely difficult to grasp. It is therefore particularly encouraging that almost all participants experienced information on HIV and AIDS provided at clinics and hospitals to be clear and easily understandable.

For physically and visually disabled service users, the present study seems to reveal stigma around HIV to be a more pressing barrier to the acquisition of information on HIV and AIDS than the accessibility of information as such. Even though there were no deaf participants, the lack of sign language interpreters at clinics, hospitals and community meetings were pointed out by many participants as a barrier to access of information on HIV, confirming findings of other studies (McCabe et al., 2000; Nosek, 2001) which have indicated the lack of accessible formats to deaf service users.

Lack of available and/or accessible transport – especially in rural areas - were indicated in the findings of the present study, serving to reinforce existing findings (Smith et. al, 2001). Poverty also plays a role in this regard, since wheelchair users have to pay double the normal transport fee – for themselves and for their wheelchairs. Considering that 11 of the 17 participants are unemployed, financial implications of added transport costs could prove debilitating.

Deaf people have been shown to be more marginalised (Groce 2004; Yousafzai et. al, 2005) than physically disabled people, which may very well stack the odds against them even further in terms of securing employment and therefore some form of income. In the light of existing findings, it may therefore be even more debilitating to access HIV and AIDS related

health services when distance is too great to access easily or too expensive to afford. It has been surprising to find that the vast majority of participants found no barriers presented by distances or means of transport to clinics. Physical accessibility was also surprisingly non-problematic to participants, given that they are all physically or visually disabled.

The negative attitudes of community members towards an HIV positive person were indicated to create and sustain considerable fear and anxiety for people who are HIV positive, resulting also in the infected person's unwillingness to disclose her status. In this regard, the findings of the present study illustrate an aspect of the relationship between stigma and the spread of the HIV pandemic.

This relationship between stigma and the spread of HIV is further compounded by the marginalised position of disabled women in society (Groce 2004), and their frequent inability to negotiate safe sex (Yousafzai et. al, 2005; Yousafzai et. al, 2004), the latter being indicated frequently and extensively by participants.

In the first of the three individual narratives, Rachel said that she found it difficult to understand what the nurses were talking about when they spoke of HIV/AIDS, because she could not see what they were talking about. It would be interesting to know whether blind people find information about HIV in Braille the most user friendly or facilitative source of information, or whether they prefer other, more creative ways to interact with the facts of HIV/AIDS.

Some observations on limitations: interviewing skills and translation

The sample of 17 women provides this research with a very small beginning in gaining some understanding of the lived experiences of disabled women in relation to HIV/AIDS, sexuality and sexual abuse. The data collectors who worked on the current project were trained for this purpose for one week, and though there were support available to them while they conducted interviews, their limited interviewing skills and experience influenced the quality and relevance of the data obtained. Some interviews were not managed well and trailed off the issues that should have been focused on. Hopefully these data collectors can be employed again by future research projects, and so continue training for data collection and develop their capacity in this regard.

The data collectors were, however, matched as far as possible to the participants in terms of language and gender. Though it is by no means a hard and fast conclusion, it seemed that different factors converged to complicate matters during interviewing – and these may be any of, or any combination of, the following: relatively inexperienced data collectors – many had not worked as data collectors at all; brief and intense data collection training may have been too brief and too intense, and therefore could not allow for extended preparatory interviewing practice before going out into the field.

The result of this is that often in interviews, words or concepts are not clearly defined, and therefore we can surmise but not confidently say that we understand what the participant refers to. An example is when Noluthando, in the second of the three individual narratives, speaks of the only information that was accessible to her being those that she was exposed to

when engaging with nurses and when attending workshops. Noluthando is a wheelchair user, and we cannot say what was meant with the term “accessible” in the context of her experience. Whether she referred to physical access, or to willingness of nurses to attend to her, or that she was allowed to enter the clinic, remains unknown.

Interviewers transcribed the interviews from the digital recorders and did the translations themselves. The level of English proficiency of the interviewers were sufficient for basic communication, but not sufficient to convey subtle nuances and/or clear understanding, and people analysing the data ranged from minimal to no understanding or proficiency in the languages that two thirds of the interviews were done, namely Zulu and Xhosa. It is clear in this regard that some limitations necessarily affect the quality of the data.

Chapter 6 - Conclusion

The information gained through the present study is potentially useful to decision makers who have to make choices of how to employ resources, as documentation and evidence to prospective donors or other funding sources, and as a tool for organisations of disabled people in setting priorities, educating their own members and the population in general, and as a basis for advocacy.

It is recommended that the results from this study be considered, in conjunction with other relevant sources, as a stepping stone for dialogue between authorities, professionals and DPOs in order to recognise the importance of investigating the lived experience of disabled women in South Africa as it relates to HIV and AIDS. This may hopefully lead to these role players, in accordance with and under pressure from disabled women themselves, to conceptualise service delivery and support to these women in informal urban and rural areas, which will be appropriate, relevant and sufficient in recognising and addressing their specific needs.

Shakespeare (2000) argues that private desires and personal relationships should be central elements on the agenda of the disability movement in order to affect change in the lives of disabled people. He elaborates on this idea by employing to the disability agenda the concept of sexual citizenship, developed initially for the lesbian and gay agenda by British gay theorist Jeffrey Weeks.

Weeks conceptualises sexual citizenship as ‘finding a home for difference’ and ‘making a claim for belonging’, and it incorporates three demands, namely a demand for control (over bodies, feelings and relationships), a demand for access (to representations, relationships and public spaces) and lastly a demand for choice (about identities, lifestyles and gender experiences). In terms of these three demands, it seems that there is a long way to go for disabled people and disabled women in particular.

The overwhelming majority of women who participated in this study indicated various forms of being powerless – in terms of their bodies, relationships, identities and lifestyles in particular. Shakespeare (2000) also argues that the barriers to sexual expression of disabled people predominantly have to do with the society in which they live, not the bodies with which they have been endowed.

The present study echoes this sentiment. Barriers to both control of participants’ experiences and identity, not only with regard to sex and sexuality, but also with regard to access to HIV and AIDS related health care, is attributed by them to stigmatised attitudes held by society at large, and also in a lesser degree to the attitudes of health care professionals.

The staggering intensity and frequency which characterised the reports by participants of this study about rape, abuse and violence speak volumes about the low status that they are awarded by society and by men specifically - and even more so by their intimate partners. It is recommended that interventions with regard to rape, abuse and violence against women, and disabled women in particular, be devised and implemented not only with a focus on

disabled women, but that it should be targeted at males and their conceptualisation of women and the construction of their identities with relation to women in particular.

If disabled women have opportunities to access education, employment, safe and accessible housing and health care, it would go a long way to redress the power imbalances that exist between them and their non-disabled peers and between them and men. This would however, not be sufficient in itself. Interventions are needed which address the way that disabled women view abuse, and which in particular address the criminal offence of *forcing* someone into having sex. The phenomenon of forced sex not being conceptualised as rape is significantly problematic, and it needs to be addressed from an inside out perspective to ensure that it is relevant to the women that it concerns.

Also, whilst men buy into patriarchal notions, whilst they see women as their property, and as long as they see that they can get away with violence against (particularly) disabled women, these women will very likely not succeed in freeing themselves from the oppressive life experiences they currently go through.

Interventions should also be devised through which an understanding can be gained of how South African health care workers conceptualise disability, and specifically of how they see the relationship between sexuality and disability. Once this has been established, attempts to address these conceptualisations can be devised so that health care service delivery, and particularly those services that relate to sexual abuse and rape, and HIV and AIDS, can be improved to address the needs of disabled women.

Lastly it is recommended that disabled people and disabled women in particular, be involved and included in public campaigns and programmes which deal with issues of sex and sexuality, HIV and AIDS, and access to health care services. As long as they are excluded in these instances, society at large is denied an opportunity to change its prejudiced views of disability. Whether the inclusion of disabled people in these regards will result in the decrease of stereotyped notions of disabled people remains to be seen, but it deserves attention.

References

- Anderson, P., & Kitchin, R. (2000). Disability, space and sexuality: access to family planning services. *Social Science & Medicine*, *51*, 1163-1173.
- Beck-Massey, D. (1999). Sanctioned war: Women, violence, and disabilities. *Sexuality and Disability*, *17* (3), 269-276.
- Beresford, P. (1996). Poverty and disabled people: Challenging dominant debates and policies. *Disability and Society*, *11*(4), 553-568.
- Birch, D. A., Angermeier, L. K., & Gentsch, D. K. (2002). HIV Prevention education for students with mental retardation. *Rural Special Education*, *21*, 15-20.
- Blanchett, W.J. (2000). Sexual risk behaviours of young adults with LD and the need for HIV/AIDS education. *Remedial and Special Education*, *21*(6), 336-345.
- Bless, C., Higson-Smith, C., & Kagee, A. (2006). *Fundamentals of social research methods: and African perspective* (4th ed). Cape Town: Juta.
- Braathen, S. H., & Kvam, M. H. (2008). 'Can anything good come out of this mouth?' Female experiences of disability in Malawi. *Disability & Society*, *(23)*5, 461-474.
- Campbell, J. C., Koziol-McLain, J., Webster, D., Block, C. R., Campbell, D., Curry, M. A., Gary, F., McFarlane, J., Sachs, C. S., Sharps., Ulrich, Y., Wilt, S. A., & Manganello, J. (2004). Research results from a national study of intimate partner homicide: The Danger assessment instrument. In B. S. Fischer (Ed), *Violence Against Women and*

Family Violence: Developments in Research, Practice and Policy (pp. II: 5-1).

[Electronic Citation]

http://scholar.google.co.za/scholar?q=campbell+koziol+webster+block&hl=en&as_sdt=2001&as_sdt=on

Chenoweth, L. (1996). Violence and women with disabilities: silence and paradox. *Violence Against Women*, 2(4), 391–411.

Chilisa, B. (2005). Educational research within postcolonial Africa: a critique of HIV/AIDS research in Botswana. *International Journal of Qualitative Studies in Education*, 18(6), 659–684.

Department of Health. (2007). HIV and AIDS and STI strategic plan for South Africa, 2007 - 2011 (Draft 9). Pretoria: Department of Health; 2007. [Electronic citation]
<http://www.doh.gov.za/docs/hivaids-progressrep.html>

Digiulio, G. (2003). Sexuality and people living with physical or developmental disabilities: a review of key issues. *Canadian Journal of Human Sexuality*, 12(1), 53-68.

Economic and Social Commission for Asia and the Pacific. (2002). *Hidden sisters: women and girls with disabilities in the Asian Pacific region*. New York: United Nations.

[Electronic Citation]

<http://www.unescap.org/esid/psis/disability/decade/publications/wwd1.asp>

Eide, A. H., & Kamaleri, Y. (2009). Studies on Living Conditions: Surveys on living conditions among people with activity limitations in Southern Africa, SINTEF.

[Electronic Citation] www.sintef.no/Teknologi-og-samfunn/global-helse/Velferd-og-levetkar/Studies-on-living-conditions/

- Eide, A. H., & Loeb, M. E. (2005). Data and statistics on disability in developing countries: Executive Summary. SINTEF Disability Knowledge and Research Programme (DKaR), 2005. [Electronic Citation]
www.disabilitykar.net/docs/thematic_stats_ex.doc
- Felce, D., & Perry, J. (1997). Quality of life: The scope of the term and its breadth of measurement. In R. Brown (Ed.), *Quality of Life for Disabled people* (2nd ed., pp. 56–71). Cheltenham, UK: Stanley Thornes.
- Fine, M., & Asch, A. (1985). Disabled women: sexism without the pedestal. In M. A. Deegan & N. J. Brooks (Eds.) *Women and Disability: the double handicap*. NewBrunswick: Transaction.
- Finkelstein, V. (2001). A personal journey into disability politics. [Electronic citation]
<http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/presentn.pdf>
- Groce, N. (2003). HIV/AIDS and people with disability. *The Lancet*, 361, 1401-1402.
- Groce, N.E. (2004). HIV/AIDS and disability: capturing hidden voices, report for the World Bank Yale University Global Survey of HIV/AIDS and Disability. Washington: World Bank.
- Groce, N. E., Yousafzai, A. K., & Van Der Maas, F. (2007). HIV/AIDS and disability: Differences in HIV/AIDS knowledge between deaf and hearing people in Nigeria. *Disability and Rehabilitation*, 29(5), 367-371.
- Hanass-Hancock, J. (2009). Interweaving Conceptualizations of gender and disability in the context of vulnerability to HIV/AIDS in KwaZulu-Natal, South Africa. *Sexuality and Disability*, 27, 35-47.

- Hanna, W. J., & Rogovsky, B. (1991). Disabled women: two handicaps plus. *Disability, Handicap & Society*, 6(1), 49-63.
- Hassouneh-Phillips, D., & McNeff, E. (2005). 'I thought I was less worthy': Low sexual and body esteem and increased vulnerability to intimate partner abuse in women with Physical Disabilities. *Sexuality and Disability*, 23(4), 227-239.
- Helander, E. (1998). *Prejudice and dignity - an introduction to community based rehabilitation*. New York, N.Y. : United Nations Development Programme.
- Howland, C.H., & Rintala, D.H. (2001). Dating behaviours of women with physical disabilities. *Sexuality & Disability*, 19(1), 41-70.
- Jewkes, R. (2002). Violence against women III: Intimate partner violence: Causes and prevention. *The Lancet*, 359, 1423-1239.
- Kitchin, R. (1998). 'Out of place', 'Knowing one's place': Space, power and the exclusion of disabled people'. *Sexuality and Disability*, 13(3), 343-356.
- Krippendorff, K., & Block, M. A. (Eds.) (2009). *The content analysis reader*. Thousand Oaks, California: Sage Publications.
- Kristiansen, K., & Traustadóttir, R. (2004). *Gender and disability research in the Nordic Countries*. Lund, Sweden: Studentlitteratur.
- Kvam, M. H., & Braathen, S. H. (2008). I thought ... maybe this is my chance: Sexual abuse against girls and disabled women in Malawi. *Sexual Abuse: A Journal of Research and Treatment*, 20(5), 5-24.

- Loeb, M., & Eide, A. (2004). *Living conditions among people with activity limitations in Malawi: A national representative study*, STF78A044511. Oslo: SINTEF Health Research. [Electronic citation] <http://www.sintef.no/lc>
- May-Teerink, T. (1999). A Survey of rehabilitative services and people coping with physical disabilities in Uganda, East Africa. *International Journal of Rehabilitation Research*, 22(4), 311-316.
- McCabe, M. P. (1999). Sexual knowledge, experiences and feelings among people with disability. *Sexuality and Disability*, 17(2), 157-170.
- McCabe, M. P., Cummins, R. A., & Deeks, A. A. (2000). Sexuality and quality of life among people with physical disability. *Sexuality and Disability*, 18(2), 115-123.
- McCabe, M. P., Cummins, R. A., & Reid, S. B. (1994). An empirical study of the sexual abuse of people with intellectual disability. *Journal of Sexuality and Disability*, 12, 297-306.
- Milligan, M. S., & Neufeldt, A. H. (2001). The Myth of asexuality: A survey of social and empirical evidence. *Sexuality and Disability*, 19(2), 91-109.
- Mmatli, T. O. (2009). Translating disability-related research into evidence-based advocacy: the role of people with disabilities. *Disability & Rehabilitation*, 31(1) 14-22.
- Morris, J. (1993). Gender and disability. In Swain, J., Finkelstein, V., French, S., & Oliver, M. (Eds.), *Disabling barriers – enabling environments*. London: Sage Publications.
- Morris, J. (1996). *Encounters with strangers – feminism and disability*. London: The Women's Press.

- Morrow, M., Arunkumar, M. C., Pearce, E., & Dawson, H. E. (2007). Fostering disability-inclusive HIV/AIDS programs in northeast India: a participatory study. *BMC Public Health, 7*, 125-135.
- Mulindwa, I. N. (2003). Study on Reproductive Health and HIV/AIDS among persons with disabilities in Kampala, Katakwi and Rakai Districts – knowledge, attitudes and practices. [Electronic Citation]
<http://v1.dpi.org/files/uploads/publications/study%20in%20kampala.pdf>
- Munthali, A., Mvula, P., & Ali, S. (2004). Effective HIV/AIDS and reproductive health information to people with disabilities: a final report. Zomba: University of Malawi: Centre for Social Research.
- Nosek, M. A., Howland, C. A., Rintala, D. H., Young, M. E., & Chanpong, G. F. (2001). National study of women with physical disabilities: Final Report. *Sexuality and Disability, 19*(1), 5-40
- Nosek, M. A., Howland, C. A., Young, M. E., Georgiou, D., Rintala, D. H., Foley, C. C., Bennett, J. L., & Smith, A. L. (1994). Wellness models and sexuality among women with physical disabilities. *Journal of Applied Rehabilitation Counseling, 25*, 50-58.
- Philander, J. H., & Swartz, L. (2006). Needs, barriers, and concerns regarding HIV prevention among South Africans with visual impairments: A key informant study. *Journal of Visual Impairment and Blindness, 100*, 111-115.
- Phillips, M. J. (1990). Damaged goods: Oral narratives of the experience of disability in American culture. *Social Science and Medicine, 30*(8), 849–857.

Rohleder, P., & Swartz, L. (2009). Education to persons with learning disabilities in the era of HIV/AIDS: Tensions between discourses of human rights and restriction.

Journal of Health Psychology, 14(4), 601-610.

Rohleder, P., Braathen, S. H., Swartz, L., & Eide, A. H. (2009). HIV/AIDS and disability in Southern Africa: a review of relevant literature. *Disability & Rehabilitation, 31*(1), 51-59.

Sandowski, C. (1993). Responding to the sexual concerns of disabled people. *Journal of Social Work and Human Sexuality, 8*, 29-42.

Sentumbwe, N. (1995). Sighted lovers and blind husbands: Experiences of blind women in Uganda. In B. Ingstad, S. R. Whyte (Eds.), *Disability and culture*. Los Angeles, CA: University of California Press.

Shakespeare, T. (2000). Disabled Sexuality: Towards rights and recognition. *Sexuality and Disability, 18*(3), 159-166.

Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *Untold Stories: The sexual politics of disability*. London: Cassell.

Shisana, O., & Simbayi, L. (2002). Nelson Mandela/HSRC study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media: household survey. [Electronic citation]
http://www.hsrc.ac.za/research/output/outputDocuments/1973_Shisana_sabssmpress.pdf

Smith, D. L. (2008). Disability, gender and intimate partner violence: Relationships form the behavioural risk factor surveillance system. *Sexuality and Disability, 26*, 15-28.

- Smith, E., Murray, S. F., Yousafzai, A. K., & Kasonka, L. (2004). Barriers to accessing safe motherhood and reproductive health services: the situation of women with disabilities in Lusaka, Zambia. *Disability and Rehabilitation*, 26(2), 121-127.
- Swain, J., Finkelstein, V., French, S., & Oliver, M. (1993). *Disabling barriers – enabling environments*. London: Sage Publications.
- Swart-Kruger, J., & Richter, L. M. (1997). AIDS-related knowledge, attitudes and behaviour among South African street youth, sexuality and the autonomous self. *Social Science Medicine*, 45 (6), 957–966.
- Swartz & Watermeyer, B. (2006). Introduction. In B. Watermeyer, L. Swartz, T. Lorenzo, H. Schneider, M. Priestley, & M. Schneider (Eds.), *Disability and social change: A South African Agenda* (pp. 1-6). Cape Town: HSRC Press.
- Thomas, C. (1999). *Female forms – experiencing and understanding disability*. Buckingham, UK: Open University Press.
- Ubido, J., & Huntington, J. (2002). Inequalities in access to healthcare faced by women who are deaf. *Health and Social Care in the Community*, 10, 247-253.
- UNAIDS. (2008). AIDS Epidemic Update: Sub-Saharan Africa. Geneva: Joint United Nations Programme on HIV/AIDS 2007. [Electronic Citation]
http://data.unaids.org/pub/FactSheet/2008/20091124_FS_SSA_en.pdf
- Uthman, A., Lawoko, S., & Moradi, T. (2010). Sex disparities in attitudes towards intimate partner violence against women in sub-Saharan Africa: a socio-ecological analysis. *BioMed Central Public Health*, 10, 223. [Electronic Citation]
<http://www.biomedcentral.com/1471-2458/10/223>

- Wazakili, M., Mpofu, R., & Devlieger, P. (2006). Experiences and perceptions of sexuality and HIV/AIDS among young people with physical disabilities in a South African Township: a Case Study. *Sexuality and Disability, 24*, 77-88.
- World Bank (2005). Social Exclusion and the EU's Social Inclusion Agenda. [Electronic Citation]. <http://siteresources.worldbank.org/INTECONEVAL/Resources/SocialExclusionReviewDraft.pdf>
- Yoshida, K., Li, A., & Odette, F. (1994). Cross-cultural views of disability and sexuality: Experiences of a group of ethno-racial women with physical disabilities. *Sexuality and Disability, 17*(4), 321-336.
- Yousafzai, A. K., Dlamini, P. J., Groce, N., & Wirz, S. (2004). Knowledge, personal risk and experiences of HIV/AIDS among people with disabilities in Swaziland. *International Journal of Rehabilitation Research, 27*, 247-251.
- Yousafzai, A. K., Edwards, K., D'Allesandro, C. D., & Lindström, L. (2005). HIV/AIDS information and services: The situation experienced by adolescents with disabilities in Rwanda and Uganda. *Disability and Rehabilitation, 27*(22), 1357-1363.

Appendix A

Semi-Structured Interview Guide

- Instruction to Data Collector: Introduce yourself and recap the purpose of the study

Introductory Questions:

Please describe yourself according to the following:

- Sex
 - Age
 - Area of residence
 - Disability type
 - Education and level of schooling complete
 - Employment experience
 - Marital status
 - Children
1. Can you tell us about your experience with accessing and using VCT services?
 2. Was it easy or difficult for you to adapt to the program?
 3. What makes it difficult or easy for you to access these programmes? – such as in your physical environment and attitudes of others (family, friends, community)

4. Is the information accessible in a format that you can use?
5. Can you tell me what you know about HIV?
6. Where have you learnt about sex?
7. Where have you learnt about HIV and AIDS?
8. Is the sexuality of people with disabilities different from the sexuality of 'non-disabled' people? How?
9. What is your perception of other people's attitudes and knowledge of the sexuality of people with disabilities?
10. Can you tell me if and how you think that your sexual practice has an influence in your life, your health and /or the lives of your family and friends?
11. How do you think the sexual practices of people with disabilities differ from those of 'non-disabled' people?
12. How/why do you think people with disabilities are more vulnerable to HIV infection compared to 'non-disabled' people?

13. Do you have any own experiences of sexual abuse, rape or violence?

14. Do people with disabilities have less knowledge about HIV than non-disabled people?

Appendix B

Note about the author

At the time of conducting this study, the author of this paper served as a project co-ordinator of the larger study around HIV and AIDS and Disability in South Africa, and was involved in every stage of the research project, including drawing up terms of reference for the requirements of data capturers, analysing CV's received for the latter, and making recommendations for these positions to be filled.

The researcher participated in the development of the data collection method and organised logistics, such as organising sign language interpreters, transport for data collectors and sufficient supplies of interview materials to the different provinces. The researcher is female, 30 years old, white and an Afrikaans first language speaker, and the present study informs her thesis for the requirements of an MA (Psychology) degree. She is also psychiatrically disabled (Bipolar Type II) and has been a service user of government health care facilities for the past five years.

In the latter two respects she shares to an extent in some of the characteristics and experiences of the participants of the study, but being HIV negative, socioeconomically in a more advantaged position than participants, an inhabitant of a urban formal area, and educated on a post-graduate level, she is in many respects also far removed from the lived experience of the participants in this study, who are all black and coloured, some are HIV

positive, who are predominantly Zulu and Xhosa first language speakers, are mostly poor, uneducated or poorly educated, and are all residents in urban informal and rural areas.

The researcher also has to her disposal a wide ranging network of diverse forms of support and acceptance from family, friends and colleagues, whereas the women who participated in this study often lacked this.