

**HIV/AIDS AND DISABILITY: AN EXPLORATION OF ORGANIZATIONS'
RESPONSES TO HIV/AIDS AS IT AFFECTS PEOPLE WITH DISABILITIES**

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DECLARATION

I, the undersigned, hereby declare that the work contained in this dissertation 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.

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Signature

.....1 February 2008.....

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SUMMARY

HIV/AIDS has emerged as one of the biggest epidemics in modern human history, and is perhaps the most researched and written about epidemic. Southern Africa is at the epicentre of the global HIV/AIDS epidemic, with almost one third of the world's HIV-positive population living here. HIV is known to affect predominantly vulnerable populations; thus it is surprising that persons with disabilities have been largely overlooked. Little is known about how HIV/AIDS affects persons with disabilities in South Africa. This dissertation, therefore, aims to explore the extent to which organizations and schools working with persons with disabilities are dealing with HIV/AIDS, and how they are dealing with it.

The study made use of an integration of quantitative and qualitative research methods. An existing survey questionnaire used in the World Bank/Yale University Global Survey on HIV/AIDS and Disability was used, with permission, as the survey instrument in a national survey of disability organizations and special needs (LSEN) schools in South Africa. The survey was distributed by post and email to 601 organizations and schools across the country, in all nine provinces. Various contacts and postings of the survey were made to organizations and schools, in an attempt to improve response rates. The response rate from national disability organizations was 57%, while the response rate for regional and local organizations and schools was very poor, with an overall response rate of 18%. The sample, however, was representative of the population. The results of the survey indicate a high level of concern about HIV/AIDS as a risk for persons with disabilities. The majority of organizations and schools were involved in providing HIV prevention education. However, most organizations and schools felt that persons with disabilities were excluded from general HIV prevention campaigns, and were thus receiving less information.

A second study, using qualitative research methods, used case studies of three organizations/schools to explore more in-depth staff difficulties, challenges and particularly anxieties related to dealing with sex, sexuality and HIV among persons with

disabilities. The case studies were analysed from a psychosocial framework, using social constructionist theory with psychoanalytic theory, to explore how social discourses about HIV and disabilities are internalized by staff. It is theorized that people draw on particular social discourses, in this case about HIV and disability, as a defence against threats to the self. Texts were analysed using discourse analysis to identify social discourses. A further analytic layer used psychoanalytic theory to identify unconscious communication of emotions and defence mechanisms. The case studies found that staff have considerable anxiety with regards raising issues of sex, sexuality and HIV with persons with disabilities. Staff from all three organizations were varyingly anxious about needing to protect the people they work with from harm. Disabled people were constructed as innocent, vulnerable, and needing protection. In other cases disabled people were constructed as deviant and their behaviour needing to be controlled.

The use of an integration of qualitative and quantitative methods is useful, in allowing to explore more in-depth the lived experience of research participants. While the survey indicated that organizations were providing HIV prevention education, the case studies revealed much anxiety about this, and in some cases education was partly avoided. The results also suggest that HIV prevention education may be used in a way to control and restrict disabled people's sexual expression, using a demonizing discourse about sex as dangerous and in some circumstances immoral. This may be done in an absence of a discourse of pleasure, where disabled people may be empowered to have fulfilling sexual lives. The study also highlights sexual abuse and rape of persons with disabilities as a serious issue. The dissertation ends with recommendations for further research, including exploring the experience of disabled people themselves, and the need to address the silence around sexual abuse and rape of persons with disabilities.

OPSOMMING

MIV/Vigs het te voorskyn getree as een van die grootste epidemies in die geskiedenis van die mens en is moontlik die epidemie waaroor daar die meeste navorsing gedoen en geskryf is. Suid-Afrika is die middelpunt van die wêreldwye MIV/Vigs-epidemie met bykans 'n derde van die wêreld se MIV-positiewe populasie wat hier woon. Dit is bekend dat MIV hoofsaaklik kwesbare populasies aantast, en dit is daarom verbasend dat persone met gestremdhede grootliks oor die hoof gesien is. Daar is min bekend oor hoe MIV/Vigs persone met gestremdhede in Suid-Afrika beïnvloed. Die doel van hierdie verhandeling was dus om na te speur in watter mate organisasies en skole wat te doen het met persone met gestremdhede MIV/Vigs hanteer en hoe hulle dit doen.

In die studie is kwantitatiewe en kwalitatiewe navorsingsmetodes geïntegreer. Daar is met die nodige toestemming gebruik gemaak van 'n bestaande opnamevraelys wat in die *World Bank/Yale University Global Survey on HIV/AIDS and Disability* gebruik is, as die opname-meetinstrument in 'n nasionale opname onder ongeskiktheidsorganisasies en skole vir leerders met spesiale onderrigbehoefte (LSOB) in Suid-Afrika. Die vraelys is per pos en e-pos aan 601 organisasies en skole regdeur die land, in al nege provinsies, uitgestuur. In 'n poging om die responskoers te verbeter, is daar op verskeie maniere en aanbiedingswyses met die organisasies en skole geskakel wat die opname betref. Die responskoers van nasionale ongeskiktheidsorganisasies was 57 persent, terwyl die responskoers van streeks- en plaaslike organisasies en skole baie swak was, met 'n oorkoepelende responskoers van 18 persent. Die steekproef was egter verteenwoordigend van die populasie. Die resultate van die opname dui op 'n hoë vlak van besorgdheid oor MIV/Vigs as 'n risiko vir mense met gestremdhede. Die meeste van die organisasies en skole is betrokke by die voorsiening van MIV-voorkomingsonderrig. Die meeste van die organisasies en skole is egter van mening dat persone met gestremdhede uitgesluit word van algemene MIV-voorkomingsveldtogte en dus minder inligting ontvang.

In 'n tweede studie, waar van kwalitatiewe navorsingsmetodes gebruik gemaak is, is daar gevallestudies van drie organisasies/skole gebruik om meer dieptenavorsing te doen oor

personeelprobleme, uitdagings en in die besonder oor kommer wat verband hou met die hantering van seks, seksualiteit en MIV onder persone met gestremdhede. Hierdie gevallestudies is ontleed vanuit 'n psigososiale raamwerk deur gebruik te maak van sosiaal-konstruksionistiese teorie saam met psigoanalitiese teorie om na te vors hoe sosiale diskoerse oor MIV en gestremdhede deur personeellede geïnternaliseer word. Daar word geteoretiseer dat mense steun op besondere sosiale diskoerse, in hierdie geval oor MIV en gestremdheid, as 'n vorm van verdediging teen bedreigings van die self. Tekste is deur middel van diskoersanalise geanaliseer om sosiale diskoerse te identifiseer. In 'n verdere analitiese laag is gebruik gemaak van psigoanalitiese teorie om die onbewuste kommunikasie van emosies en verdedigingsmeganismes te identifiseer. Deur hierdie gevallestudies is bevind dat personeel baie kommer het ten opsigte daarvan om kwessies soos seks, seksualiteit en MIV met persone met gestremdhede te bespreek. Die personeel van al drie organisasies het in 'n wisselende mate kommer daaroor gehad dat hulle die mense met wie hulle werk, moes beskerm teen leed. Mense met gestremdhede is gekonstrueer as onskuldig, kwesbaar en met 'n behoefte aan beskerming. In ander gevalle is mense met gestremdhede gekonstrueer as afwykend met gedrag wat beheer moet word.

Die gebruik van 'n integrering van kwalitatiewe en kwantitatiewe metodes is nuttig en maak daarvoor voorsiening dat groter dieptenavorsing gedoen kan word oor die ervarings wat navorsingsdeelnemers beleef. Terwyl die opname aangedui het dat organisasies besig was om MIV-voorkomingsonderrig te verskaf, het die gevallestudies blootgelê dat daar baie kommer hieroor is en in sommige gevalle word onderrig deels vermy. Die resultate het ook te kenne gegee dat MIV-voorkomingsonderrig op so 'n wyse gebruik kan word dat dit persone met gestremdhede se seksuele uitdrukking kan beheer en beperk, omdat dit gebruik maak van 'n afkeurende diskoers wat seks as gevaarlik voorstel en in sekere omstandighede as immoreel. Dit kan gebeur in die afwesigheid van 'n diskoers van plesier wat persone met gestremdhede sou kon bemagtig om 'n vervullende sekslewe te hê. Die studie beklemtoon ook dat die seksuele mishandeling en verkragting van persone met gestremdhede 'n ernstige saak is. Die verhandeling sluit af met aanbevelings vir verdere navorsing, insluitende die ondersoek na die ervaring van persone met

gestremdhede self en die behoefte wat daar bestaan om die stilte om die seksuele mishandeling en verkragting van persone met gestremdhede te hanteer.

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CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

1.1.1 The Global HIV Epidemic

Since the discovery of the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) in the first years of the 1980s, HIV/AIDS has grown to become one of the biggest epidemics, if not the biggest, in modern history. Since the onset of HIV/AIDS, an estimated 65 million people have been infected with HIV and 25 million have died of AIDS (UNAIDS, 2006a). It is perhaps the most researched and written about disease. It is also perhaps the most stigmatized disease in modern history (Sontag, 1991).

The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2006b) estimates that the total number of people in the world living with HIV in 2006 was approximately 39.5 million, of whom an estimated 4.3 million were newly infected in 2006. An estimated 2.9 million deaths related to AIDS were recorded in 2006.

The global epidemic is concentrated in Sub-Saharan Africa, with 24.7 million people living with HIV; two-thirds (63%) of all the children and adults living with HIV globally (UNAIDS, 2006b). UNAIDS further estimates that just under three-quarters (72%) of AIDS deaths during 2006 occurred in Sub-Saharan Africa. Southern Africa is at the epicentre of the global epidemic, with 32% of HIV-positive people living here, and 34% of AIDS deaths occurring here in 2006.

1.1.2 HIV in South Africa

The South African Department of Health conducts yearly survey studies of HIV prevalence among pregnant women attending antenatal clinics. These prevalence rates are extrapolated to estimate the prevalence rate among the general population. The

Department of Health (2007a) estimated a prevalence rate of 29.1% among pregnant women in 2006, a slight decrease from 30.2% in 2005. The prevalence rate was highest for women aged 25 to 29. Using these statistics, the Department of Health (2007a) estimates that 5.41 million people are living with HIV in South Africa.

A survey conducted by the Human Sciences Research Council and commissioned by the Nelson Mandela Foundation (Shisana et al., 2005) estimated that the prevalence of HIV infection in South Africa's general population is 10.8%, with persons aged 20 to 40 years being most affected. This survey also indicates that the prevalence among women is higher than that of men. The prevalence among children aged 2 to 14 was 3.3%, with many of infections for children aged 2 to 9 being non-vertically transmitted; that is not through mother-to-child transmission, but rather through other means, including sexual abuse (Shisana et al., 2005).

South Africa's official response to the epidemic has been controversial and in the international spotlight for a number of years. In more recent years, South Africa's State president, Thabo Mbeki, has been criticized for his "initial flirtation with AIDS 'dissident' theories" (Robins, 2004; p. 654), which has led to some confusion about the link between HIV and AIDS, and about the severity of the HIV epidemic, among the general population. South Africa's minister of Health, Dr Manto Tshabalala-Msimang has also been a source of controversy, advocating traditional 'African' remedies and nutritious foods as treatment for HIV/AIDS, while the government is seen as hesitating in providing antiretroviral (ARV) treatment to all. In August 2003, after years of controversy and debate, the South African announced its plan to provide a national antiretroviral treatment programme at health care clinics, through the provision of antiretroviral drugs (ARVs) (Department of Health, 2003).

The care and management of HIV/AIDS in the public health system is primarily served through dedicated voluntary counselling and testing (VCT) centres, which offer patients HIV testing, in combination with pre- and post-test counselling. Shisana and colleagues (2005) found that most people who had gone for VCT, had gone to the public sector, and

that there has been an increase over time in the number of people being tested. In terms of awareness created by HIV prevention campaigns, they found that there was a relatively high exposure to national HIV campaigns through mass communication media, but that the reach of these campaigns in rural areas is generally poor.

1.1.3 HIV/AIDS and Disability

The global HIV/AIDS epidemic statistics reported above are astounding. It has been established that vulnerable groups, such as women, are most at risk for HIV. It is surprising then that people with disabilities, a vulnerable group, have been largely overlooked with regards HIV/AIDS (Groce, 2005). It is estimated that as many as one in ten of the world's population are reported to be disabled, and the majority of persons with disabilities live in the 'developing world' (World Bank, 2004).

In South Africa, persons with disabilities have been included, for the first time, as a vulnerable group in the draft HIV and AIDS and STI Strategic Plan for South Africa 2007-2011 (Department of Health, 2007b).

Little is known about HIV/AIDS as it affects persons with disabilities, and there has been a call for much needed research in this area (Groce, 2005).

1.2 Aims and Rationale for the Study

The problem to be studied is that of the extent to which South African organizations working with disabled persons are dealing with HIV/AIDS, and how they are dealing with it.

This study forms part of a larger study on HIV/AIDS as it affects persons with disabilities, led by Stellenbosch University, the Human Sciences Research Council (HSRC), SINTEF Health Research in Norway, South African National AIDS Council, and Disabled People South Africa. As an initial exploration into some of the issues involved, this doctorate study has as its focus organizations working with disabled persons. This will provide a much needed general picture of what the response has been

to HIV/AIDS and persons with disabilities at institutional and public level. This will provide essential information that will inform future research projects. The experiences and perceptions of disabled persons themselves, essential for an understanding of the issues involved, was not focused on in this doctoral study, as this will be a future research project of the principal research team. The plan is to conduct future interviews with disabled persons themselves to learn of their experience and perceptions.

This doctoral study aimed to gain as much information as possible about institutional and social response to HIV as it affects persons with disabilities. In order to do this, a combination of research methods were used, that would allow for the collection of comprehensive and complimentary data that would provide a broader exploration of what is going on.

1.3 Structure of the Thesis

This thesis is organized around eight chapters. This first chapter provides a brief introduction to the topic. Thereafter, the three consecutive chapters will provide a review of literature relevant for this study. In the first, chapter two, I look at disability in South Africa, looking firstly at the definition of disability from a medical, social and psychoanalytic approach. I then go on to look at the disability movement in South Africa, as well as the prevalence of disability, using two recent prevalence studies. In chapter three, I look at HIV/AIDS and its risk factors, related to persons with disabilities. As the chapter indicates, there is a paucity of literature on HIV and disability. However, there is considerable literature on risk factors associated with HIV, namely unsafe sexual behaviours, poverty, lack of education, sexual abuse and rape, substance abuse, restricted access to health care, stigma and isolation. Chapter four provides the theoretical framework for the analysis of qualitative data for the study; that of a psychosocial approach, combining social constructionist theory with psychoanalytic theory. The use of psychoanalytic theory may be viewed with scepticism by some, and so the chapter provides an argument for why psychoanalytic theory may be appropriate to use. In chapter five, I outline the research method used in this study. As will be seen, this study makes, perhaps an unusual, combination of both quantitative and qualitative research

methods. As will be argued, this is seen to allow me to make a more comprehensive, triangulated exploration of the issues under study. The use of a quantitative survey provides much needed data that gives a general sense of organizations' response to HIV/AIDS and persons with disabilities. The addition of qualitative case studies, allows me to make a deeper, more descriptive exploration of some of the issues involved. The results of the survey study are reported on in chapter six, followed by the results of the three case studies made in chapter seven. This thesis ends with the concluding chapter eight, in which I discuss the limitations of the study, highlight some important findings, and discuss some recommendations for further research. The concluding chapter is followed by the list of references used, and four addenda.

1.4 A note on Terminology

Throughout this thesis I make use of a variety of terms to describe groups of people. The uses of some of these terms are worth explaining here.

Disabled People South Africa (2000) recommends the use of the terms “disabled person” and “people with disabilities”. In this thesis I make use of variations of these, using “disabled people”, “disabled persons”, “persons with disabilities”, and “people with disabilities” interchangeably. In addition I have also referred to “non-disabled” persons or people, and persons or people “without disabilities”.

When referring to persons with intellectual disabilities, I have used the terms “intellectual disability” and “learning disability” interchangeably. The use of the term “intellectual disability” is common practice in South Africa, whereas in other countries, for example the United Kingdom, the term “learning disability” is preferred.

In this thesis I have also made use of referring to “Deaf persons”, using the capital “D”, which is considered to be the acceptable way of identifying Deaf persons (Disabled People South Africa, 2000).

CHAPTER TWO

DISABILITY IN SOUTH AFRICA

2.1 Introduction

The main purpose of this chapter is to provide a clearer understanding of the complexity in defining 'disability', as well as to gain a picture of the prevalence of disability in this country. I begin by outlining the predominant debate amongst theorists to the definition of disability, by looking at the so-called medical and social models for understanding disability. In addition I will look at a psychoanalytic understanding of disability, which will provide some conceptual background for my analysis of the case studies. I then look at disability in South Africa, beginning with a brief look into the history of the disability movement, followed by looking at the prevalence of disability in South Africa.

2.2 Defining Disability

Defining 'disability' has been a focus of a large body of theoretical work, raising much debate and controversy amongst theorists. The task of defining disability is political, and related to issues of inclusion and exclusion (Oliver, 1996a). It is beyond the scope of this dissertation to examine the many published works on disability studies, but it is important to look critically at some of these various ways of conceptualizing and thinking about disability.

The term 'disability' is often used co-terminously with physiological or biological impairment, but current disability studies theorists emphasize the role of social factors such as exclusion and discrimination as contributing significantly or even centrally to the experience of disability (Marks, 1999a). Disability is regarded as important to sociological study as is race, class, gender and sexuality (Barnes & Oliver, 1993). Disability studies theorists make a distinction between 'impairment' and 'disability', which Finkelstein and French (1993a) define as follows:

Impairment is the lack of part of or all of a limb, or having a defective limb, organ or mechanism of the body.

Disability is the loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others due to physical and social barriers. (p. 28)

Such a distinction in terminology forms the basis of the so-called ‘social model’ for understanding disability, which arose as a critique of the prevailing medical approach to understanding disability.

2.2.1 The Medical Model of Disability

In the health and social services field, the dominant model for understanding disability is the so-called ‘medical model’, which views disability as the result of impairments caused by an underlying disease or disorder (Johnston, 1996). The World Health Organization (WHO) in 1980 conceptualized disability in this way. They distinguished between ‘impairment’, ‘disability’ and ‘handicap’, which they define as follows:

Impairments: “any loss or abnormality of a psychological, or anatomical structure or function”

Disability: “any restriction or inability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being”

Handicap: “any disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal...for that individual” (World Health Organization, 1980, p.1)

WHO has since moved on from this definition (discussed below), but at that time, they defined disability as a functional limitation caused by a physical or psychological impairment as a result of a disease or disorder. A person’s disability causes them to be socially handicapped. An individual can also be handicapped because of an impairment, but not necessarily be disabled (see Figure 2.1). For example, in the case of a facial

disfigurement, a person may be socially handicapped because of this impairment, but not be disabled by it.

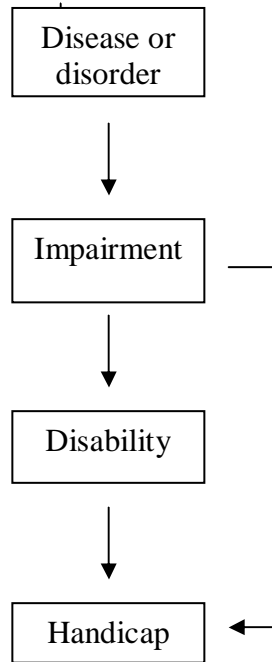


Figure 2.1: WHO model of Disability (WHO, 1980)

Edwards (1997) highlights at least three characteristics of ‘disability’ within the WHO model. That is:

1. That ‘disabilities’ result from impairments;
2. are “context-neutral” (p. 591) and not determined by the individual’s particular social context;
3. and are intrinsic to the individual.

Marks (1999a) points out that this classification “remains heavily reliant on medical assumptions” (p. 53), with impairment being seen as central to the experience of disability and handicap. Brisenden (1986) criticizes the medical model’s conceptualising of disability in terms of medical ‘facts’, saying that ‘disability’ becomes a label imposed on an individual. In the medical model then, the attention is placed on the individual “impairment” and attributes their social struggles to the person’s bodily impairment, and

solutions to defects are found through medical interventions. The ‘disabled’ and ‘handicapped’ replaced the ‘anomaly’ in medicine, and comes under the gaze of medical power (Arney & Bergen, 1983). In this model, it is the individual who is seen as alterable, while the assumption is made that the individual’s physical environment is fixed and unalterable (Barnes & Oliver, 1993).

Oliver (1986) states that the medical model views disability as a “personal tragedy”, where a disabled person is unable to participate fully in society as a direct consequence of the ‘tragedy’ of disease or disorder. The term ‘disabled’, is then “used as a blanket term to cover a large number of people who have nothing in common with each other, except that they do not function in exactly the same way as those people who are called ‘normal’” (Brisenden, 1986, p. 175).

The medical model of disability has had a strong influence on how people understand the definition of ‘disability’. In South Africa, for example, in focus group interviews with parents of children with and without disabilities and adults with or without disabilities (Schneider & Couper, 2007), respondents reportedly understood disability as referring to “a permanent feature of an individual”, which is generally a visible (and in some cases invisible) or physical impairment, that “renders a person dependent on others as they are unable to do anything for themselves” (p. 39).

2.2.2 The Social Model of Disability

In the 1970s disability activists began to challenge prevailing understandings of disability. One of the most influential groups, the Union of the Physically Impaired Against Segregation (UPIAS) was instrumental in reformulating an understanding of disability. In contrast to the WHO medical model at the time, UPIAS stated that

it is society which disables physically impaired people. Disability is something that is imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from the full participation in society (UPIAS, quoted in Barton, 1998, p. 56.)

Disability is then seen as “a particular form of social oppression” (UPIAS, quoted in Barton, 1998, p. 56).

Oliver (1986) points out how increasingly, disabled people have argued that personal limitations are not what prevent full participation, but rather the restrictions which society imposes upon them. He expanded on the UPIAS ideas on disability to develop ‘the social model of disability’ (Oliver, 1986; 1990; 1996b). The social model of disability has the concept of oppression as a focus of the experience of disability (Abberley, 1987).

Through the concept of oppression, disability is understood as representing the “social, financial, environmental and psychological disadvantages inflicted on impaired people” (Abberley, 1987, p. 17). This arises from a social environment that is constructed by non-impaired people, and constructed in their interests (Abberley, 1998). As articulated by Oliver (2004),

the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, sensory or intellectual. The barriers disabled people encounter include inaccessible education systems, working environments, inadequate disability benefits, discriminatory health and social support services, inaccessible transport, houses and public buildings and amenities, and the devaluing of disabled people through negative images in the media (p. 21).

In order to reduce the experience of disability, an adjustment to the social and physical environment is needed that meets the needs of persons with disabilities (French, 1993a).

Some theorists (Hughes & Paterson, 1997; Oliver, 1996a; Shakespeare & Watson, 1997) have highlighted some of the prevailing criticisms of the social model of disability, particularly the exclusion of the lived experience of impairment. French (1993a), for example, argues how her blindness should be conceptualized as impairment, whereas the availability of literature accessible largely to only sighted persons is a disability. With

this criticism, there have been calls to integrate understandings of impairment with the social model of disability (Hughes & Paterson, 1997; Johnston, 1997). Oliver (1996a) states, however, that the social model is an attempt to understand and deal with the social barriers of disability, and not the restrictions caused by impairment.

The social model of disability asks for an emancipatory or critical approach to research (Humphrey, 2000; Kitchin, 2000), which moves away from a medical approach to research, which treats persons with disability as objects to be studied. Within the social model there is a call for the involvement of persons with disability in the research making process (Bricher, 2000; Kitchin, 2000). Humphrey (2000) points out that the social model's view of research creates "a dichotomy between non-disabled and disabled people which becomes coterminous with the dichotomy between oppressors and oppressed" (p. 64). He argues that there are dangers with the social model that certain disabled identities are privileged, marginalizing differently-disabled or non-disabled identities. There is much debate in the literature about the inclusion of non-disabled people within the disability movement (see for example the debate between Branfield, 1998; 1999; Drake, 1997; and Duckett, 1998).

With the emergence of the social model approach to disability and its increasing support, the World Health Organization replaced its *International Classification of Impairments, Disabilities and Handicaps* with the *International Classification of Functioning (ICF)* (WHO, 1998). The ICF attempts to integrate the social model with the medical approach, and replaces the use of 'impairment', 'disability' and 'handicap', with:

- *Impairment*: "problems in body function or structure such as a significant deviation or loss";
- *Activity*: "activity limitations are difficulties an individual may have in executing activities"; and
- *Participation*: "Participation restrictions are problems an individual may experience in involvement in life situations" (WHO, 1998, p. 10).

Disabled Peoples' International adopts the ICF definition of disability as "the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers he/she may face" (Disabled Peoples' International, 2005).

2.3 A Psychoanalytic Understanding of Disability

Psychoanalytic thinking applied to working with disability will be taken up further in chapter 4, but a brief look at the psychoanalytic understanding of disability is useful at this stage, as it forms part of a critique of the social model of disability.

Marks (1999a; 1999b) critiques the social model of disability for excluding people's subjective experience from its analysis of disability. She argues that 'disability' involves a relationship between the body and the environment as well as the psyche, and so insists that "disability does not reside in a particular body or environment, but rather is an embodied relationship" (Marks, 1999b, p. 611). She draws on psychoanalytic theory when she argues that stereotypes that society has for persons with learning disabilities, for example, form a type of social and cultural oppression which is internalized by the person with disability to become an embodied experience. She notes "denigration and exclusion as the two key forms of psychic oppression suffered by disabled people" (Marks, 1999a, p. 25), which are then internalised and impact on their self esteem, and may often keep disabled people submissive.

Sinason (2001) refers to a 'secondary handicap' that occurs, which she refers to as the "defensive, extra-handicapping that comes from the emotional pain at being different" (p. 2). She goes on to argue how most of us may have experience of being different in some contexts with regards religion or gender, for example, but that there are other contexts in which we are accepted and wanted. With regards disability, however, she states that "there is no country in the world where parents long for a handicapped baby, however much gifted families love and bond. The handicapped take on the role of the 'other'" (Sinason, 2001; p. 2). The person with disability can be locked in a dynamic interrelationship with others in an attempt to manage the anxieties that the disabilities cause. French (1993b) provides a personal example of this, describing how family

members would anxiously try to get her to see things, in an attempt to manage their fear and anxiety with regards to her increasing loss of colour vision. She describes attempts to alleviate others' anxieties, by declaring that she could see, denying the fact that she could not.

Marks (1999a) argues that there exists a “narcissistic culture” (p. 21), where individuals in society strive for independence and perfection. The unacceptable parts of the self such as dependency and physical imperfections, are “kept outside conscious awareness and come to be split off and projected onto those who have been socially constituted as damaged” (p. 21). Able-bodied people project their anxieties about their own mortality onto disabled people, and so disabled people and their impairments “remind non-disabled people of their own vulnerability” (Shakespeare, 1994, p. 297). There is a denial or disavowal on the part of able-bodied people of their own physical vulnerability and mortality, which is projected onto disabled people who come to represent this vulnerability, becoming ‘dustbins for this disavowal’ (Shakespeare, 1994).

Sinason (1992) feels strongly about how the vocabulary and terms used to refer to intellectual disability are changed and adapted in an attempt to disguise difference. She provides an extensive historical list of the vocabulary and terms used to describe and refer to intellectual disability – vocabulary such as ‘backward’, ‘deficient’, ‘feeble’, ‘idiot’, ‘moron’, ‘retard’ and ‘stupid’, among many others. She argues that vocabulary is changed and used as euphemisms for things that begin to feel too emotionally evoking and disturbing. She argues that euphemisms attempt to deal with painful differences, and are used to disguise things that evoke “anxiety, guilt wishes and terror” (p. 41). Intellectual disability, for example, attracts the use of euphemism as it is a difference that cannot be changed or repaired, and it challenges our unconscious wish to control and be able to change (Watermeyer, 2006). In changing the vocabulary and terms used, we attempt to eliminate the difference by trying to find more acceptable terms that suggest equality.

2.4 The Disability Movement in South Africa

The election of a first democratic government in South Africa in 1994, led to the formulation of a new Constitution, which included the recognition that persons with disabilities had been disadvantaged and discriminated against. In the early 1980s, the experience of many white¹ persons with disabilities was that of discrimination with regards health care and social welfare, while for African persons with disabilities there experience was further compounded by the experience of oppression and inequality under apartheid (Howell, Chalklen, & Alberts, 2006).

Disabled People South Africa (DPSA) was launched in September 1984, by a group of disabled activists wanting to overcome the experience of oppression of black and white disabled people under the system of apartheid. The DPSA is a national assembly of disabled people in South Africa, recognized by Disabled Peoples' International (DPI). It is a cross-disability organization, comprising of a number of smaller community-based disabled people's organizations. One of the aims of the DPSA was to "mobilise and organise disabled people throughout the country through building and supporting self-help organizations, with a particular emphasis on capacity building initiatives and training programmes" (Howell et al., 2006, p. 53).

As the DPSA expanded, they were called on more and more to provide legal assistance for persons with disabilities, resulting in an establishment of a human rights office and the development of the *Disability Rights Charter of South Africa* in 1992, which aimed to influence the development of policies and thinking about disability (Howell et al., 2006).

The DPSA had had a number of frustrations with working with the apartheid South African government, who displayed a lack of commitment in engaging in initiatives with the DPSA (Howell et al., 2006). However, following the election of a democratically elected government in 1994, and its Reconstruction and Development Programme (RDP),

¹ Under apartheid, South Africa's population was classified into different racial groups, and registered in their racial categories under the Population Registration Act. The racial categories that were used were 'African', 'coloured', 'Indian' and 'white'. 'Coloureds' was used to refer to peoples of a mixed-race heritage.

disability issues were identified as an area needing to be addressed. In May 1997, the Office on the Status of Disabled Persons (OSDP) was established, and was moved to within the State President's office in 1999. The OSDP was established, among other things, to ensure the inclusion of disability issues in government policies and programmes of development, and so “mainstream disability issues into all sectors of society” (Matsebula, Schneider & Watermeyer, 2006, p. 85). Using the *Disability Rights Charter of South Africa* as a basis from which to develop a national policy on disability, the government published the *White Paper of an Integrated National Disability Strategy* (INDS) in 1997 (ODP, 1997).

The *White Paper of an Integrated National Disability Strategy* (INDS) (ODP, 1997) was designed as a guideline for the provision and delivery of services, on the part of government and social structures, for persons with disabilities in South Africa. The INDS uses the social model to understand disability, although South Africa still has legislation (for example legislation regarding the provision of disability grants), which uses the medical model (Swartz & Schneider, 2006).

In terms of the INDS (Government of the Republic of South Africa, 1997), Disabled People's Organizations (DPOs) in concert with the Office on the Status of Disabled Persons (OSDP) nationally and in the provinces, are tasked with providing and coordinating services for disabled people.

2.5 The Prevalence of Disability in South Africa

There is a paucity of data available as to the prevalence of disability within South Africa's population. McLaren, Solarsh and Saloojee (2004) argue that the lack of consensus around defining 'disability' seriously hampers the ability to identify people with disability, develop disability indicators and conduct research on disability. The authors feel that until there is consensus on definitions of disability, “obtaining accurate disability data and the development of indicators to measure disability and rehabilitation programmes will remain problematic” (p.12).

The *International Classification of Functioning* (ICF) (WHO, 1998), as a useful definition of disability, understands disability as a relationship or interaction between an individual's health and his or her context. It includes three levels of disability – the bodily, the personal and the societal. Self-reported questionnaires generally include only the personal level, and so other aspects of disability (societal and bodily, as well as environmental factors) are not always measured (Schneider & Couper, 2007).

The most recent surveys which provide some data on the prevalence of disability in South Africa, are the National Population Census of 2001 (Statistics South Africa, 2005), which provides some information about serious, largely visible disabilities, and the Community Agency for Social Enquiry (CASE) Disability Survey conducted for the Department of Health (Schneider et al., 1999). I shall report on the Census 2001 first, as this was the most recent prevalence survey conducted. However, as will be shown it provided a narrow measure of disability, and so I will also then look at the CASE Disability Survey, conducted a few years earlier, which provides the only prevalence survey on disability alone.

2.5.1 National Population Census 2001

Statistics South Africa conducted a census in 2001, the second national census to be carried out in democratic South Africa. In this census, respondents were asked:

Does the person have any serious disability that prevents his/her participation in life activities? None 0; Sight 1; Hearing 2; Communication 3; Physical 4; Intellectual 5; Emotional 6. (Statistics South Africa, 2005, p. 8)

From this question and the respondents' answers on other demographic questions, data on disability was included in the reported statistics.

The report on Census 2001 (Statistics South Africa, 2005), indicated that 2 255 982 persons in South Africa reported having a disability. This constituted 5% of the total

population. The African population reported the highest prevalence rate per population group (5.2%), and more women than men reported having a disability (see Table 2.1).

Table 2.1: Number of disabled persons by population group and gender²

Population Group	Male		Female		Total	
	N	%	N	%	N	%
African	879 680	5.2	974 696	5.3	1 854 376	5.2
Coloured	88 583	4.6	80 095	3.9	168 678	4.2
Indian/Asian	21 550	4.0	19 685	3.5	41 235	3.7
White	92 230	4.4	99 463	4.5	191 693	4.5
Total	1 082 043	5.1	1 173 939	5.0	2 255 982	5.0

(Data taken from Statistics South Africa, 2005, p.12)

The prevalence of disability within age groups showed a steady percentage increase among those aged 40 years and less, and increased rapidly for those older than 40 years. Among persons aged below 30 years, 8.6% reported having a disability; among people aged 30 to 59, 22.5% reported having a disability; and among people aged over 60 years, 57.6% reported having a disability.

Statistics across South Africa's nine provinces indicated that the KwaZulu-Natal province had the highest number of people reporting disabilities, and the Northern Cape province the least (See Table 2.2).

Table 2.2: Number of disabled persons by province and gender

Province	Male		Female		Total	
	N	%	N	%	N	%
Eastern Cape	173 229	5.8	199 037	5.8	372 266	5.8
Free State	87 758	6.8	97 619	6.9	185 377	6.8
Gauteng	164 588	3.7	167 023	3.8	331 611	3.8
KwaZulu-Natal	219 685	5.0	250 903	5.0	470 588	5.0
Limpopo	124 128	5.2	144 774	5.0	268 902	5.1
Mpumalanga	87 319	5.8	94 874	5.8	182 193	5.8
Northern Cape	23 620	5.9	23 353	5.5	46 973	5.7
North West	105 169	5.8	106 054	5.7	211 223	5.8
Western Cape	96 549	4.4	90 301	3.9	186 850	4.1
South Africa	1 082 043	5.1	1 173 939	5.0	2 255 982	5.0

(Data taken from Statistics South Africa, 2005, p.12)

² Note: the tables in this thesis have not been constructed in strict accordance to APA format. This has been done for ease of reading.

The question relating to disability that was included in Census 2001, referred to types of disability. Results indicated that the prevalence of sight disability was the highest, and communication disability the lowest. More males reported having a physical disability, whereas more females reported having a sight disability (See Table 2.3).

Table 2.3: Percentage of disabled persons by type of disability

Type of disability	Male	Female	Total
Sight	28.3	35.6	32.1
Physical	30.7	28.6	29.6
Hearing	19.4	20.7	20.1
Emotional	17.3	14.3	15.7
Intellectual	13.5	11.3	12.4
Communication	7.2	5.8	6.5

(Data taken from Statistics South Africa, 2005, p.14)

The Census 2001 report further indicated that disabled persons had a higher percentage of persons having received no education and lower rates of employment than those who did not report a disability, with disabled women being at a greater disadvantage in this regard. Fewer persons with disabilities reported being in school, compared to the rest of the population. On average 10% fewer disabled persons between the ages of 6 and 18 were in school than non-disabled persons.

The report cautions on the validity of the data, due to the varying definitions of disability, as well as possible constraints on the respondents' willingness to report disability or even consider themselves as being disabled. Despite these limitations, the survey results do provide some useful indication on the prevalence and demographics of disability in South Africa. McLaren and colleagues (2004) further argue that the survey question mainly identified people with severe disabilities, and the prevalence rates may be underestimated. Schneider and Couper (2007) similarly conclude that the Census 2001 survey may have discouraged individuals from reporting themselves as disabled, because of the use of the term "serious disability"; individuals might have self-identified as being "disabled", but not as having a "serious disability". In their focus group discussion used to assess a series of questions of disability for possible inclusion in Census 2011, they

found that some persons with visual and physical disabilities, who responded as disabled in the focus groups, did not respond as being disabled in Census 2001. The reported results in Census 2001, therefore, cannot be taken as an accurate indication of the prevalence of disability in South Africa.

The only study to attempt to measure the prevalence of disabilities only, was conducted some time before the Census 2001. They are not as recent as the results from Census 2001, and are now 10 years old, but they perhaps provide a more inclusive measure of disability than Census 2001 does.

2.5.2 CASE National Baseline Disability Survey

The only South African national survey on disability was conducted in 1997 by the Community Agency for Social Enquiry (CASE) for the Department of Health (Schneider et al., 1999). This was a population-based survey, describing reported moderate and severe disability and captured some of the lived experiences of disabled people through in-depth interviews. The CASE Disability Survey defined disability as “a limitation in one or more activities of daily living. The activities used [are] those of seeing, hearing, communication, moving, getting around, daily life activities, learning, intellectual and emotional” (Schneider et al., p. 2). For each of these activities the respondents were asked a series of probing questions which assisted the respondent in identifying some possible limitations in these activities.

The researchers for the CASE Disability Survey obtained information from 42 974 people, of whom 2 435 reported being disabled. From this data, figures were extrapolated to the general population, and used to estimate a prevalence rate of disability as 5.7% to 6.1% of the total population (2.3 million to 2.5 million people). The data indicates that Africans have a higher prevalence rate than other races (see Table 2.4). The Eastern Cape Province had the highest prevalence rate among the nine provinces (see Table 2.4).

Table 2.4: Prevalence of disability by province and race

Province	Total prevalence rate	Size of sample	African (%)	Coloured (%)	Indian (%)	White (%)
Eastern Cape	8.9	6 743	9.0	6.1	-	11.8
Free State	5.8	2 814	6.1	0.0	-	5.6
Gauteng	5.2	7 753	5.5	5.5	1.8	4.5
KwaZulu-Natal	6.7	8 900	6.9	9.4	5.3	6.2
Limpopo	6.3	5 198	5.8	-	-	10.4
Mpumalanga	4.5	2 963	4.7	-	-	2.6
Northern Cape	4.5	888	4.0	4.3	-	7.4
North West	3.1	3 596	2.9	-	-	5.8
Western Cape	3.8	4 081	3.9	3.9	2.3	3.3
Total (average %)	5.9	42 936	6.1	4.5	4.8	5.3

(Data taken from Schneider, et al., 1999, pp. 14-15)

As was the case in Census 2001 (Statistics South Africa, 2005), The CASE Disability Survey found a steady increase in prevalence rates among age groups, with a sharp increase in old age.

The survey measured disability as a limitation on a number of activities. Statistics on type of disability indicates a higher prevalence rate of disability related to movement, with communication disability having the lowest rate of prevalence (see Table 2.5).

Table 2.5: Prevalence rates by type of disability

Type of disability	Prevalence rate (%)
Movement activity	2.0
Daily life activities	1.8
Seeing	1.7
Moving around	1.7
Learning	1.2
Emotional	1.1
Intellectual	1.1
Hearing	1.0
Communication	0.8

(Data taken from Schneider, et al., 1999, pp. 17)

The survey further indicates that the majority (58%) of the respondents had multiple disabilities, with almost a third having more than three disabilities. Rural respondents

under the age of 10 were twice as likely to have three or more disabilities, than respondents from urban areas.

The survey found that health and medical rehabilitation services were reported as the services most needed by people with disability. Three quarters of the respondents with disabilities had received health services, but only 2 out of every 5 persons received needed medical rehabilitation services. Fewer than one-fifth of people received counselling or welfare services.

Questions were also asked around school attendance. Results indicated that the most accessible level of education was primary school, with 12% of respondents attending special schools and 79% attending mainstream primary school. The results indicated that fewer than half of the respondents (44%) attended mainstream high school, and 9% attended special high schools. The researchers found that vocational training was generally lacking as an educational resource. It was argued that the “lack of attention to disabled children’s special educational needs in primary school means that they do not reach high school” (Schneider et al., 1999, p. 23), which explains the drop in attendance at the high school level. Children with communication, or learning, and particularly intellectual disabilities, were less likely to be in high school. African children were most likely to be out of school at the high school level, than other races. The authors conclude that “the majority of Africans are disadvantaged, and as a result of Apartheid, seem to experience the most difficulties in education” (Schneider et al., 1999, p. 26).

The survey results indicated that White disabled persons are most likely to be employed. Women and people with more than one disability are less likely to be employed. Overall only 12% of respondents were employed. This is less than a third of the rate employment for the general population.

In summary, Census 2001 (Statistics South Africa, 2005) and the CASE Disability Survey (Schneider et al., 1999) provide the most recent quantitative data on the prevalence of disability in South Africa. Direct comparisons and interpretations of the data is difficult

to make, due to the difference in definitions used, and the difference of what was being measured. However some overall conclusions can be drawn:

- The overall prevalence rate of disability ranges from 5% (reported in Census 2001) to 5.9% (reported in the CASE Disability Survey).
- Africans had the highest rate of prevalence.
- KwaZulu Natal has the highest number of disabled people.
- The prevalence of disability increases steadily with age, with a sharp increase in older ages.
- Physical (or motor) and sight disability was the most common, with communication disability having the lowest reported prevalence.
- Children with disabilities are less likely to be in school, particularly high school, than the general population.
- People with disability are less likely to have employment than the general population, with disabled women being most disadvantaged in this regard.

2.6 Conclusion

In this chapter I have attempted to provide a definition of disability and an indication of the prevalence of disability in South Africa. As has been shown, defining 'disability' is a contested, and complex process, but disability has generally now been understood as a relationship between individual impairment and the environment and society. Due to the complications and variations in defining disability, it is not an easy task to measure the prevalence of disability. There are only two national studies in South Africa that has attempted to measure the prevalence of disability in South Africa, which is estimated to be between 5% and 6%, perhaps even more. With this understanding of 'disability' the next chapter will look at literature relating to HIV/AIDS and persons with disabilities.

CHAPTER THREE

HIV/AIDS AND PERSONS WITH DISABILITIES

3.1 Introduction

In this chapter, I review literature related to HIV and persons with disabilities. I begin by observing the paucity of literature available internationally on specifically HIV with regards persons with disabilities. Following from this, I review the literature regarding various risk factors for HIV infection, for persons with disabilities, looking at poverty; lack of education; sexual activity; vulnerability to sexual abuse and rape; lack of sex education and knowledge about HIV and safe sex; substance abuse; limited access to health care; and stigma and isolation. Finally I discuss the reported results from the World Bank/Yale University Global Survey on HIV/AIDS and Disability.

3.2 HIV and Persons with Disabilities: An Absence of Research

The sexuality of people with disabilities has historically been handled by a denial of sexuality and exclusion in sex education and sexual health services (Kempton & Kahn, 1991; Milligan & Neufeldt, 2001). The onset of HIV/AIDS, internationally, has led to a focus on the need to provide sex education (Kempton & Kahn, 1991), including for persons with disabilities. Despite this, however, little is known about how HIV affects persons with disabilities. In South Africa, there are currently no figures that exist that give an indication of the prevalence of HIV/AIDS among persons with disabilities.

In the international literature, there are few studies that investigate specifically issues of HIV/AIDS and persons with disabilities. These include:

- HIV education for persons with intellectual disabilities (Birch, Angermeier, & Gentsch, 2002; Cambridge, 1998; Robertson, Bhate, & Bhate, 1991);
- Issues for HIV prevention and education with men with intellectual/learning disabilities who have sex with men (Cambridge, 1997; Thompson, 1994);

- Evaluation of an HIV education programme for youth with intellectual disabilities (Newens & McEwan, 1995);
- HIV and the Deaf community (Bat-Chava, Martin & Kosciw, 2005; Doyle, 1995; Kennedy & Buchholz, 1995; Peinkofer, 1994; Van Biema, 1994);
- HIV among persons with psychiatric illnesses (Collins, Geller, Miller, Toro, & Susser, 2001; McKinnon, Cournos & Herman, 2002; Tate & Longo, 2000).

In Africa, there have been a few studies on HIV knowledge and testing services among persons with disabilities in Malawi (Munthali, Mvula & Ali, 2004), among persons with hearing disabilities in Nigeria (Groce, Yousafzai, & van der Maas, 2007), adolescents with disabilities in Rwanda and Uganda (Yousafzai & Edwards, 2004; Yousafzai, Edwards, D'Allesandro, & Lindström, 2005), people with disabilities in Swaziland (Yousafzai, Dlamini, Groce, & Wirz, 2004), and persons with disabilities in Uganda (Mulindwa, 2002).

Only two studies were found dealing with HIV/AIDS and persons with disabilities in South Africa. Wazakili, Mpofu and Devlieger (2006) investigated the knowledge and perception of HIV/AIDS among youth with physical disabilities, finding limited knowledge about HIV/AIDS. Philander and Swartz (2006) investigated the views and perceptions regarding HIV education for persons with visual impairments, from key informants in the field in South Africa.

There is a larger quantity of literature related to the sexuality of persons with disabilities and other issues related to risk for HIV infection. Using this literature and the literature on HIV and disability cited above, I turn now to a review of the key risk factors for HIV for persons with disabilities.

3.3 Risk Factors

Risk factors associated with HIV infection and transmission include poverty, lack of education, lack of sex education and knowledge about safe sex practices, sexual abuse and rape, substance abuse, access to health care, and social isolation (Groce, 2004).

While there is limited literature on HIV and persons with disabilities, more literature exists on disabilities and sexuality, particularly around sexual functioning, and issues related to HIV risk, particularly the problem of sexual abuse. Not all of the literature is relevant for this thesis, for example much of the literature in sexual functioning among persons with physical disability, but a look at some of the more significant and relevant findings from this literature provides essential knowledge related to HIV and persons with disabilities.

3.3.1 Poverty

In a review of the literature related to poverty and disability, Elwan (1999) concluded that persons with disabilities are more likely to be unemployed, have lower income, and less likely to have assets compared to the rest of the population in both developed and developing countries. She further concluded that “not only does disability add to the risk of poverty, but conditions of poverty add to the risk of disability” (p. 34), through inadequate nutrition, sanitation and health care, resulting in increased risk for disabling diseases. Emerson (2004) reviews studies that indicate the association of poverty to the increased prevalence of intellectual disabilities, relating to the increase in poverty as a result of the cost of caring for a child with intellectual disability, as well as to the biological risk to developmental impairments as a result of poverty. In developing countries, persons with disabilities are particularly at risk for poverty, and it is estimated that disabled people make up between 15 to 20 percent of the poor in low-income, developing countries (Helander, cited in Elwan, 1999). Groce (2003a) reveals how 80% of the world’s youth (under the age of 24) with disabilities, live in the developing world, and that they are “among the poorest and most marginalized of all the world’s young people” (p. 3).

In South Africa, as with the rest of the world, persons with disabilities are “disproportionately represented among the poor” (Emmett, 2006, p. 221). Persons with disabilities in South Africa are more likely to be unemployed than the general population (Schneider et al., 1999; Statistics South Africa, 2005).

Women may be particularly excluded from work and adequate income. In the USA, for example, Hanna and Rogovsky (1991) indicates that women with disabilities are more likely to not have employment, and have a lower monthly income, compared to disabled men and non-disabled men and women. In a study of women with psychiatric disabilities, the majority (83%) of women participating in the study were unemployed (Collins et al., 2001). Poverty may lead some women with disabilities to turn to prostitution as a means to survive, increasing their risk for sexually transmitted diseases and HIV infection (Smith, Murray, Yousafzai, & Kasonkas, 2004). McCarthy (1993) highlights the practice of exchange of sex for money and other material goods in the experiences of women with learning disabilities in institutional settings in England. Although McCarthy does not specify that this is an issue related to poverty, she does point out how it is generally the case than it is men who have the means to pay. In addition, women with disabilities may be financially dependent on men, and may not have “the freedom to prioritize their safety in sexual relationships above material needs” (Collins et al., 2001, p. 163).

Poverty also plays a role in the ability for disabled people to cover the cost of transport in order to access health care services, and the cost of medical care itself (Smith et al., 2004). A lack of money was one of the reasons reported by caregivers of disabled children, for under utilizing available services in South Africa (Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2007).

HIV infection and the costs of health care associated with HIV and AIDS, may lead to income loss and further levels of poverty (Rajaraman, Russel & Heymann, 2006). In South Africa, an individual may be eligible for a disability grant, on the basis of their HIV/AIDS related illness. This is a much needed support for an HIV-positive person, but the issue may become complicated with the provision of anti-retroviral treatment. When an individual’s health improves on anti-retroviral treatment, they may become able to work again, and thus no longer be eligible for a disability grant. However, given South Africa’s high rate of unemployment, the consequences a loss of a disability grant can raise serious concerns for the individual and their family (Swartz, Schneider & Rohleder, 2006).

3.3.2 Lack of Education

Elwan (1999) found that persons with disabilities have generally lower levels of education than the rest of the population in both developed and developing countries. Hanna and Rogovsky (1991) found that disabled men and women received less formal education in the USA than non-disabled men and women. They found that 33% of disabled men and 42% of disabled women did not graduate from high school (compared to 16% of non-disabled men and 18% of non-disabled women). As the authors argue, this does not reveal differences in the quality of education received, but does indicate that there is a difference in level of educational attainment. In Malawi, Munthali and colleagues (2004) found that persons with disabilities in their study had poor levels of education, and that literacy levels among persons with disabilities were lower than in the general population.

Disabled children and adolescents may be excluded from school, as education may be seen as unnecessary as the child can not learn, or the child may be perceived as a nuisance or disruption to the other children, and schools may be physically inaccessible to children with physical and visual disabilities (Groce, 2003a; 2004). Lower levels of education has consequences for the disabled person's opportunity for employment and earning potential, and as has been discussed above, persons with disabilities are more likely to be unemployed or receiving a lower monthly income.

In low-income countries, scarce resources may result in parents choosing to exclude their disabled children from education, in favour of their non-disabled children (Groce, 2003a), with the expectation that the educated, non-disabled child will guarantee a job. In a South African study, Saloojee and colleagues (2007) found that few children with disabilities in an impoverished peri-urban township, were attending pre-school or school. In these cases, disabled female children may be at a greater disadvantage (Groce, 2003a).

In South Africa, access to education for disabled children is further compounded by the disparities in resources across the country, as a result of unequal development under apartheid (Soudien & Baxter, 2006), with some areas having higher prevalence of

disabled learners but fewer special education schools, and other areas having fewer disabled learners but more schools. As discussed in chapter two, Census 2001 (Statistics South Africa, 2005) found that persons with disabilities in South Africa were more likely to have received no education than persons without disabilities.

3.3.3 Sexually Active

Persons with disabilities are often perceived as being asexual because they are considered to have diminished or absent sexual needs, or lack the capacity to engage in relationships (Craft, 1987; Milligan & Neufeldt, 2001). This, however, is a myth and various studies indicate that persons with disabilities are sexually active. This is shown in studies among a variety of population groups:

- *Physical Disability*: A national study in the United States of America (Nosek, Howland, Rintala, Young & Chanpong, 2001), indicated that 94% of women with physical disabilities have had sex with a partner in their lives. In studies of men and women with physical disabilities following spinal cord injury, the majority indicated that they had had sexual intercourse since their injury (Jackson & Wadley, 1999; White, Rintala, Hart & Fuhrer, 1993; White, Rintala, Hart, Young & Fuhrer, 1992). Among adolescents with physical disabilities there has been found to be an equal prevalence of sexual activity between disabled and non-disabled peers (Cheng & Udry, 2002).

- *Intellectual/Learning Disability*: Blanchett (2000), in a study conducted in the USA, found that 51% of young adults (aged 18 to 26) with learning (intellectual) disabilities reported being sexually active. Youth with learning disabilities in the United States, are found to be more likely to have had sexual intercourse before the age of 12, than non-disabled peers (Blum, Kelly, & Ireland, 2001). In an earlier study, female adolescents across the range of severity of intellectual disability had reportedly had sexual intercourse (Chamberlain, Rauh, Passer, McGrath & Burket, 1984).

- *Psychiatric and Emotional Disabilities*: Studies reviewed by Cook (2000), show that despite the myth of mentally ill patients being asexual, one-third to three-quarters report

being sexually active. Youth with emotional disabilities in the United States, are (similarly to youth with learning disabilities) found to be more likely to have had sexual intercourse before the age of 12, than non-disabled peers (Blum et al., 2001).

- *Visual Disabilities*: In a study at a school for the blind in the Gauteng province in South Africa, (Kelly, Ntlabati, Oyosi, van der Riet, & Parker, 2002), it was found that children engaged in sexual activity at an early age, and it was suggested that it was expected for someone to engage in sexual activity after a certain age (which ranged from 10 to 18).

- *Hearing Disabilities*: Peinkofer (1994) reviews literature on sexuality and HIV-related issues for the Deaf, indicating that persons with hearing disabilities are sexually active.

- *Chronic Illness*: In a national study among adolescents with chronic conditions in France, it was found that more disabled adolescents reported having had sexual intercourse than adolescents without chronic conditions (Choquet, Du Pasquier Fediaevsky, & Manfredi, 1997).

These studies clearly refute, then, the myth that persons with disabilities are asexual.

3.3.4 Lack of Sex Education

Milligan and Neufeldt (2001), in a review of literature on the myth of asexuality in persons with disability, showed that discussion of issues of sexuality was historically considered unnecessary in rehabilitation services, and the topic was generally avoided. The authors go on to show that despite increased knowledge about sexual functioning in persons with disability (particularly physical disability), there still remains a resistance towards engaging with sexual issues on the part of staff working with persons with disability.

Myths around the sexuality of disabled people are perhaps more prevalent with intellectual disability. Craft (1987) highlights two contradictory constructions of sexuality in intellectual disabilities. On the one hand, men and women with intellectual disabilities

are often regarded as “forever children” and thus asexual. On the other hand, intellectually disabled people are also often “seen as having very strong sexual inclinations, coupled with poor personal control, making them a menace to society at large” (Craft, 1987, p. 14). With these constructions, sex education with persons with intellectual disability is often seen as dangerous (in that it encourages sexual expression) or unnecessary (as intellectually disabled persons are considered to be asexual). Similar sentiments are found in a study by Heyman and Huckle (1995), who found that informal carers of adults with learning disabilities regarded sexuality as a source of danger. Such dangers included: the adults being unable to understand the physical and emotional issues involved with sexuality; that sexuality leads to a vulnerability to unplanned pregnancy and sexual abuse; that allowing a sexual relationship would legitimate uninhibited sexuality; and that adults with learning disabilities would not understand social mores, and will display inappropriate sexual activity. Heyman and Huckle (1995) found that informal carers were resistant to the provision of sex education, and attempted to control the sexuality of adults with learning disabilities (for example by limiting the opportunity for men and women with learning disabilities to be alone together). The authors argued that displays of “inappropriate sexual behaviours” (such as public sexual displays) may be a result of the restrictions placed by carers, as well as a result of cognitive ability.

Coupled with this, is the need for specific training around sexuality and disability. Studies have indicated that while teachers and carers agree to the importance of sexuality education for persons with disabilities, many feel inadequately trained to do this (Bratlinger, 1992; Christian, Stinson & Dotson, 2001; Howard-Barr, Rienzo, Pigg & James, 2005; Parritt & O’Callaghan, 2000). In a study of the curricula of training programmes for special educators in USA, found that many programs (41%) did not cover sex education coursework in their curriculum (May & Kundert, 1996). Such lack of training increases the anxiety of the teacher or carer in relation to sexuality education. Parritt and O’Callaghan (2000) found that counsellors and psychotherapists expressed greater anxiety raising issues of sexuality with disabled clients than with non-disabled clients. However, in their study the participants had little actual experience of working with disabled clients. Part of the anxiety that was expressed was around feeling

inadequately trained for working with sexuality and disability. Bratlinger (1992) found that teachers, in addition to feeling inadequately trained, were anxious about adverse reactions from students with intellectual disabilities and their parents. For example, one teacher commented: “I had a sense of foreboding about it – like thinking that it would get out of hand” (Bratlinger, 1992, p. 37).

Many disabled people have not received any sex education (Berman et al., 1999; Heyman & Huckle, 1995; McCabe, 1999; Pueschel & Scola, 1988). McCabe (1999) found that 50% of people with physical disabilities and intellectual disabilities have not received any sex education. In a study of adults with learning disabilities (Heyman & Huckle, 1995), only one in twenty adults reported remembering receiving sex education. In a study of students who are Deaf in the USA, it was reported by teachers that their sexuality education materials were appropriate for Deaf students, but not for students who are Deaf and have additional disabilities (Getch, Young & Denny, 1998). With adults with intellectual disabilities research suggests that adults may be referred to sex education classes only after an event or specific concern is raised. For example, McCarthy (1996) found that the most common reasons for referring an adult with intellectual disability for sex education, was staff concern about the sexual vulnerability of women, and men who were perpetrators of sexual abuse. This was followed by a need for general knowledge around sex and sexuality.

In instances where students with disabilities have received sexuality education, Lumley and Scotti (2001) argue that programmes traditionally intend to increase knowledge, but very often do not have a mechanism to evaluate their effectiveness. Those programmes that have evaluated their effectiveness have shown an increase in knowledge, but not a sustained level of mastery of skills (in their case they review literature in relation to students with intellectual disabilities). For example, in an evaluation on a sex education course for persons with intellectual disabilities (Lindsay, Bellshaw, Culross, Staines, & Michie, 1992), the researchers evaluated the level of knowledge with regards various aspects of sex education, such as body parts, birth control, sexual intercourse, pregnancy, and venereal diseases. They found an increase in knowledge among learners following

sex education, sustained at 3-month follow up. However, this investigation does not assess to what extent the knowledge and skills learnt have been incorporated into the person's daily life.

In a review of the literature by Milligan and Neufeldt (2001), a significant number of persons with disabilities reported having received little or no information or counselling about sexuality and disability, particularly women. Low levels of sexual knowledge have been reported by people with physical disabilities (Berman et al., 1999; McCabe, 1999; McCabe, Cummins & Deeks, 2000), hearing disabilities (Peinkofer, 1994), and intellectual disabilities (McCabe, 1999) in the international literature. Women with physical disabilities in USA have reported lacking information about sexually transmitted diseases (Becker, Stuijbergen, & Tinkle, 1997). Berman and colleagues (1999), in their survey interview study with males and females with physical disabilities, conclude:

they have little knowledge about sexuality in general and about the effects of their own disability on sexuality and reproductive function in particular; they have few ideas as to how they can obtain this knowledge (p. 193)

While there are low levels of sexual knowledge, there is, it seems, a desire to know more (Berman et al., 1999; Heyman & Huckle, 1995; McCabe et al., 2000).

3.3.5 Knowledge about HIV and Safe Sex Practices

With little or no education about sex and sexuality for persons with disabilities, knowledge about safe sex practices and protection against HIV would therefore be limited. Research has found that knowledge about HIV transmission among persons with disabilities is low (for example, Munthali et al., 2004), and lower than the knowledge among non-disabled persons (for example Yousafzai et al., 2004). Low levels of knowledge about HIV/AIDS has been found among the Deaf, particularly Deaf sign language users (Bat-Chava et al., 2005). Bat-Chava and colleagues (2005) also found that few Deaf persons, who had participated in their study, had gone for HIV testing. However, in an earlier study, Doyle (1995) had found high levels of HIV knowledge

among Deaf participants in his study. The participants however, were college students, whereas in the study by Bat-Chava and colleagues (2005), the participants were more diverse, and they noted variations in levels of HIV knowledge, which they suggest may reflect, among other things, level of education. In South Africa, research has found that youth with physical disabilities have limited knowledge about HIV (Wazakili et al., 2006), and that knowledge about HIV/AIDS among persons with visual disabilities is low, as reported by service providers (Philander & Swartz, 2006).

Studies also indicate that the extent to which HIV/AIDS is covered or included in sex education programs varies. For example, Getch and colleagues (1998) found that HIV/AIDS is covered by 99% of schools involved in their study of sexuality education for Deaf students. On the other hand, in a study of teachers working with students with intellectual disabilities, only 27% reported addressing HIV/AIDS in sexuality education classes (Howard-Barr et al., 2005). In a school for learners with visual disabilities in South Africa, it was found that HIV education was done sporadically and informally, and mostly with male learners who were suspected to be sexually active (Kelly et al., 2002). The provision of HIV prevention education may also vary according to the severity of disability. For example, students with mild intellectual disability were more likely to receive HIV education than students with moderate or severe intellectual disability (Birch et al., 2002). Similarly, Yousafzai and colleagues (2005) found that the quality of HIV knowledge among adolescents with disabilities in Rwanda and Uganda, varied according to the severity and nature of disability. In addition, research has shown that persons with disabilities face various barriers to accessing information about HIV prevention, such as accessing information in Braille formats, sign language or accessing information that is understandable to persons with intellectual disabilities, and accessing services that are too far or inaccessible to wheelchair users (Munthali et al., 2004; Yousafzai & Edwards, 2004; Yousafzai et al., 2004; Yousafzai et al., 2005). People with disabilities also face barriers to accessing HIV testing and counselling (Yousafzai & Edwards, 2004).

There are a number of studies that include an investigation of the prevalence of unsafe sex practices among persons with disabilities. International studies have indicated that

many persons with disabilities do not always wear condoms during intercourse (for example, Blanchett, 2000; Chuang & Atkinson, 1996; Cook, 2000; Jackson & Wadley, 1999; Nosek et al., 2001). In a national study of adolescents with chronic conditions in France (Choquet et al., 1997), more than half (59%) the boys in the study reported using condoms always, with the remainder reporting using condoms only sometimes or never. However, fewer numbers of girls (38%) reported using condoms always. The majority reported using condoms only sometimes or never. In Malawi, Munthali and colleagues (2004), found that 73% of persons with disabilities in their study had not used a condom during sex, and in Uganda only 24% of men with disabilities and 10% of women with disabilities were wearing condoms during sex (Mulindwa, 2002). Doyle (1995) found that, despite high level of knowledge about HIV, Deaf students participating in his study reported low levels of condom use.

Studies have also indicated the prevalence of sexually transmitted diseases (STDs) among persons with disabilities (Jackson & Wadley, 1999; Mulindwa, 2002; Nosek et al., 2001), indicating unsafe sexual practices. Females with disabilities, because of possibly being at increased vulnerability for sexual abuse and coercion, and perhaps being more dependent, may be less able to negotiate the use of condoms during sex, and so providing women with alternative choices of protection (for example the female condom), may increase women with disabilities' ability to protect themselves (Collins et al., 2001).

In addition, some research shows that there is a lack of knowledge about modes of HIV transmission, resulting in some misconceptions about how HIV is contracted. For example, women with learning (intellectual) disabilities in Britain, believed that keeping their bodies clean prevented infections, including AIDS (McCarthy, 1998). In a study of persons with psychiatric disabilities (Kelly et al., 1992), 43% of participants believed that heterosexual women could not get AIDS. Groce and colleagues (2007) found that Deaf people in Nigeria were more likely than hearing persons, to believe that HIV can be transmitted through kissing, mosquito bites, touching and hugging, dirty places and germs in the air. Similarly, in Swaziland, participants in a study measuring levels of HIV knowledge among disabled and non-disabled persons, showed that the persons with

disabilities that participated in the study had many more misconceptions about the mode of HIV transmission than the participants without disabilities (Yousafzai et al., 2004).

Lack of knowledge about sexuality and disability, also resulted in misconceptions around sex. For example, adults with learning disabilities referred to sexual acts as “rude” and that sex education was “rude” and “bad” (Heyman & Huckle, 1995). Furthermore, due to the attitudes from carers towards sexuality, adults with learning disabilities in this study feared that sexual relationships would be met by disapproval from carers.

3.3.6 Sexual Abuse

An epidemiological study in North America conducted by Sullivan and Knutson (2000) shows that children with disabilities are 3.4 times more likely to be maltreated than non-disabled children, through abuse and neglect. The study found that prevalence rates of maltreatment among children with disabilities was higher for that of non-disabled children for all types of disabilities (excepting Autism), with behavioural disorders, intellectual disability and learning disabilities having the highest prevalence rates for maltreatment. The study further found that neglect was the most prevalent form of maltreatment, followed by sexual abuse for both children with disabilities and non-disabled children. It was also found that children with disabilities were more likely to have experienced multiple forms of maltreatment, as well as multiple episodes of maltreatment, than non-disabled children. In studies that investigate gender differences in the prevalence of maltreatment in children with disabilities (Sobsey, Randall, & Parrila, 1997; Sullivan & Knutson, 2000), it was found that more males with disabilities experienced maltreatment than females with disabilities, specifically physical abuse and neglect. However, more females with disabilities experienced sexual abuse than males with disabilities, as with non-disabled children. Sobsey and colleagues (1997) further found that there were a higher proportion of male children with disabilities who were abused than the proportion of males without disabilities, across all types of abuse (physical, sexual, emotional abuse, and neglect).

Looking at sexual abuse specifically, as it has been suggested, persons with disabilities “are up to three times more likely to be victims of physical abuse, sexual abuse, and rape” (Groce, 2004, p. 10). Persons with disabilities are seen to be vulnerable for sexual abuse both at home (Hassouneh-Phillips & Curry, 2002; Sobsey & Doe, 1991), and in institutions (Crossmaker, 1991; Furey, Niesen & Strauch, 1994; Sobsey & Doe, 1991). Sobsey and Doe (1991) found that in 37% of cases, abuse of persons with varying disabilities took place in “environments that the victim encountered as a result of being disabled” (p. 249), such as hospitals, institutions, and in specialized transport vehicles. Studies have been conducted in various countries that investigate the high prevalence of sexual abuse among persons with intellectual disability (for example Furey, Niesen & Strauch, 1994; McCabe, Cummins, & Reid, 1994), physical disability (for example Nosek et al., 2001; Sobsey & Doe, 1991), hearing impairments (for example Kvam, 2004; Sobsey & Doe, 1991), visual impairments (for example Kvam, 2005; Sobsey & Doe, 1991), psychiatric disabilities (for example Collins, 2001; Collins et al., 2001; Kelly et al., 1992), and autism (for example Mandell, Walrath, Manteuffel, Sgro, & Pinto-Martin, 2005; Sobsey & Doe, 1991).

Incidents of sexual abuse of persons with disability are often repeated and chronic (Hassouneh-Phillips & Curry, 2002; Sobsey & Doe, 1991). As expected, studies show that the majority of the victims of sexual abuse are female with the perpetrators being male (Brown & Turk, 1994; Dickman & Roux, 2005; Hassouneh-Phillips & Curry, 2002; Sobsey & Doe, 1991), although reports of males being abused are also given. In sexual abuse and assault cases studied by Sobsey and Doe (1991) in North America, over half involved vaginal or anal penetration, and in the majority of cases the perpetrator was known to the victim. Similarly, in England more than half of reported cases of sexual abuse in a study of persons with intellectual disabilities, involved penetration (Brown & Turk, 1994). In South Africa, Dickman and Roux (2005) analysed 100 cases of sexual assault of a person with intellectual disabilities, and found that in the majority of cases (89%), the perpetrator was known to the individual abused, either as neighbours, friends or family. In 40% of cases the victim was under the age of 16. Of these cases studied, 90% of the charges involved rape, and in all cases where the victim was a male, the

charge was sodomy. Similarly, in a study by Kelly et al. (2002) at a school for the blind in South Africa, issues were raised about the vulnerability for abuse of children with disability, and it was suggested that most perpetrators were known to the children.

Andrews and Veronen (1993, cited in Nosek et al., 2001), cite eight possible reasons for the increased vulnerability of persons with disabilities for abuse. These are:

- (1) A denial for the person's human rights which may result in powerlessness,
 - (2) Persons with disabilities are dependent on others for care,
 - (3) Persons with disabilities have less education about what is considered appropriate and inappropriate sexual activity,
 - (4) Some survivors of abuse are not believed,
 - (5) Perpetrators feel they are less likely to be discovered,
 - (6) Persons with disabilities are more socially isolated and at greater risk of manipulation,
 - (7) Persons with disabilities may be physically vulnerable and helpless in public spaces,
 - (8) There are moves towards inclusivity and integration of persons with disabilities.
- However this may be done without careful consideration of an individual's capacity for self-defence.

Nosek and colleagues (2001) argue that all women, whether disabled or not, have "vulnerabilities that can be used as avenues for the exertion of power and control; disability serves as an additional vulnerability factor" (p.186). So, women with physical disability have a reduced physical ability to defend themselves, and because of social stigma also have reduced emotional defences against abuse (Nosek et al., 2001). The marginalised and stigmatised position of women with disabilities has also been cited as a vulnerability factor by other authors. For example, Beck-Massey (1999) argues that women with disabilities are at increased risk for sexual abuse, because of society's perception of disabled women as pitiful and that they "should be grateful that any man wants to marry, date, or have sex with them" (p. 270). Similarly, Hassouneh-Phillips and McNeff (2005) found that women with physical disabilities interviewed in their study,

perceived themselves to be unattractive and sexually inadequate in comparison to non-disabled women, making them vulnerable to entering potentially abusive relationships and staying in them rather than being alone.

The myth of persons with disabilities being asexual also may put disabled people at risk. For example, Groce and Trasi (2004) found a reported high prevalence of “virgin rape” among persons with disability. The incidence of “virgin rape” may be as a result of beliefs about “virgin cleansing” that has arisen in various parts around the world, where the belief is that a person who has a sexually transmitted disease (including HIV) can rid themselves of the infection by having sex with a virgin. Persons with disability are assumed to be asexual and therefore virgins, so they become targets of such practices.

Another possible reason for the vulnerability of persons with disabilities for sexual abuse is the lack of knowledge and education about abuse. For example, McCabe, Cummins and Reid (1994) conducted a study in Australia comparing the knowledge and experience of sexual abuse among persons with mild intellectual disability and students without intellectual disabilities. With regards knowledge about sexual abuse, the authors found that persons with intellectual disabilities were less likely to understand and know the meaning of “rape” and “incest”. Persons with intellectual disabilities were also less sure about what to do and how to say ‘no’ to unwanted touch. As regards experience of sexual abuse, once the persons with intellectual disabilities were educated about the meaning of the terms “rape”, the authors found that persons with intellectual disability were more likely to have been raped than those without intellectual disability - 27% of respondents with intellectual disability reported having been raped, compared to 8% of respondents without intellectual disabilities.

Related to this is the difficulty around access to psycho-legal services for persons with disability, and the disabled person’s competency to give witness. In some international studies, it was found that cases of sexual abuse and assault of persons with disabilities generally go unreported, and few reach conviction (Brown & Turk, 1994; Sobsey & Doe, 1991). Persons with disabilities, particularly intellectual disabilities, are often not able to

receive legal protection for their experience of sexual abuse, as their intellectual functioning and competence to give evidence in trial is questioned (Pillay & Sargent, 2000). In many cases, however, this is not the case and Pillay and Sargent (2000) show, in a study of cases of rape survivors in South Africa that many individuals with intellectual disability are able to give an account of what happened to them. Similarly, Dickman and Roux (2005) found that rates of conviction in sexual assault cases where the complainant had an intellectual disability were comparable to rates of conviction in the general population, but only after the courts had received special training by mental health professionals on issues of disability and sexual abuse.

With regards psychological and medical services following sexual abuse, it has also been shown that persons with disability who have survived sexual abuse and assault, experience difficulty in accessing treatment services, including psychological counselling and medical care (Groce, 2004; Sobsey & Doe, 1991).

Some of the difficulty experienced by disabled people in accessing legal and medical assistance for sexual abuse and rape, may be as a result of the diminished value given to persons with disabilities. Marks (1999a), points out how the seriousness of sexual and assault crimes committed against persons with disabilities are often diminished, being referred to as “abuse” rather than being considered as a crime. She quotes Williams who states: “Women with learning disabilities are ‘sexually abused’ – other women are raped. Men with learning disabilities are ‘physically abused’ – other men are assaulted” (Williams, 1995, cited in Marks 1999a, p. 41). Perpetrators of such crimes committed against persons with disabilities are then referred to as ‘abusers’ rather than ‘criminals’, and crimes go unpunished.

3.3.7 Substance Abuse

Substance abuse has been suggested as being a serious issue for persons with disabilities (Bachman, Drainoni, & Tobias, 2004). In the Global Survey on HIV/AIDS and Disability (Groce, 2004), drug abuse was reported among women with physical disabilities, and the Deaf. In a South African study on youth with physical disabilities following spinal cord

injuries, substances were reportedly used as a means to cope with the frustrations in adjusting to a new identity as a physically disabled youth (Njoki, Frantz, & Mpofu, 2007). Some studies indicate that persons with disabilities may be at increased risk for using substances. For example, Li and Ford (1998) conducted a survey study among women with various disabilities in the United States. They found that women with disabilities reported higher rates of illicit drug use than women without disabilities in general population studies, with the use of marijuana and cocaine being the most prevalent. Similarly, in a study of American youth with physical disabilities and emotional disabilities, it was found that physically disabled youth were more likely to have reportedly used alcohol than non-disabled peers (Blum et al., 2001). The study also found that youth with emotional disabilities were more likely to have reportedly used marijuana than non-disabled peers. Peinkofer (1994), in a review of HIV-related literature on the Deaf, cites studies that report a greater incidence of substance abuse among the Deaf community as compared to the hearing community.

The use of substances has been considered as a risk factor for HIV transmission, particularly when substances are used during sexual intercourse. This may have the effect of reducing the individual's sexual and behavioural inhibitions, leading to an increased possibility of engaging in unsafe sex. Persons with disabilities are not excluded from this. For example, Blanchett (2000) found that 36% of young adults with learning disabilities in her study had used alcohol or drugs during sexual intercourse. Similarly, persons with psychiatric disabilities have reported engaging in sexual intercourse after using alcohol or drugs (Kelly et al., 1992).

3.3.8 Access to Health Care

Persons with various disabilities may experience both physical and attitudinal barriers to accessing health care services. Physical barriers, for persons with physical disabilities, may include facilities that are not accessible for wheelchair users, and medical equipment that is not designed for persons with disabilities (Becker et al., 1997). In a study of family planning services in Northern Ireland (Anderson & Kitchin, 2000), it was found that all facilities were not fully accessible to persons with disabilities. While wheelchair users

faired better in terms of provisions for physical access, persons with sensory disabilities did not, with only two facilities out of the thirty-four who responded being accessible for Deaf people, for example. The authors further found that family-planning information was not accessible for persons with sensory disabilities. Anderson and Kitchin (2000) concluded that the lack of physical and information access indicates that there is an expectation that disabled people do not need to use family planning facilities. Further barriers are experienced due to varying perceived and experienced negative attitudes from health care providers towards persons with disabilities. Gething (1992), for example, in a study of attitudes of Australian health professionals towards persons with physical disabilities, found that “the presence of the wheelchair led to a general devaluing of the disabled person” (p. 812), in judgements about the disabled person’s psychological and social adjustment.

In a study of women with physical disabilities in USA (Nosek et al., 2001) it was found that disabled women do not receive the same quality of gynaecological health care (including birth control, hysterectomy and cancer screening) as do women without disabilities. The study also found that, although women with physical disabilities make more use of health care services than able-bodied women, there still exist significant barriers to access of quality health care. For example, it was found that 31% of women have experienced being refused consultation with a physician because of their disability.

Due to the myth of disabled people being asexual, health care providers may also focus on the disability of the person rather than on their sexual activity and sexual health needs (Welner, 1999a). As a consequence, sexually transmitted diseases in persons with disabilities may go undetected (Welner, 1999b). American women with physical disabilities in a study by Becker and colleagues (Becker et al., 1997), reported that they were often treated as asexual by health care providers, and reported how staff at times appeared shocked at the woman’s request for contraception. The women in the study also reported feeling that health care providers were insensitive and unaware of sexuality and disability issues, and that providers were reluctant to discuss sexual issues and birth control options with them. Myths about sexuality, reproduction and disability raises

issues for the provision of health care for women with physical and women with intellectual disabilities. As argued by Tilley (1998):

Women with physical disabilities are stereotypically characterised as ‘asexual’, so commonly they are instructed/presumed to be unable to manage pregnancy, birth and motherhood and are implored to ‘rationally’ forgo these possibilities. In contrast, women with intellectual disabilities are commonly constructed as hyper- and inappropriately sexual and unable to ‘control’ their sexual selves. It is these women who are often deemed unable to decide for themselves and for whom sterilisation is promoted (pp. 96-97).

This was also found to be the case in South Africa, where women with physical disabilities attending family planning clinics reported often being treated as if asexual by health care staff, and questioned about why they felt they should attend the clinic (Mgwili & Watermeyer, 2006). The women also reported hostility directed at them, leaving them feeling as though their presence at the clinic was a problem.

The socio-economic status of persons with disabilities also affects access to health care services. In Zambia, it has been found that women with physical disabilities struggle to access health care services due to lack of assistive devices and lack of suitable transport (Smith et al., 2004). The study also found that access to health care was hampered by the attitude of the staff and health care facilities. For example, pregnant women with physical disabilities reported that they could physically access a health care centre, but were then referred on to a university hospital for labour and deliver as their disability made them ‘complicated cases’. The women in the study also reported feeling cautious about approaching health care services as they expected to encounter negative attitudes from the staff there.

3.3.9 Stigma and Social Isolation

Disability is a stigmatized experience, and as discussed in chapter 2, persons with disabilities are often the recipients of stigmatising attitudes and projections from non-

disabled persons. Stigma around disability impacts on the person's self-esteem. How persons with disabilities may be perceived by others, seems to be a significant issue. For example, in a study of men (White et al., 1992) and women (White et al., 1993) with physical disabilities following spinal cord injury, some of the most mentioned concerns of respondents were:

- Feeling sexually unattractive (49% of men and 51% of women);
- Others viewing them as sexually unattractive (47% of men and 51% of women); and
- Finding a partner (43% of men and 26% of women).

In a South African study on the sexual self-esteem of adolescents with physical disabilities following spinal cord injuries (Potgieter & Khan, 2005), similar concerns were found, where adolescents expressed ambivalent feelings about being sexually unattractive to others, feeling that attention from others would be out of pity for their disability, rather than showing romantic interest. The adolescents in their study reported on incidents where they felt rejected by able-bodied peers. In a study of physically disabled women in South Africa, it was reported that it was other person's view of them as disabled that was the worst (de Klerk & Ampousah, 2003). The women in the study reported that

in spite of their own feelings of self worth, satisfaction and well being, other people still see them as abnormal and maybe a little stupid (de Klerk & Ampousah, 2003, p. 1136)

De Klerk and Ampousah (2003) refer to various aspects of the self – the private, public, material and physical self. The authors conclude that the women with physical disabilities in their study had a positive sense of their “Private Self”, while their public self was more negatively influenced by others' opinions. However, if we look more closely at the comments made by the women in the study there is some indication of a compromised sense of self. For example, one woman comments that she likes “to compare myself with *normal* people” (p. 1137; italics inserted here for emphasis). Another states; “Sometimes I feel shy because I want to be like able people” (p. 1136). Such comments indicate a

sense of themselves as different. Women, it has been suggested, are perhaps most vulnerable to stigmatization, and being female as well as disabled is “often referred to as being doubly disabled” (Groce, 2003a, p. 9).

Low self-esteem in relation to attractiveness and sexuality has the potential for negative consequences in sexual behaviour. For example, women with physical disabilities in USA (Becker et al., 1997) have suggested that women may become sexually promiscuous as they become appreciative and accepting of any sexual attention received. They may also put up with some levels of abuse from their partners “because they feel they are lucky to have anyone who wants them” (Becker et al. 1997, p. S-30). Yousafzai and Edwards (2004) similarly found that young girls with disabilities felt less confident about negotiating safe sex than non-disabled peers, because of low self-esteem.

Stigma, and other issues related to the identity of persons with disabilities, may result in social isolation. Adolescents with physical disabilities have been found to be less popular at school than non-disabled peers, resulting in disabled adolescents being more socially isolated (Cheng & Udry, 2002). Women with disabilities have been reported as being isolated in social relationships, with disabled women being more likely to be unmarried, divorced or separated than disabled men and non-disabled men and women (Hanna & Rogovsky, 1991).

Kelly et al. (2002) found that children with (visual) disabilities are often confined to the home and isolated from other children and adults in the rest of the community. This was reportedly done by parents in an effort to protect their children from possible sexual abuse. Youth with disabilities are also often excluded from participating in social, cultural and religious activities and ‘rites of passage’ (Groce, 2003a). Such isolation increases disabled people’s barriers to accessing education, health care, and the development of supportive social relationships. Related to stigma and social isolation, is disabled people’s risk for suicide; it has been reported that youth with disabilities are more likely to have attempted suicide than non-disabled youth (Blum et al., 2001).

The stigma and social exclusion associated with disability, contributes to the difficulty in talking about sexuality, for persons with disabilities themselves. As Shakespeare (2000) states:

Sexuality, for disabled people, has been an area of distress, and exclusion, and self-doubt for so long, that it was sometimes easier not to consider it, than to engage with everything from which so many were excluded. Talking about sex and love relates to acceptance on a very basic level – both acceptance of oneself, and acceptance by significant others – and forces people to confront things which are threatening, given the abuse and isolated lives of many disabled people (p. 160).

In South Africa, Wazakili and colleagues (2006) found that the need to be loved among youth with physical disabilities, and their need to be accepted, was more important than having to practice safe sex.

3.4 The Global HIV/AIDS and Disability Survey

Yale University in partnership with the World Bank have conducted a global survey on HIV/AIDS and disability (Groce, 2004). The survey made use of snowball sampling. Survey questionnaires were initially emailed or posted to 2800 organisations. The questionnaire was also made available on various electronic newsletters and websites of various advocacy organisations. In addition the survey questionnaire was made available on a dedicated website for the global study. Groce (2004) estimated that the survey was reached by approximately 5000 to 6000 organisations and sites across the world. According to the published results so far, the response rates were not great, with only 476 completed surveys received, and a further 678 emails received with additional information (Groce, 2004). Responses came from 57 different countries from all continents. Forty-three percent of the surveys received came from Sub-Saharan Africa, the epicentre of the global HIV pandemic. Further data was obtained from a review of the literature, training manuals, and other resources relevant to HIV/AIDS and persons with disabilities.

The findings of the global survey reviewed below, are taken from publications by Groce (2003b; 2004; 2005). Some findings have already been commented on in the above sections of this chapter. The survey findings indicated that persons with disabilities were at significant risk for HIV infection across the world, with risk factors for HIV infection being increased for persons with disabilities. As discussed above, these are that disabled people are more likely to be poor, less educated, lacking in information and resources on safe sex, at greater vulnerability for sexual abuse and rape, possibly abusing substances at higher rates, experience limited access to health care facilities and services, and are “doubly stigmatized” for being HIV-positive and disabled. The survey found that disabled people are not being reached by general HIV prevention campaigns, as they lack the education to be fully able to obtain and process relevant information, and because information is inaccessible to persons with various disabilities (for example radio campaigns about HIV are not reached by the Deaf). The survey further found that disabled women and disabled members of minority groups are at particular risk, as they tend to be the most marginalized. The global survey found that HIV/AIDS was of an “immediate concern” (Groce, 2005, p. 222) to the large majority of organisations working with disability.

3.5 Conclusion

Despite a paucity of literature dealing specifically with HIV/AIDS and persons with disabilities, findings from literature on associated risk factors for persons with disabilities, indicate that they are at increased risk for HIV infection. As Groce (2004) points out, it is surprising that one of the world’s most marginalized and vulnerable populations, persons with disabilities, has been overlooked with regards HIV/AIDS. Perhaps a reason for this silence may stem from the emotional reaction that issues such as HIV, sexuality and disability evoke in people. The next chapter will explore a psychosocial framework for understanding how people (human service workers in particular) respond emotionally to working with HIV and working with disability.

CHAPTER FOUR

WORKING WITH HIV/AIDS AND PERSONS WITH DISABILITIES: A PSYCHOSOCIAL FRAMEWORK

4.1 Introduction

In chapter 2 I looked at literature relating to disability, and in chapter 3 I looked at HIV-related issues as it applies to persons with disabilities. Following from these previous chapters, this chapter provides a theoretical framework for understanding emotional responses to working with HIV/AIDS and persons with disabilities. It discusses the psychosocial framework used particularly in the analysis of data for the case studies in chapter seven. The chapter begins with a look at social construction, with a reference to the social constructions of HIV and disability. I then look at the notion of the psychosocial subject, that is an individual (and in this case, a research subject) that is both social and psychic. In order to understand this better I discuss the useful contribution of psychoanalytic theory as applied to understanding human service work and in particular the theories of the British psychoanalyst, Melanie Klein. The chapter ends by looking at how psychoanalytic theory can be used to understand emotional reactions to HIV/AIDS as well as disabilities.

4.2 Social Construction, HIV/AIDS and Disability

In Social Construction theory, reality, and what we know to be “true” about the world, is created or constructed through shared discourse and language (Bruner, 1991; Burr, 1995; Gergen, 1985; Wetherell & Maybin, 1996). It is not only reality that is created and constructed, but images and understandings of the self are also constructed socially through shared discourses. Burr (1995) explains:

All the 'objects' of our consciousness, including our 'self', our notion of what it means to be a person, and our own identity, are all constructed through language,

and that it is discourses as coherent systems of representation that produce these things for us (p. 56).

Shared social discourses are incorporated to shape our own identities and the identities of others. For example, the identity of “man” and “woman” are created through what is socially regarded as attributes and roles belonging to males and females. So our shared ideas and discourses of what the roles and characteristics associated with the male sex or female sex are used to construct an image of what it means to be a “man” or what it means to be a “woman”. Such constructions of the ‘self’ and the ‘other’ are continuously shaped through the prevailing, and changing, social discourses.

What we know about “HIV”, “AIDS” and the “HIV-positive person”, is also socially constructed through attributions made about the disease. Similarly, what we understand to be a “disabled person” is also socially constructed. The social model of disability draws on this perspective to argue that disability is not located in the individual, but rather in society’s constructions of the environment and what is considered to be “normal” and what is “abnormal”. This may also vary from one context to the other. For example Marks (1999a) illustrates how a person who is deaf may be considered to be severely disabled and excluded in one social context, while in another social context a person who is deaf is more integrated in society.

Susan Sontag (1991) has argued that HIV has emerged as the most stigmatized disease in recent history, with the greatest potential to spoil an identity (Goffman, 1963). Since its discovery in the early 1980s, HIV and AIDS has been attributed to deviant identities and outsiders, particularly homosexual men – HIV was for many years seen as a “gay disease” (Shilts, 1987). HIV and AIDS has been commonly (socially) regarded as a plague, associated with sin and evil (Sontag, 1991). Gilmore and Somerville (1994) discuss how socially constructed metaphors of HIV and AIDS (metaphors of HIV/AIDS as punishment; crime; death; war; as otherness; as villain; and as horror), are used by society to understand the disease and those affected. In South Africa, as with the rest of

the world, HIV/AIDS campaigns have generally constructed and portrayed HIV/AIDS as resulting from deviance (Joffe, 1995).

As with HIV/AIDS, impairments and disabilities are also the recipients of stigma (Susman, 1994). Goffman (1963) discussed “abominations of the body” (p.14) as a type of stigma, referring to physical deformities, abnormalities and impairments. An individual impairment or “abnormality” becomes labelled as different and deviant, creating (as with HIV) a “spoiled identity”. More recent theorists on stigma (Alonzo & Reynolds, 1995; Gilmore & Somerville, 1994) argue that stigma serves as a socially constructed inequality, reinforcing what is considered to be acceptable, and excluding what is found to be deviant and unacceptable.

Hollway and Jefferson (2000) argue that a social constructionist view of the self does not fully account for a diversity of experiences among individuals in similar contexts, and individuals whose identities one would expect to have been constructed similarly. They support their argument through research on the experience of fear of crime in a particular community, finding differing experiences of the fear of crime by members of the same community – some individuals felt more vulnerable and fearful of crime in the area than others, using different constructions of the severity of crime. Hollway and Jefferson (2000) argue that people make use of varying social discourses to position themselves in particular relations to others. They embed a view of the person as influenced by personal individual development within a broader social constructionist framework. They refer to the self as a ‘defended subject’, arguing that individuals draw on particular social discourses in order to defend themselves emotionally against constructions that threaten the self. They draw on postmodern psychoanalytic theory, combining psychoanalytic theory with social constructionist theories of discourse analysis, to argue that individuals are both psychic and social – they are psychosocial subjects (Hollway, 2001; Hollway & Jefferson, 2000), rather than merely socially constructed.

4.3 The Psychosocial Subject

As mentioned above, Hollway and Jefferson (2000) argue that a socially constructed view of the self does not fully take into account the diversity of experience among subjects. They argue that researchers “need to account for individual differences in the way in which people make sense of available information; that is, the discourse or systems of meaning within which they may be positioned”(Hollway & Jefferson, 2000, p. 15).

In referring to the notion of the ‘defended subject’, Hollway and Jefferson (2000) draw on psychoanalytic theory to argue that social constructions about identities may create a threat to the self creating anxiety, which precipitates the use of unconscious defence mechanisms in an effort to protect the self against this threat. Psychoanalytic theory proposes that a dynamic unconscious defends against anxiety through unconscious defence mechanisms – for example by means of denial.

Some may be puzzled by the use of psychoanalytic theory to understand social issues, such as HIV and disability. Psychoanalysis is commonly understood as an individual psychology, and not always thought to be relevant to such social issues. It may be worth pausing at this point, to explore debates concerning the usefulness of psychoanalytic theory to understand human reaction to HIV and disability.

4.4 Why Psychoanalysis?

Psychoanalysis, as a theory for understanding ‘inner’ emotional processes, has been incorporated, by some theorists, with discursive psychology, to allow for a more critical understanding of how individuals use discourse to express both conscious and unconscious emotion and experience (Billig, 1997; 2006; Frosh, Phoenix & Pattman, 2003). Billig (1997) points out how discursive psychology and psychoanalysis are at first glance seen to be incompatible. Discursive psychology understands psychological phenomena to be socially constructed through discourse, and does not encourage exploration of ‘inner’ experience, which is “hypothetical, and essentially unobservable” (Billig, 1997, p. 140). Psychoanalysis, on the other hand, often understands social activity to be expressions of internal, unobservable emotional forces; it “presumes that hidden,

unconscious motive-forces lie behind the surface of social life” (Billig, 1997, p. 140). However, Billig (1997) argues that there is a “dialogical unconscious”, where dialogue or discourse also includes a repressive component as well as an expressive one; that is discourse constructs and reproduces the more conscious and moral social norms, as well as repressing the more unconscious and ‘immoral’ motivations (Billig 1997). The focus of a discourse analysis is to observe how individuals make sense of and explain the social world. But, as Billig (2006) argues, what is unsaid can be as important as what is said. Psychoanalysis also allows one to consider why individuals are (emotionally) invested in particular social discourses to the exclusion of others (Frosh et al., 2003; Hollway & Jefferson 2000).

4.5 Psychoanalysis as a Method for Understanding Anxieties in Human Service Work

Psychoanalysis is considered by many to be an individual psychology, and indeed has been criticized, amongst other things, for being individualistic, a-social, and Western in its thinking (Frosh, 1999). However, psychoanalysis as a theory and method has a rich and diverse history of application to social contexts and group dynamics.

4.5.1 Foundations of a Social Psychoanalysis

Earlier theorists, such as Bion (1961) developed a psychoanalytic approach to understanding group functioning. Bion drew on the psychoanalytic theories of Melanie Klein to show how members of a group develop an unconscious group dynamic, where the group may operate defensively when there is increased anxiety. Klein’s theoretical contribution will be discussed in more detail in section 4.6 below. Bion (1961) showed how, in moments of anxiety, the members of the group may collectively take a defensive position in an effort to protect themselves against this increased anxiety. Bion (1961) noted two levels at which the group operated. On the first level, the primary task of the group, the group has a rational, conscious focus on a particular task or purpose for the group. At a second level, what he termed the ‘basic assumption’ group, members are united as group in an unconscious activity that may work counter to its primary task – the group may become dependent on the leader for support and comfort thus sustaining the

existence of the group, or the group may produce a hope in a person or idea that will come and ‘save’ or help the group, or the group may start to fight or avoid a perceived threat in the group. While the group operates in these defensive ways, it provides relief to anxiety, becoming the ongoing work of the group, while acting as a distraction from the primary task or purpose of the group (Hinshelwood & Chiesa, 2002).

Trist (1950/1990) introduced the notion of institutional ‘culture’ as a psychosocial system, linking sociological aspects of the institution, with psychological processes of the institution’s members. Conscious and unconscious psychological forces interact with the sociological and structural forces of the institution, combining to create a dynamic pattern or ‘culture’. Trist (1950/1990) states that culture consists of a “variety of psycho-social patterns which persons and groups actively operate in order to take roles and make relationships in the institutionalized social systems of their society” (p. 544). He cited rituals, customs, strategies and attitudes as examples of ‘culture’. His ideas provide us with the means to think about an institutional culture that operates at an unconscious level, experienced by individuals but influences the pattern of interaction and operation in institutions (Gibson, 2002). Trist’s ideas were developed further by Jaques (1953; 1955), who understood that institutions may be used by their members to develop shared organizational patterns that work as a defence against shared individual anxieties. He draws on Klein’s psychoanalytic theory, and the defence mechanisms such as ‘denial’, and ‘projection’ to argue that individuals in an unconscious attempt to defend against anxiety, may create defensive processes within the organization.

4.5.2 Psychoanalytic Theory Applied to Human Service Organisations

Psychoanalytic theory applied to the understanding of group dynamics has been used to understand the emotional experiences of people working in human service organizations (for example hospitals). This body of work is relevant for understanding the emotional experience of people working with disability, often involving service and care work.

The influential case study work of Menzies (1960), later known as Menzies Lyth, provides an illustration of the ideas of Jaques (1953; 1955). She conducted a study of the

practices of nurses in a general hospital, and demonstrated how nurses developed ritualized tasks in their nursing work as a defence against the anxiety evoked by working with sick and 'damaged' patients. Nurses would conduct ritualized tasks, which were divided amongst the nurses, allowing nurses to only have a part experience of the patients, rather than a more holistic relationship with the patients. For example, one nurse would be chosen to make the beds on the ward. These tasks were allocated to the nurses, with specific instructions on how to carry them out. In this way, the nature of the work functioned as a defence against anxiety by splitting up the nurses' contact with the patient. In addition, the regulation of tasks allowed nurses to have a detached emotional experience to their work – they would be performing a specific task, rather than relating to the patient as a whole.

Since these early works, there have been numerous works on understanding human service organizations from a psychoanalytic approach internationally (Hinshelwood & Skogstad, 2000a; Obholzer & Roberts, 1994), as well as in South Africa (Gibson, 2002; Gibson & Swartz, 2001; Swartz, Gibson & Gelman, 2002; van der Walt & Swartz, 1999; 2002). In South Africa, for example, Van der Walt and Swartz (1999; 2002) use the observations of Menzies Lyth to discuss how nurses within the public health care system use a task-orientated approach to their work in an effort to defend against anxiety.

Roberts (1994) argues that human service work has the potential to evoke powerful unconscious anxieties in staff, related to working with 'damaged' patients and clients. She argues that those who chose to work in such professions are often drawn there by an unconscious need to make 'reparation' for their potential to harm. She draws this thinking from Klein's understanding of the infant's development from a split emotional experience of the mother as nurturing and loving in times of feeding, and frustrating and hostile in times of hunger. When the infant matures and is able to have a more ambivalent experience of the mother as both nurturing and frustrating, the infant feels unconscious guilt for its past hatred and unconscious aggression towards the frustrating mother (see a more detailed discussion in section 4.6 below). For an infant these are overwhelming feelings, that it does not have the capacity to understand and work through, and are

instead defended against. These feelings linger, however, in us as adults – they are remnants of, what is referred to in psychoanalysis, as ‘primitive anxieties’. Thus, according to Roberts (1994), the human service care worker would be drawn to care work, in an unconscious attempt to alleviate these primitive anxieties of aggression, hatred and guilt, by making ‘reparation’ through helping and ‘fixing’ hurt and damage in others. Roberts (1994) refers to this as the “self-assigned impossible task” (p. 110), as workers are inevitably frustrated by the frequent failure to cure and repair damaged patients and clients.

The care worker also brings with him or her, the hope and expectation to not do harm to the client, but rather to be helpful, tolerant and understanding (Salzberger-Wittenberg, 1970). This raises fear and anxiety, as so often care work involves intrusive, emotionally and physically painful treatments. A good example is shown in the observations by Frenkel (2002) of nurses working in a burns unit of a children’s hospital in South Africa. Part of the nurses work involved very painful, but necessary, procedures of changing bandages and conducting skin grafts of burn wounds. This was extremely painful for the children, and was a source of intense anxiety for the nurses. The nurses defended against this through unconscious processes of depersonalisation and detachment, and a denial of feelings, so that the nurses over time would end up performing this task efficiently and with a perception of being “used to it”.

In addition to the anxieties of the staff in human service professions, very often there are projections of distress from the patients and clients own experiences (Gibson, Swartz & Sandenbergh, 2002; Moylan, 1994; Salzberger-Wittenberg, 1970), which may lead to what Moylan (1994) refers to as ‘contagion’, where the staff struggle to cope with the pain instilled in them by the client. Instances of vicarious or secondary trauma (Gibson, Swartz & Sandenbergh, 2002) would be examples of this, where care workers are themselves traumatized by the experience of trauma in their clients or patients.

Much of the work discussed above, draws on the psychoanalytic theory of Melanie Klein (1959; 1997). In order to understand some of what is meant by anxiety and defences, and

the unconscious emotional experience of human service work, it is necessary to explore briefly some of Klein's theory.

4.6 The Psychoanalytic Theory of Melanie Klein and the Defended Subject

Melanie Klein has been one of the more influential thinkers in psychoanalysis. However, her ideas are not easy to grasp, and she tends to use jargon which many find unpalatable. One of the more influential ideas developed by Klein involve her developmental understanding of the self. Klein speaks of defensive positions that occur during the first years of an individual's life – what she has termed the 'paranoid-schizoid position', and the 'depressive position'. People unfamiliar with the theories of Klein may interpret such terminology as referring to 'madness' (by using phrases such as "paranoid" and "schizoid") or to the mental illness 'depression'. However, Klein used these terms to refer to the infant's unconscious emotional response to its environment.

4.6.1 The Paranoid-Schizoid Position

Klein (1959; 1997), from clinical observations with patients, argues that the early experience of the infant involves anxiety arising out of his or her dependence on the primary care-giver (usually the mother). The infant is governed by its internal sensory experience, and because it has not yet acquired an understanding of space and time, cannot tolerate the sensory experience of hunger with the expectation or knowledge that it will soon be fed. Thus, the infant has separate polarized sensations and emotions when hungry (frustrated) and when fed (satisfied). The infant in turn is not yet able to experience the mother as a separate, whole person, only having a part experience of her. Klein speaks of the infant's experience of the mother as a relationship to the breast – so the infant has a polarized experience of the mother; experiencing her as a frustrating, hated object (breast) when hungry and frustrated, and a separate nurturing, loved object (breast) when fed and satisfied. When the mother feeds the infant, the feelings of hunger are gradually satisfied. The infant takes in (or incorporates) the feelings of goodness and nurturance of the mother as his own, and the infant has a good experience of self, and the mother is experienced as 'good'. When the infant is hungry and frustrated, the sensation of hunger is attributed to the withholding breast of the mother. So the 'bad' internal

feelings (hunger pains, frustration) are projected onto the withholding breast/mother and so the mother is perceived as 'bad' (frustrating and hurtful). This split experience of the mother serves as a defence function – the 'bad' experience of the mother is split off and kept separate from the 'good' mother (and self). The term 'schizoid' is used to refer to the fragmented mental state of experiencing the environment as part objects, while the term 'paranoid' is used to describe the persecutory feelings associated with the frustrating 'bad' object (Hinshelwood, 1991).

4.6.2 The Depressive Position

As the infant matures, it begins to experience its mother as a whole object, and the mother becomes both the 'good', nurturing mother, as well as the 'bad', withholding mother. The infant is now better able to tolerate these ambivalent feelings, and so does not have a split experience of the mother (and self). Klein referred to this as the *depressive* position, because she theorized that the infant, aware now that the mother is both 'good' and 'bad', feels unconsciously guilty (and sad) for the hatred felt towards the mother when previously frustrated. What may result is an unconscious wish to make reparation for the 'damage' caused by the aggression felt towards the 'bad' mother of the paranoid-schizoid position. These are the ideas that Roberts (1994) draws on when arguing that individuals may be drawn to human service work in an unconscious wish to 'repair damage'.

Although these positions are understood as following a developmental sequence, they are not considered to be developmental stages, as an individual may continue to use these defensive positions throughout their lives, particularly during times of stress (Segal, 1992). In moments of stress, an individual may move into a paranoid-schizoid position, defending their experience of a 'good' self from 'bad' experience. There is then a splitting of the ego, where the 'bad' parts of the self are split off and projected onto an object (or person), thus attributed as belonging to others. This mechanism allows us to understand the more irrational aspects of 'othering' (Frosh, 2002). For example, a white racist may feel fear and an aversion when in the presence of a black person, this fear is then projected out, in an effort to protect the 'good' self, and the black person is then

perceived as threatening. The black person becomes the object of blame for the feeling of fear, rather than the fear being acknowledged as belonging to the irrational, racist assumptions of the white person. At other times we operate from the depressive position and are able to acknowledge both good and bad aspects in ourselves and in others.

4.6.3 The Defended Subject

This brings us back to the psychosocial subject and Hollway and Jefferson (2000), who draw on the psychoanalytic theories of Klein to understand how individuals position themselves in relation to particular social discourses. Social constructionist theory argues that individuals create an image and understanding of themselves and others through shared discourses that prevail in society. We draw on social discourses to create an understanding of objects and people. For example, we may draw on various discourses such as discourses of sexuality, morality and relationships, as well as images and representations, to construct an image and understanding of a 'lesbian woman'. What Hollway and Jefferson (2000) argue, however, is that people make use of a variety of social discourses, drawing on particular discourses, and not others, in order to position themselves in a particular relationship to others. Thus one person may draw on particular social discourses to construct a negative understanding of 'lesbian woman', while another person may draw on other discourses to construct a more positive understanding of 'lesbian woman'. Individuals may invest in certain discourses in order to defend themselves against threats to the self – individuals are thus 'defended subject'.

4.7 A Psychoanalytic Approach to Understanding Anxieties in Working with HIV/AIDS and Disability

4.7.1 HIV and AIDS

A psychosocial exploration, using psychoanalytic theory, has been used to understand how individuals position themselves in relation to construction of risk for HIV infection (Joffe, 1999; Rohleder, 2007; Rohleder & Gibson, 2006). Joffe (1999), using the psychoanalytic theory of Klein argues how individuals position themselves in relation to construction of HIV-risk in an attempt to defend against threats to the self.

With transmittable diseases such as HIV, fears arise for the individual of their body being invaded or penetrated and polluted by viruses. Joffe (1999) argues that with such intense fears, individuals need to “draw a distinction between ‘us’ and ‘them’” (p. 23). This can be seen, for example, in the account by Shilts (1987) of the first few years of the HIV epidemic in the United States. He documents a sustained slow response in addressing the epidemic at public health level in the first few years of the epidemic, as the disease was perceived to be a largely ‘gay disease’ and a disease affecting other deviants, such as injecting drug-users and prostitutes, and not a disease affecting ‘the general population’. Until the death of actor Rock Hudson from AIDS in 1985, HIV/AIDS was not regarded as an urgent concern for the general population, despite the fact that up till then 12 000 American men and women had already died from AIDS-related illnesses. Treichler (1999) refers to the ‘4-H list’ which was initially constructed around high-risk categories in USA: Homosexuals, Haitians, heroin addicts and haemophiliacs. She argued that such a construction of risk-group, “contributed to the view that the major risk factor in acquiring AIDS is being a particular kind of person rather than doing particular things” (p. 20).

Joffe (1999) uses psychoanalytic theory to show how individuals position themselves in relation to social representations of HIV as a defence against threats to the self. She draws on Kleinian theory to show how, in relation to perception of HIV risk we tend to split of ‘bad’ aspects of ourselves onto others, who then come to represent those affected by HIV/AIDS. As discussed above, when a person’s self feels threatened, it arouses anxieties, and the individual may begin to function from what is referred to as the paranoid-schizoid position, splitting reality into ‘good’ and ‘bad’. Joffe (1995; 1999) shows how representations of AIDS are constructed as being a disease originating from the ‘Other’; it is represented as being foreign and affecting outsiders. It is also associated with deviant and perverse practices. Representing AIDS as a disease that affects “others”, functions as a defence against the anxiety and fear of being at risk for infection. Thus HIV/AIDS is seen as affecting “others” and “not me”.

Treichler (1999) argues that such splits in representations of HIV are fuelled by existing divisions in societies. She states:

The reproduction in AIDS discourse of existing social divisions appears to be virtually universal, whether it is white or black AIDS, gay or straight AIDS, European or African AIDS, wet or hot AIDS, East or West German AIDS, central or west African AIDS, foreign or native AIDS, or guilty or innocent AIDS (p. 116)

I have argued elsewhere that in South Africa, similar splits in representations and understanding of HIV/AIDS exist around racial identity and politics (Rohleder, 2007). Not only do these unconscious defensive processes occur in relation to risk for HIV, but when an individual becomes HIV-positive, and has to incorporate these split of constructions around deviance and blame, he or she may attempt to defend against this threat to the self, by once again splitting unwanted attributes on to others (Rohleder, 2007; Rohleder & Gibson, 2006; Soskolne, Stein, & Gibson, 2004).

For human service staff working with HIV, these constructions around HIV/AIDS evoke anxiety in them. Health workers working with HIV-positive patients have reported feeling anxious that people will perceive them as being HIV-positive themselves, because of their association with HIV-positive and AIDS patients (Kahn, 2003; Rohleder, 2003). Working with HIV-positive and AIDS patients may require engaging with intimate topics such as sex, dying and death; topics that may be emotionally difficult and stressful for the health care worker (Buwalda, Kruijthoff, De Bruyn, & Hogewoning, 1994). In the case of AIDS patients, because there is currently no cure for AIDS, the inability for the health care worker to 'cure' and 'save' the patients may cause the health care worker to feel anxious and helpless (Brugha, 1994; Kahn, 2003; Rohleder, 2003). In addition, health care workers may also be anxious with regards their own risk for HIV infection in working with AIDS patients (Rohleder, 2003). Kahn (2003) and Rohleder (2003) illustrate how health care workers and counsellors struggle to manage these anxieties, and have an ambivalent account of their work, alternating between positive and negative

(good and bad) experiences of their work. In an organizational context managing the emotions in working with HIV/AIDS patients, may be managed by a task-orientated approach to nursing and medical care (Rohleder & Swartz, 2005) and splitting off the emotional, holistic component of care work within the organizational structure – counsellors are then positioned in the organization as the emotional container, but, perhaps given the incurable nature of AIDS, this work may then be denigrated, and HIV counsellors may be marginalized among health care staff (Rohleder & Swartz, 2005).

4.7.2 Disability

As with HIV, disability (as discussed briefly in Chapter 2) also evokes powerful anxieties in the self, which precipitates unconscious defence mechanisms in an attempt to manage these anxieties and fears.

Disability carries with it numerous socially constructed attributes. As discussed in Chapter 3, persons with disabilities are often regarded as innocent and asexual or sexually inappropriate, even dangerous. Persons with disabilities are also often regarded as being passive, dependent and needing to be protected (Marks 1999a). What was considered as normal, in terms of able-bodies and disabled-bodies, became an increased concern during the industrialization of societies (Marks 1999a; Oliver, 1993), as a mechanised, uniform work force was required. With industrialization, also came the creation of unproductive and therefore economically dependent (disabled) people who were contained in specialised institutions and workhouses (Oliver, 1993). Thus Oliver (1993) sees the ‘dependency’ of disabled people as being socially constructed.

Marks (1999a) provides a review of the historical representations of persons with disability. For example, in the Middle Ages disabled people were seen with superstition as the conditions were perceived to be as a result of divine punishment for a sin (similar metaphors as exist for HIV today). In later years, disabled people were seen as ‘freaks’, to be exhibited to the public at shows – the ‘Elephant Man’ being a famous example of this. There is also the disturbing history of eugenics, euthanasia and the systematic murder of disabled people in Nazi Germany. This points to the revulsion expressed

towards disabled people, seen as sub-human monsters. Things are much different in modern day, however the response (often unconscious) of deformity and monstrosity towards disabled people still prevail. Marks (1999a) argues how “existential and developmental fears about monstrosity and stupidity can be projected onto disabled people, who are then experienced as threatening or pitiful” (p. 23). People would then tend to avoid disabled people so as not to be reminded of these disavowed aspects.

As discussed in chapter 2, unacceptable parts of the self, such as dependency, physical imperfections and damage, vulnerability and mortality, are split off and located in the person with disability (Marks, 1999a; Shakespeare, 1994; Watermeyer, 2006). This is done in an attempt to protect the self against the threats of such aspects of our identity. Watermeyer (2006) points out how we have all at some stage of our lives had experience of vulnerability, dependence, shame and rejection, inadequacy, feeling undesirable, ugly and unacceptable. He goes on to argue that

By constructing and regarding disabled people as broken, damaged, defective and dysfunctional, members of the broader nondisabled society are able to reaffirm and reinforce an identity of being the opposite of those unwanted characteristics (Watermeyer, 2006, pp. 33-34).

In interactions with persons with disabilities, non-disabled people may become uncomfortable and anxious, what Goffman (1963) refers to as ‘sticky interactions’, as we experience things in the interaction that feel unmanageable. These anxieties are then managed defensively, through mechanisms such as splitting, projection and idealization (Marks 1999a; Watermeyer, 2006). Splitting and projection has already been discussed where non-disabled people may split off unwanted aspects of themselves, and projecting them into persons with disabilities, who then become representatives of these unwanted aspects (e.g. dependent, damaged, dysfunctional). There may also be a process of idealization where the disabled person is attributed with excessive positive aspects and admiration. Watermeyer (2006) uses the example of the movie *Scent of a Women*,

indicating the admiration of the central character's achievements despite or perhaps because of his blindness.

Working with persons with disabilities involves working with 'damaged' clients, evoking anxieties in care workers and human service workers who are unable to repair such damage. As stated by Sinason (1992):

when it comes to children and adults who are severely handicapped, professionals can sometimes shut their eyes and go stupid not just because it is painful, but because it is unbearable to see damage and not be able to repair it, not be able to put it right. (p. 36)

This is unbearable for the care worker, who is often drawn to this human service work with an unconscious wish to make reparations for damage (Roberts, 1994). This often leads to feelings of inadequacy in health care staff in facing the degree of damage and the limits to what they can do about it (Mawson, 1994). As Mawson (1994) found, this may lead to feelings of despair and depression. The 'unrepairable' aspect of some disability impacts on some of the perceived primary tasks of certain professions. For example, Obholzer (1994) observes at a school for physically disabled youth, how teachers, who generally understand their role to be one of developing skills and competencies for future adult lives, had to face the reality that much of what they taught would not be used in this way.

Human service work often evokes conflicting feelings of caring and helpfulness on the one hand and more destructive feelings of disgust and anger on the other hand (Hinshelwood & Skogstad, 2000b). In working with disabled people, care workers may have an ambivalent emotional experience, having both caring feelings with a wish to help and repair and feelings of anger and frustration at their inability not to. It is difficult to hold these feelings at the same time for the same person, so staff may unconsciously deny the more destructive feelings, projecting them on to others, who are then blamed for things not working (Zissis, 1999).

Psychoanalysis then, provides us with a useful theoretical lens in which to understand, and identify, some of the internal emotional experience of HIV illness and disability, and the powerful process of othering that can result as individuals (and society) attempt to manage the anxieties and fears that 'illness', 'disease' and 'damage' evokes. This may be a useful framework to use to understand some of the underlying anxieties and difficulties around providing HIV prevention education for persons with disabilities. Given the results of the World Bank/Yale University Global Survey on HIV/AIDS and Disability (see chapter 3), it is likely that disabled people in South Africa have been generally excluded from HIV prevention campaigns. A psychoanalytic framework may help to explore why there may be difficulties and even resistance to providing HIV and sex education.

4.8 Conclusion

In this chapter, I began by exploring some of the constructions around HIV/AIDS as well as disabilities, from a social constructionist perspective. However, social constructionist theory does not fully encapsulate how different individuals draw on various social discourses to have differing experiences within the same contexts. Discursive psychology does not take fully into account internal emotional experience of social reality.

Psychoanalytic theory has been used by critical discursive psychologists as a useful framework for understanding some of the more irrational emotional responses to social realities. The chapter discussed the notion of a psychosocial, defended subject – a person that is both social and psychic, and showed how HIV/AIDS as well as disabilities are not only socially constructed, but evoke powerful emotional reactions in us, as we associate HIV/AIDS as well as disability, with 'disease', 'damage' and 'monstrosity'. This forms the framework from which the qualitative data in this dissertation is analysed, which will be discussed in more detail alongside the quantitative methods, in the next chapter.

CHAPTER FIVE

METHOD

5.1 Introduction

In this chapter I give an outline of the methodology used in this research. I begin by reviewing the aim of the study and the key research questions. I go on to describe the research approach, discussing both the use of a quantitative method, and a qualitative method using a psychoanalytic framework of analysis. I will outline how the sample was identified, and how the data was collected, using both quantitative and qualitative methods. Finally, I shall describe the approach I used in the analysis of the data material collected, and discuss some important ethical considerations.

5.2 The Aims of the Research

This research aimed to study:

1. The extent to which organizations working with disabled persons are dealing with HIV/AIDS, and,
2. How they are dealing with it.

In terms of the Integrated National Disability Strategy (INDS) (Government of the Republic of South Africa, 1997), Disabled People's Organizations (DPOs) in concert with the Office on the Status of Disabled Persons (OSDP) nationally and in the provinces, are tasked with providing and coordinating services for disabled people.

At the time that this study was initiated, there existed no comprehensive study exploring how these organizations are responding to the HIV epidemic. The study would thus be an exploratory one, attempting to find out how organizations are responding to the HIV epidemic, and to what extent persons with disabilities are excluded or included in HIV

prevention campaigns. The study thus aimed to answer the following key research questions:

1. Do the organizations consider HIV to be a significant problem for disabled persons? If yes, why? If not, why not?
2. What, if any, interventions have been provided to address HIV for the population they serve?

Given the international literature, and from informal conversations with people active in the disability field, it was hypothesized that there has been limited response to the HIV epidemic as it affects disabled people. Thus a further aim of the study was to explore what some of the reasons may be for a limited intervention with persons with disabilities, and to specifically ask:

1. What anxieties are expressed by various care-workers at organizations regarding HIV, sexuality and disability?

As little is known about HIV and persons with disabilities in South Africa, such exploration would provide invaluable data for future research.

5.3 The Research Approach

This study makes use of a combination of quantitative and qualitative research methods. This is an unusual approach, in that research studies typically tend to rely on either quantitative or qualitative methods, with one being seen as incompatible with the other. I have made use of a combined approach, as I believe it may provide a more comprehensive exploratory and descriptive picture of an area in which there is very little known; HIV/AIDS as it affects persons with disabilities. Using a combined approach provides a variety of perspectives from which to explore HIV/AIDS and disability, providing a deeper understanding of issues that would perhaps be achieved if only one or other method was used. It was considered useful to attempt to find out as much as

possible in one study in order to learn about the issues involved and form the basis of understanding for how to move forward.

The use of combined quantitative and qualitative research methods has been supported by some theorists, who argue that using a combination of approaches attempts to help compensate for some of the weaknesses of individual qualitative and quantitative methods (Connidis, 1983; Steckler, McLeroy, Goodman, Bird, & McCormick, 1992). In this way it allows for the triangulation of results. Steckler and colleagues (1992) have argued that health education and promotion programmes, for example, “are complex phenomena which require the application of multiple methodologies in order to properly understand or evaluate them” (Steckler et al., 1992, p. 4). This is worth considering in this study which focuses on issues of health education, namely educating persons with disabilities on issues related to sex, sexuality and HIV/AIDS.

Steckler and colleagues (1992) outline four possible approaches to integrating quantitative and qualitative methods:

1. Qualitative methods are first used in order to help develop and construct quantitative research measures. For example, conducting a focus group interview to gather data that will help in the development of a quantitative survey questionnaire.
2. Qualitative methods are used to support and help in understanding a predominantly quantitative research study. For example the inclusion of open-ended questions that will provide further information on closed-ended questions in a survey questionnaire.
3. Quantitative methods are used to support the findings of a qualitative study. For example, administering a survey questionnaire to members of an in-depth ethnographic study.
4. Both quantitative and qualitative methods are used equally and in parallel to one another, and the results of both are compared and evaluated against each other.

For this study I have used a combination of the second and fourth approach. As this is an exploratory study into an under-researched area that deals with health education and promotion, HIV and persons with disabilities, I expected that it would be a complex phenomenon that required multiple ways of understanding it. For this study I will use a combination of a survey methodology and a case study methodology.

5.3.1 Quantitative Survey

One part of the study used an existing survey questionnaire (see further description below), which used predominantly quantitative methods for gathering data, through a variety of closed-ended questions. The survey questionnaire also contained open-ended questions which allowed respondents to elaborate on the answers given in closed-ended questions.

A survey is very useful in this study as it allows me to gain an overall picture of what is happening with regards HIV/AIDS prevention and education with persons with disabilities. Very little is known about this, so a survey questionnaire permits me to gather masses of information from a wide source. However, survey research does have its limitations. Some of the criticisms levelled at survey research include the arguments that surveys are unable to uncover the deeper meanings of social actions, looking at particular actions and beliefs rather than the social context, and “neglect the role of human consciousness” (De Vaus, 1996, p. 8). De Vaus (1996) argues that criticisms such as these can be addressed through proper survey design, by the inclusion of questions that aim to provide data to some of these deeper and situated meanings. However, I did use as a point of departure the argument that surveys provide a limited set of data, relying on what detail respondents choose to give to various questions. As the survey was to be administered by post and email, it also did not provide the opportunity for me as researcher to easily ask respondents to elaborate on answers given in the questionnaire, as would be the case in an interview-administered survey, for example.

A qualitative case study would allow me the opportunity to explore some of the deeper issues that may be involved in HIV prevention for persons with disabilities, allowing me also to explore the context in which action takes place.

5.3.2 Case Study Methodology

A case study allows one to investigate a phenomenon within its context (Hartley, 2004; Yin, 1993). Case studies allow for “*thick description*” (Stake, 2000, p. 439) that researchers use to explore, explain and describe a phenomenon in its context (Yin, 1993). As described by Hartley (1994):

Case study research consists of a detailed investigation, often with data collected over a period of time, of one or more organizations, or groups, within organizations, with a view to providing an analysis of the context and processes involved in the phenomenon under study (pp. 208-209)

Case study is not regarded as a methodology, but rather as a research strategy, which would generally use multiple methods, either qualitative or quantitative (Hartley, 1994; 2004). The theoretical foundation is key to the case study. Hartley (2004) argues that a case study “cannot be defined through its research methods. Rather, it has to be defined in terms of its theoretical orientation” (p. 324). Case studies have typically been used to understand organizational phenomena and experiences, from within a variety of frameworks, including psychoanalytic (see for example, Gibson, 2002; Hinshelwood & Skogstad, 2000a; Obholzer & Roberts, 1994). My interest in this study of exploring the anxieties of staff working with disabilities, around issues of sex, sexuality and HIV, using psychoanalytic theory as a framework for understanding, therefore makes the use of case studies a suitable approach.

Case studies generally employ a variety of methods for gathering data, including interviews, documents, observation, focus groups and questionnaires. This allows for the exploration of multiple perspectives, and for the triangulation of results (Hartley 1994; 2004; Stake, 2000). I have made use of the narrative interview, focus group interviews,

responses from the survey questionnaire, and, in one case, participant observation as the method of data collection (see below).

Case study research may make use of either single case studies or multiple case studies. I have chosen to use a multiple case study research, using three studies to investigate a phenomenon (the experience of staff around working with sexuality and HIV with disabled persons) across different context. This approach Stake (2000) refers to as ‘collective case studies’. Rather than analyse the experience of staff within a particular context from a psychoanalytic framework, using multiple case studies, allows me to attempt to generalize the analysis to other cases. As Stake (2000) points out, the pursuit of atypical features in single cases limits the “study of the generalizable” (p. 439).

Stake (2000) also points out the importance of recognizing that case studies are interpretive, that is, the researcher is actively involved in how the story of the case is told. The researcher enters the case with an expectation of finding certain events, experiences and problems. Researchers might discover phenomena that are different to what is expected. But what Stake (2000) argues is that the researcher cannot know, nor report the *full story*, and so decides what the focus of the story is, what is included in the reporting of it and what is excluded, and that “less will be reported than was learned” (p. 441). This is most relevant to the actual writing up of the case. As Stake (2000) states:

In private and personal ways, ideas are structured, highlighted, subordinated, connected, embedded *in* contexts, embedded *with* illustration, laced with favour and doubt. However moved to share ideas, however clever and elaborate their writings, case researchers, like others, pass along to readers some of their personal meanings of events and relationship – and fail to pass along others. They know that the reader, too, will add and subtract, invent and shape – reconstructing the knowledge in ways that leave it differently connected and more likely to be personally useful. (pp. 442-443)

This is fitting to a social constructionist framework, where reality is understood as being constructed through shared meaning and discourse (Bruner, 1991; Burr, 1995; Wetherell & Maybin, 1996). Thus the researcher is actively involved in the construction of meaning. Likewise using a psychoanalytic framework for further analysis, makes use of the researchers own emotional experience as a source for understanding data (see below).

5.4 Method of Data Gathering

Both quantitative and qualitative methods were used to investigate organisations' response to HIV for persons with disabilities. I shall outline the method used for data gathering for the quantitative study and the qualitative study separately.

5.4.1 Quantitative Survey

5.4.1.1 The Survey Questionnaire

Prof. Nora Groce (at Yale University), in collaboration with The World Bank, are involved in a global survey on HIV/AIDS and disability, discussed in *HIV/AIDS and Disability: Capturing Hidden Voices* (Groce, 2004). Prof. Groce granted permission for me to use this questionnaire as the quantitative instrument in my research (the questionnaire, as it was used, is attached as Addendum A).

The survey questionnaire makes use of a combination of closed and open-ended questions, and is divided into various sections. The first section asks the participant to fill in some background information about the organization, including contact details, and the nature of the organization and population served. Thereafter questions are asked in four main parts:

Part I: This section asks the respondent to answer questions related to awareness around risk for HIV/AIDS; awareness both on the part of the person completing the questionnaire (as a representative of the organization) and what they perceive to be the level of perceived awareness of the disabled people the organization serves.

Part II: This section asks questions regarding the extent to which education around HIV and issues related to HIV are provided by the organization themselves and other organizations of and for disabled people. Questions also ask for information about HIV education programmes.

Part III: This section asks questions about the extent to which non-disability organizations are providing education related to HIV and issues related to HIV. Questions also ask the participant to assess to what extent he or she feels that disabled people are excluded from general HIV prevention programmes.

Part IV: This section asks questions regarding the amount of assistance and support received by disabled people in relation to HIV/AIDS. It asks to what extent disabled people are able to access HIV testing and health care. Respondents are also given the opportunity to provide additional comments or observations.

The survey questionnaire was used in various countries across all five continents in the World Bank Global Survey on HIV/AIDS and Disability. As part of the global survey, the questionnaire had previously been sent to national level organizations in Southern African countries, and was therefore seen as appropriate for use in this study, without the need to make changes to the questions asked. Furthermore, it was an existing survey questionnaire that was found to be valid and reliable.

5.4.1.2 The Sample

An initial comprehensive list of organizations of and for disabled people and Schools for Learners with Special Education Needs (LSEN schools) was collated from various lists provided by Disabled People South Africa (DPSA), the peak body for DPOs in South Africa, the OSDP, other organizations and contact persons, as well as the internet. This initial list contained the names and contact details of 685 organizations and schools. Some of the source lists from which the organizations' details were obtained were old

and out-dated or incomplete³. During the course of the first round of sending the survey questionnaire to organizations and schools via email or post, contact details were updated or verified. Through this process the list of organizations and schools was updated and refined as a result of the following:

1. Some organizations were found to no longer be in existence
2. Contact details for some organizations that we had were incorrect as emails were undelivered or post was returned to sender. Alternative contact details for these organizations could not be obtained.
3. Some organizations had changed their names, and both the new and old names were listed, so the old details were removed from the list.
4. In some cases, separate organizations had amalgamated into one organization.

As the details were verified, the list was reduced to a final 601 organizations and schools across all nine provinces in South Africa. Table 5.1 provides a breakdown of the number of organizations and schools per province.

Table 5.1: Number of Organizations and Schools per Province

Province	Disability Organization	LSEN School
Eastern Cape	12	41
Free State	14	21
Gauteng	77	125
KwaZulu Natal	21	58
Limpopo	9	18
Mpumalanga	16	20
Northern Cape	4	9
North West Province	7	40
Western Cape	45	64
Total	205	396

³ It is a matter of some concern that the Office on the Status of Disabled Persons in the Presidency (OSDP) does not appear to have a complete and up-to-date list of DPOs and other organizations working with disabilities in South Africa

Of the 601 organizations, 14 organizations were international or national DPOs; umbrella bodies for disability groups in South Africa.

5.4.1.3 Data Collecting

Response rates to mail surveys in particular tend to be poor. Suggestions have been made of ways to improve response rates, including sending the survey with a good covering letter, including a self-addressed return envelope with postage already paid, sending reminders, and doing a second mailing of the survey (Goodwin, 2003; Mangione, 1995).

In attempt to improve the response rate the survey was administered with the institutional support of the Human Sciences Research Council (HSRC) and Stellenbosch University. The Human Sciences Research Council is a national research organization that has a Disability Studies program. A covering letter (attached as addendum B) was sent with each questionnaire giving information about the aims of the study, that the organization's or school's participation was voluntary, and that information would be used anonymously in any publication of the results. The covering letter included a consent form which the organization or school was requested to complete and sign and return with the completed questionnaire. This covering letter included the corporate logos for both the HSRC and Stellenbosch University and was signed by myself, the HSRC as well as my supervisor, Prof Leslie Swartz, who is well known to DPOs nationally and who has consulted extensively with the disability sector and established Disability Studies, in the HSRC. It was further agreed that the HSRC would provide the logistical support in managing the survey. The questionnaires were posted from the HSRC, and emails sent from a dedicated email address at the HSRC. This was managed by a research assistant at the HSRC offices in Pretoria.

The questionnaire and covering letter was addressed to the key person in each organization (generally the director of the organization or principal of the school), who was invited to complete the survey and return the questionnaire by post or email. The covering letter explained that if that person felt unable to answer the questionnaire, s/he

may forward the questionnaire to a person better able to answer the questions for the organization. One completed survey was requested per organization.

The first batch of questionnaires was sent out to organizations and schools by email during the second and third weeks of February 2006. A total of 215 survey questionnaires were sent by email. Following this, questionnaires were sent by post to organizations for which we did not have an email address, during the last week of February and first week of March 2006.

Unfortunately, during the last few days of March 2006, we discovered that the covering letter sent out with the survey questionnaire contained the incorrect return address. This was realized after we received a questionnaire which was forwarded by post to Stellenbosch University, with the (incorrect) HSRC address crossed off. What had happened is that the street number for the HSRC's physical address was used incorrectly as the post office box number. It took some time to trace the owner of the (incorrect) post office box as the South African Department of Agriculture, and we eventually made contact with their mail department in the first week of April. They confirmed that they had been receiving post addressed to the HSRC, which they had sent back to the post office marked "incorrect address". They could not state for sure how many surveys they had received, but estimated that there were "not more than 30".

By this time the response rate to the survey had been very poor, with only 16 completed surveys having been received. It is very difficult to assess how many completed survey questionnaires were lost as a result of this address error, but the following calculations can be made:

1. Of the 16 completed surveys which had been received at that time, six were received by email, and ten were received by post. These posted questionnaires had been forwarded on to the correct HSRC address. The fact that only six surveys were returned by email (out of 215 emails sent), indicated however, that the initial response rate to this first round of posted questionnaires had been poor, and that in all probability not many completed questionnaires had been returned by post.

2. After making contact with the Department of Agriculture mail department, a further five completed posted questionnaires were retrieved, bringing a total number of 15 completed surveys having been received by post and six by email.

Thereafter a new covering letter was drawn up explaining what had happened, and giving the correct return address. A second round of survey posting was made via email at the beginning of April 2006. This was followed by questionnaires being sent by post to those organizations for which we did not have an email address. A stamped self-addressed envelope was included with the posted questionnaires.

By June, however, the response rate remained poor, and a third batch of emails was sent to organizations and schools. For those organizations for which we had no email addresses, contact was made through telephone calls to each organization during end of July, and start of August. The organizations were contacted by me, where I introduced myself as a student conducting this survey study, and requesting their participation. Organizations were asked for a contact email address, and in cases where they did not have an email address, their postal addresses were confirmed. With the information gathered during these phone calls, survey questionnaires were sent by email and post.

In a further effort to improve response rates, I contacted schools and organizations in the Western Cape province of South Africa, and arranged to drop off the survey questionnaire and to collect completed questionnaires from them some days later. Due to the costly nature of such personal contact, only organizations and schools within Cape Town were approached in this way, as I was based in Cape Town. A total of seventeen schools and organizations were approached in person, from which nine completed surveys were obtained.

A final contact was made to all remaining organizations and school in September 2006, by means of a follow-up email, reminding them of the survey and requesting that completed surveys be returned as soon as possible. This was to be the final contact made to organizations and school across South Africa.

In February 2007, a Masters Psychology student at the University of Stellenbosch was interested in doing a study of LSEN schools in the Western Cape, and their response to the HIV epidemic. This student made use of the same survey questionnaire used in this study. This student approached schools from whom we had not received a survey and who had not indicated that they did not wish to participate in the survey study. The student arranged to conduct individual interviews with a staff member at a school, for which the survey questionnaire was used as the interview schedule for each interview. From this a further thirteen completed survey questionnaires were obtained and is included in this study.

Despite the various contacts made and efforts to improve response rate (outlined in Table 5.2), the final response rate remained disappointingly low. This will be discussed further in the results chapter below.

Table 5.2: Summary of Recursive Efforts to Improve Response Rate to the Survey

Dates	Actions taken
February to March 2006	First batch of survey questionnaires sent by email and post
April 2006	Second batch of survey questionnaires sent by email and post
July to August 2006	Telephone calls made to organizations and schools who had not yet responded, followed by a third batch of survey questionnaires sent by email and post
August to September 2006	Survey questionnaires delivered in person to organizations and schools in Cape Town, and completed questionnaires collected
September 2006	Follow-up emails to organizations and schools who had not yet responded
February to April 2007	Interviews conducted by masters student at LSEN schools in the Western Cape

5.4.2 Qualitative Case Studies

5.4.2.1 Choice of Organizations for Case Studies

Three organizations which had participated in the survey by having completed a survey questionnaire were used as case studies. As I was located in Cape Town, accessibility and convenience dictated that organizations selected are located in the Western Cape, specifically in Cape Town itself. The intention was to select organizations that work with different areas of disabilities, and who had a differing response to the HIV/AIDS epidemic (as indicated on their completed survey questionnaire). However as only a relatively small percentage of organizations had completed a survey questionnaire (see chapter six) the selection of organizations was largely based on convenience and accessibility. It was the case that three organizations were used that work with different disabilities.

Case study 1 was of an organization for persons with intellectual disabilities. This organization is a regionally based organization that does not work directly with disabled people themselves, but rather provides support services to a number of organizations and schools working with persons with intellectual disabilities. This organization had indicated in their completed survey questionnaire that they had developed a Sexuality and HIV education programme for adolescents and young adults with intellectual disabilities, and were providing training for facilitators of this programme. The organization had enclosed a copy of the programme manual with their completed survey questionnaire. Although this organization does not work directly with disabled people, they were selected as a case study because of having developed an HIV education programme. In addition the organization provided a supervision group for teachers from affiliated schools who were currently involved in facilitating the education programme at their schools.

Due to the larger number of schools than organizations in this survey study, the remaining two case studies are of LSEN schools. Case Study 2 is that of a school for learners with visual impairments, this includes learners who are partially sighted as well as learners who are blind. Case Study 3 is of a school for learners with cerebral palsy.

Although the school was established as a school for cerebral palsy children and adolescents, in recent years the school has included learners with intellectual disabilities as well.

5.4.2.2 Sources of Data for each Case Study

The sources of data will be discussed separately for each case study. A discussion of the procedures used for data collecting will be provided in the section 5.4.2.3.

Case Study 1

The organization which was used for Case Study 1 was approached through the director of the organization. A phone call was made to the director, requesting their participation as a case study. An appointment was made to meet face-to-face and discuss the purposes of the case study research and what would be required for this study. During this meeting various individuals were identified as being useful persons to interview for the case study. As the organization provides a supportive service to a variety of schools and organizations that work with intellectual disabilities, individuals were identified from different affiliated organizations and schools who had been involved as facilitators on the Sexuality and HIV education programme developed by the principal organization. These individuals were then first approached by the director of the organization to discuss my research project and their possible involvement as interview subjects, after which I was provided with each persons contact details in order to set up appointments. Four individual persons were interviewed for this case study. These four were:

1. The director of the organization
2. The developer of the Sexuality and HIV education programme and principal facilitator and trainer of the programme. This person also led the supervision group for teachers who were facilitating the programme at various schools.
3. An HIV counsellor who had recently joined the organization as a co-supervisor of the teacher supervision group. This person had also completed the sexuality and an HIV education programme at one of the affiliated schools, with the developer of the programme.

4. A senior staff member at an affiliated organization for persons with intellectual disabilities, who had run this education programme at her organization, with groups of young adults.

In addition, a group of three teachers from two different affiliated schools were interviewed as a group. They were approached by the programme developer at one of the supervision sessions that the teachers attended. Three of the teachers in the supervision group agreed to take part, and I then contacted them to arrange a time for the group interview.

All people interviewed individually and in groups were provided with an introductory letter and a consent form (addendum C) which they each completed and signed.

In my initial discussion with the director of the principal organization, it was suggested to me that I pay the developer of the programme and the co-supervisor (interviewees 2 and 3 described above) for their time. The director felt that these two individuals were not employed by the organization, but rather contracted their services. The director felt uncomfortable with asking their involvements as a research participant on behalf of the organization, without their time being compensated for. This was agreed to by me, and the two interviewees were paid for their time once the interview was concluded.

As a further source of data to the five formal interviews discussed above, I requested to the director of the organization and the education programme developer/supervisor whether I could (a) sit in as an observer during one of the teacher supervision groups, and (b) sit in as an observer during one of the sexuality and HIV education groups. It was not possible for me to sit in on a supervision group, however, as that particular group was due to come to an end. It was also felt that it would compromise confidentiality if I sit in on one supervision session. With regards the sexuality and HIV education programme, the suggestion was made that rather than sit in on one session of the sexuality and HIV education programme, which would have a negative impact on the development of trust for the participating learners, that I participate as a co-facilitator for the duration of a

whole programme. A programme was due to start at a school for learners with intellectual disabilities, with a group of young adult males who were preparing to graduate from the school. Consent was gained by the school principal and the teacher of the group of learners for me to take part as a co-facilitator of the group. It was agreed that I would sit in and participate in the activities, but that the sessions would not be recorded and that I would not write notes during the sessions. This was acceptable to me, as it was not the aim or purpose of my research to evaluate the programme. The group sessions and the participating students were not the objects of my investigation. Rather it was my own experience of being involved in this group, and my own experience of being a co-facilitator that was to be observed. This is in keeping with a psychoanalytic framework of analysis (discussed in chapter four, and below), where it is the 'educators' own anxiety and countertransference feelings which is being investigated. Countertransference is a psychoanalytic term, referring to the feelings that are evoked in the therapist (or in this case researcher) in interaction with the patient (or in this case research subject); feelings that may either be an unconscious communication of the patient's (research subject's) own emotional experience, or feelings that stem from the therapist's (researcher's) own history (Hinshelwood, 1991). Thus my own experience and countertransference feelings would be a source of data, as it may inform me of what some of the unconscious emotional experience of the research participants would be, as I attempt to be conscious of my own emotional response to the work.

I took part in a 10-session sexuality and HIV education group with a group of 8 young adult males. This group was co-facilitated by the programme developer and a teacher at the school and me.

Case Study 2

As discussed above, the second case study is of a school for learners with visual disabilities. The deputy-principal at this school had completed and returned the survey questionnaire during the survey study. The deputy-principal was contacted by email requesting their permission to take part in a qualitative case study. After having discussed this with the school principal, the deputy-principal indicated that they agreed to

participate in the study. In further email contacts, I informed the deputy-principal that I would like to interview some key staff members individually as well as a group of teachers in a focus group. Staff members were identified and approached by him, and a time was set up for me to come and meet everyone. At this meeting I introduced myself, and explained the purposes of my research, and the nature and method of interviewing. The various staff members were given an information letter and consent form (addendum C), and times for the various interviews were arranged. For this case study, the following interviews were conducted:

1. An individual interview with the deputy-principal who had completed the survey questionnaire
2. A second deputy-principal of the school, who had worked at the school for many years
3. The school psychologist
4. The school nurse
5. A group of three teachers. Initially four teachers had agreed to participate. However the group interview had to be rescheduled twice due to unforeseen events, and when I arrived for the group interview on the third occasion, one of the teachers was on sick leave. Thus the interview was conducted with the three teachers who were present.

Some of the staff members at the school had visual disabilities themselves. One of the teachers who participated in the focus group interview was blind and had been at the school for many years.

Case Study 3

The final case study is of a school for learners with Cerebral Palsy. The survey questionnaire had been completed and returned by the staff nurse and nursing sister. In order to gain permission from the school for their involvement as a case study, the school principal was contacted by telephone. The principal was unavailable, so I was put through to the deputy-principal. After I introduced myself and explained the reason for my call, the deputy-principal requested that I detail my request in writing, so that he could forward

it and discuss with the principal and staff. A letter detailing my request, as well as a copy of the information sheet and consent form was dropped off at the school for the deputy-principal's attention. After a week had passed and I had not heard from him, I contacted him again by telephone. He indicated that the principal had agreed to the school's participation. A time was set up for me to meet with the staff and discuss the interview procedures. When I arrived to this meeting the staff was unavailable, and I met briefly with the deputy-principal. He indicated that he was prepared to be interviewed and a second appointment was made. When I arrived to this appointment he announced that he was unavailable. Again he could not put me in contact with other staff members. He suggested that he rather set up a time for me to meet the staff nurse; that he would discuss this with her and get back to me. After I had not heard from him, I called him back and a time was confirmed for me to meet the staff nurse.

This process of attempting to gain access to the staff at the school could be interpreted by some as resistance or uncertainty about taking part in a study. However, as it happens, during this time, there was a national strike in South Africa in the public service sectors. Teachers and nurses in particular had started a nationwide strike in protest of what they felt was an insufficient annual pay increase. Thus at the time when I had arrived to meet with the staff, many of the teachers were attending a public protest march. The strikes continued during the time that I was available to conduct interviews at the school, thus interview subjects were approached on the basis of who was available. The nursing sister facilitated the recruitment and scheduling of interview subjects, which proved to be helpful in that the strikes made contacting staff and scheduling times difficult. For this case study, the following interviews were conducted:

1. An individual interview with the nursing sister
2. An individual interview with the staff nurse who had worked at the school for many years.
3. A focus group interview with three teachers at the school
4. A group interview with two hostel care workers

Due to the disruptions caused by the strikes and time limitations no further interviews were scheduled, and an interview with the deputy-principal never took place.

5.4.2.3 Procedure for Collecting Data

All individual interviews and focus group interviews were conducted by myself, and were done in English, with the consent of the participants. At times participants also communicated in Afrikaans when they struggled to express something in English. The interviews and focus group interviews followed the guidelines of the free association narrative interview as described by Hollway and Jefferson (2000), and used in my own previous research (Rohleder, 2003; Rohleder & Gibson, 2005; Rohleder & Swartz, 2005).

In a narrative interview, “the agenda is open to development and change” (Hollway & Jefferson, 2000, p. 4). It proposes that the *story* is co-constructed during the interview process, following the unconscious logic (Hollway, 2001) of the narrator, as well as the interviewer. For each individual and group interview, I made use of a semi-structured interview schedule (see Addendum D), which attempted to guide discussion around HIV and disability. However the participants are left to freely narrativise their own experience, with the aim of allowing interviewees to express their anxieties about addressing HIV, sex and sexuality with the disabled people they work with. Questions are asked as a way to elicit the stories of the participants, following on what they have said, and not said. The interview narrative is co-constructed as it is subject to interpretation by the interviewer. As the interviewer, I follow the nuances of the emotions in the interview, picking up on what is said and what is left unsaid. My own countertransference feelings become important sources of information for understanding and guiding the interview process. Hollway and Jefferson (2000) argue that the researchers own feelings evoked in the interview become important sources of information for interpreting emotional nuances in the interview narrative. They also inform the researcher’s choice of where and when to ask probing questions in order to explore further areas that may be important.

The focus group interviews, informed by my training and experience in group facilitation, allowed for a more interactive discussion on HIV and Disability. I also made use of the

narrative interview, as participants in the focus group were allowed to freely narrativise their experience as a group. The use of both interview and focus groups data, allows for more comprehensive qualitative results, as well as for methodological triangulation.

The interviews were between 1 and 1½ hours in duration, and were tape-recorded. The recorded interviews were then transcribed by a student assistant, employed by me to do this work.

5.5 Analysis of Data Material

5.5.1 Analysis of Data from the Survey

The survey questionnaire made use of both close-ended and open-ended questions, thus the analysis of the data collected in the questionnaires used both quantitative and qualitative methods.

The analysis of data from the close-ended questions, were analysed using descriptive statistics. Questions were given variable names, and answers were coded and analysed on SPSS using descriptive statistics, following the guidelines of Field (2005). I also consulted with a researcher at Stellenbosch University, experienced with using SPSS, who gave guidelines for coding answers and inputting on SPSS, and my codes were checked by him, to ensure validity. As there were no comparisons to be made to a control group, more complex statistical analysis was not required. I made use of frequencies to examine how respondents responded to set questions. The results of the analysis were checked by my supervisor, to ensure validity.

As the survey made use of the questionnaire developed for the World Bank Global Survey on HIV/AIDS and Disability, it was agreed that results from this study would be made available to the global survey.

The responses to the open-ended questions were generally quite short. These answers were analysed using a combination of thematic content analysis (Boyatzis, 1998) and discourse analysis (Banister, Burman, Parker, Taylor & Tindall, 1994). First, the survey

questionnaires were glanced over to get a sense of the themes of the answers that were given. Themes were also driven by the nature of the questions. A list of codes was developed for some of the open-ended questions, and the responses given were analysed using these codes, and grouped into themes. Thereafter, social constructionist theory was used to gain a discursive understanding of this qualitative data. Particular social discourses were identified within the text, to gain a further understanding of the responses given. For example, an answer such as the following:

We people with disabilities are like any other people – we make love with our loved ones! We might be at risk for HIV/AIDS

In doing a thematic content analysis of this quote, I would use this as an example of a theme of, say, “HIV risk due to sex”, and include it with other answers reflecting the same theme. In addition though, I would interpret the words as drawing on the social discourse that disabled people are asexual, and the respondents answer comments on the myth of this social discourse, when he or she states that they “are like any other people”.

5.5.2 Analysis of Data for the Case Studies

Transcripts of interviews conducted for the case studies were analysed in two phases. In the first, discourse analysis, following the guidelines in Banister et al. (1994) and Marshall (1994), were used, taking account of the role of discourse and language in constructing reality (Bruner, 1991). Discourse analysis has as its focus language used in written and spoken texts, with attention given to “the structure and organization of discourse with concern for the possible consequences of the use of particular versions or constructions in the text” (Marshall, 1994, p. 91). Discourse analysis involves the examining of the various meanings and constructions of events and phenomena in society that people draw on to make sense of their world (Marshall, 1994). The analysis involves the identification of “interpretive repertoires” (Marshall, 1994, p. 93), which are clusters of words, terms and phrases which together construct a particular discourse.

Marshall (1994) describes a number of steps involved in discourse analysis. The texts or transcripts are first read and reread, and recurrent patterns in the text, or 'interpretive repertoires' are picked out and placed under broad headings. Variations are paid attention to in order to consider the range of various repertoires that are being used. These repertoires are then examined for the way in which they are used by the subject in the text, and lastly attention is then given to the consequences of using the various repertoires.

Banister and colleagues (1994) also point out that the researcher is actively involved in the reconstruction of the discourses of research subjects. They state

There is more *variability* in human action and experience than that expressed in language; as researchers we *construct* our own image of the world when we reconstruct 'discourses'; and we have some responsibility for how our analysis will *function*. (Banister et al., 1994, p. 106)

In the second phase, following the guidelines of Hollway and Jefferson (2000), a psychoanalytic framework was used to identify defensive structures and unconsciously communicated feelings in the narratives. This provides a further analytic layer, allowing one to explore the internalization of social discourses. As discussed in chapter four, Hollway and Jefferson argue, that individuals draw on particular discourses as a defence against threat to the self, or in order to manage anxiety. This further layer of analysis thus allows us to "account for individual differences in the way in which people make sense of the available information; that is, the discourses or systems of meaning within which they may be positioned" (Hollway & Jefferson, 2000, p. 15). Psychoanalytic theory is utilized in the analysis of the texts in order to identify unconscious defence mechanisms and unspoken emotions. Part of this psychoanalytic analysis of the material occurs during the interview process, where the researcher, using his or her own countertransference feelings, gets a sense of the emotional content of the interview material, and uses this to interpret information and guide the interview process. As Hollway and Jefferson (2000) argue, the researcher's countertransference feelings become important sources of

information and data. Personal notes were taken of my own reactions and feelings during, and after, each interview. During the process of data analysis, the transcripts are read in order to get a sense of the overall emotions being conveyed. Furthermore, psychoanalytic theory is drawn on to understand defensive mechanisms, such as splitting, and so help to give meaning to how particular discourses might be used in a defensive manner.

5.6 Ethical Considerations

Prior to starting the study, the protocol for the study was given approval by the Research Ethics Committee of the HSRC, as well as the Committee for Human Research (CHR) at Tygerberg Hospital (University of Stellenbosch). During the first posting of the survey questionnaire, one of the schools contacted made it known that permission had to be granted by the Department of Education. I had not been aware of this, and so subsequently learnt that permission to conduct the study at government LSEN schools needed to be granted by the provincial education departments; permission could not be requested at national level. All the departments of education at all nine provinces were immediately contacted by email. In my contact with them, I provided a copy of the research proposal which had been approved by the research committees mentioned above. I had also explained that the survey had already been sent, so that approval was being requested retrospectively. Only two provincial departments responded with information on how to submit an application for research approval. The remaining seven departments were contacted again by telephone and a letter was sent to them again by post and email. Despite all nine provincial departments being contacted three times; by email, telephone and post, only five departments responded to my query. These five departments subsequently granted approval for me to conduct my research at LSEN schools. These were the departments of education for the following provinces:

- Free State Province
- Gauteng Province
- North West Province
- Northern Cape Province
- Western Cape Province

As the remaining four provinces had not responded to my enquiries, and that the permission was granted at five provinces, it was decided to continue with the research at LSEN schools in all nine provinces, as no specific objection was received. Permission was granted by the Western Cape Province to extend the research study into 2007, when the Masters psychology student conducted interviews with school representatives, using the survey questionnaire.

The survey questionnaire was sent to organizations and schools with a covering letter and a consent form (see addendum B) which they were requested to sign and return with the completed questionnaire. They were informed that their participation was voluntary, and that a feedback report would be provided to them upon completion of the study and analysis of data. Most of the completed surveys were returned with a signed consent form. In the cases where no signed consent form was included, consent was assumed by the submission of a completed questionnaire.

With regards the qualitative case study interviews, signed informed consent was given by each participant prior to the interview (see addendum C for a copy of the information sheet and consent form). For case study 1, I had the experience of participating in a HIV, sex and sexuality education group for adolescent males with intellectual disability. Consent for my participation in this group, was gained from the school principal and the class teacher. My presence was discussed with the parents of the adolescents. I was informed by the school that the parents gave their consent. The understanding was that the adolescents taking part in the education program were not the object of research, but rather it was my own experience of co-facilitating the group which I was using as material for the research study. Prior to my joining the group, the participating adolescents were informed that I would be co-facilitating.

For the survey study and case studies, confidentiality was assured in that no names of respondents will be revealed in any report or dissemination of data. There may be limits to confidentiality, however. An organization may be identifiable. In reporting results from the survey, attempts will be made to disguise the organization, using descriptions

that cover a variety of organizations. However, in the case of some disabilities there may be only one organization nationally. In the case of an organization used as a case study, the organization may likewise be easily identifiable, due to being the only organization in the area working with a particular disability, or because of being a unique type of organization (as in the case of the organization used as Case Study 1). These anticipated limits to confidentiality were included in drafting of consent forms, and were openly discussed with the organizations that took part in the case studies.

It was not expected that the questions asked in the survey or the qualitative interviews would be of a distressing nature. However, my contact details as the primary researcher were given in all communications, so that participants could contact me should they need to.

CHAPTER SIX

RESULTS OF THE HIV/AIDS AND DISABILITY SURVEY

6.1 Introduction

This chapter reports on the results of the survey conducted of organizations and schools working with persons with disabilities. I begin by reporting and discussing the response rate achieved by the survey study. I then go on to report the results of the responses given, under the headings: background information of organizations and schools; Risk and awareness of HIV/AIDS; Teaching disabled people about HIV/AIDS through disability organizations; Teaching disabled people about HIV/AIDS through non-disability organizations; Help and support for disabled people who are infected with HIV/AIDS. I also include additional qualitative comments or observations made at the end of the survey questionnaire.

6.2 Response Rate

After the initial omission of invalid organizations, or organizations where there were no contact details, a total of 601 organizations and schools were approached by email and post with the survey questionnaire. Of these, 14 organisations were international and national disability organizations. A total of 112 surveys were returned, however two of these surveys were returned with identifying details provided but with all remaining questions left unanswered. There were thus 110 complete valid surveys. Of these, eight completed surveys were from international and national disability organizations. This gives a response rate of 57% for international/national disability organizations in South Africa.

The response rate from provincial and regional organizations and schools, however, was very poor. The resulting overall response rate was therefore 18%. A breakdown of the responses from the various provinces is detailed in Table 6.1.

Table 6.1: Survey Response Rate per Province

Province	LSEN Schools			Organizations			Total Response Rate for the Provinces
	Sent	complete	%	Sent	complete	%	
Eastern Cape	41	6	15%	12	3	25%	17%
Free State	21	8	38%	14	2	14%	29%
Gauteng	125	11	9%	77	12	16%	11%
KwaZulu Natal	58	7	12%	21	3	14%	13%
Limpopo	18	1	6%	9	1	11%	7%
Mpumalanga	20	2	10%	16	3	19%	14%
Northern Cape	9	2	22%	4	3	75%	38%
North West	40	4	10%	7	1	14%	11%
Western Cape	64	34	53%	45	7	16%	38%
Total	396	75	19%	205	35	17%	18%

As can be seen from the table above, similar response rates were achieved from schools (19%) and from organizations (17%), although more numbers of completed surveys were received from schools than from organizations. The lowest response rate overall was from Limpopo Province (7%). The highest response rate was from Northern Cape Province and the Western Cape Province (38%). The higher response rate in the Western Cape Province is as a result of schools and organizations being approached in person. The sector that had the highest rate of response was from organizations in the Northern Cape Province, where 75% of the organizations responded to the survey. However, there were only four organizations in this province.

Although the overall response rate is only 18%, the sample covered all disability groups (see Table 6.3). In addition, a majority 57% of international/national disability organizations in South Africa responded to the survey. These organizations represent many of the provincial organizations that were included in the survey. For these reasons, the sample is regarded to be representative of all disability groups.

6.2.1 Reasons Given for Non-participation in Survey Research

A handful of schools and organizations formally declined to take part in the survey research. Four schools declined their participation in writing, and a further five schools and two organizations declined to participate when they were contacted by telephone. Generally two main reasons seemed to be given. In some cases, the school or organization was “too busy”. For example, one school’s comment on the telephone was:

I understand it to be voluntary; so please don’t pressure me to do anything ... it’s a lengthy questionnaire, and we don’t know anything about who has HIV – we do the education, but we don’t know who has HIV

Another reason given, in many cases by schools for severe or moderate intellectual disability, was that the school felt that the questionnaire was not applicable. Some typical responses from schools were:

We are a school for mentally disabled learners and most of the survey is not applicable to us.

Our people are not supposed to have sex ... they are sterilized

Does not affect us; we deal with young children

Some of these responses suggest a lack of awareness around risk to HIV infection. The feeling from staff that the issue of HIV is “not applicable” to their learners suggests a possible lack of thinking about how disabled learners may actually be at risk. One response from a training centre – “our people are not supposed to have sex” – is interesting, as while the idea is expressed that the population they work with are not sexually active, the addition of the word “*supposed*” alludes to some level of awareness of the existence of sexual activity.

In one case, there was an outright rejection of HIV as an issue or a reality. This school stated:

We don't have a problem at ALL here; none of our pupils, parents or teachers are HIV-positive ... parents don't want us to teach our children about sex... our children are very sheltered

This person's comments suggests HIV/AIDS as not being an issue for them, but also their comment suggests that parents may be opposed to providing sex education at the school.

6.3 Results from Completed Surveys

The survey questionnaire as designed for the World Bank Global Survey on HIV/AIDS and Disability, contains various questions posed under the headings: Background information; Risk for HIV/AIDS: Awareness; Teaching disabled people about HIV/AIDS through disability organizations; Teaching disabled people about HIV/AIDS through non-disability organizations; Help and support for disabled people who are infected with HIV/AIDS (see Addendum A). The results of the completed surveys are reported here using these headings. Results are reported using the quantitative data from the survey questionnaire as well as some of the qualitative data, where open-ended questions were asked, or respondents were invited to elaborate on a response.⁴

6.3.1 Background Information of Schools/Organizations

In this section of the survey questionnaires, organizations were asked to provide details of the type and nature of their organization as well as the type of services provided.

6.3.1.1. Type of Organization

The questionnaire asked respondents to indicate what type of institution they were, whether a governmental organization at a national, provincial or regional level, or a non-governmental organization at an international, national or regional level. However, when

⁴ Qualitative responses given are generally recorded as they were given. In some cases only minor corrections to grammar and spelling were made for ease of reading.

analysing these responses, there were a number of instances where it was clear that the answer given was incorrect. For example a school might have referred to themselves as a governmental organization at a national level – clearly incorrect. The breakdown of the results of these responses into the various categories will therefore not be valid. However, what can be drawn from this is that 74 respondents (67% of the sample) referred to themselves as a governmental organization (many of these were public schools), and 35 respondents (32%) as a non-governmental organization. One respondent did not answer this question, and it could not be deduced whether this organization was a governmental organization or a non-governmental organization.

Respondents were also asked whether their organization was an organization of disabled people (controlled by disabilities themselves). Twenty-eight respondents (25.5%) indicated that they were and 82 (74.5%) indicated that they were not an organization of disabled people. As discussed above, the majority of international/national disability organizations responded to the survey.

6.3.1.2. Type of Services Provided

The questionnaire asked respondents to indicate the type(s) of services provided. Respondents could indicate more than one, so the percentage of responses for each type of service does not add up to 100%, as in many cases respondents did choose more than one answer. The types of services that the respondents provided are shown in Table 6.2.

Table 6.2: Type of Services Provided

	Frequency	Percent
Valid Advocacy/Policy	23	20.9
Education	88	80.0
Medical/Counselling	40	36.4
Rehabilitation Services	27	24.5
Developmental/Economic	27	24.5
Legal	3	2.7
Other	17	15.5
Total	110	100.0

Many did not specify other services; those that did indicated: accommodation, information, and social services.

6.3.1.3. Type of Population Served

The survey questionnaire asked respondents to indicate the types of disability that they worked with or served. Details of the responses are shown in Table 6.3. Respondents were given the opportunity to choose more than one, which many did, so percentages indicated in Table 6.3 do not add to 100% of the sample.

Table 6.3: Type of Disability Served

	Frequency	Percent
Valid Physically Disabled	45	40.9
Blind/Low Vision	19	17.3
Deaf/Hard of Hearing	37	33.6
Intellectually Disabled	68	61.8
Mentally Ill	13	11.8
Multiply Handicapped	38	34.5
Epilepsy	42	38.2
Chronic Disease	13	11.8
Haemophilia	5	4.5
All Disability Groups	11	10.0
Other	18	16.4
Total	110	100.0

As can be seen from Table 6.3, the most represented disability is intellectual disability, with 62% of organizations that responded serving persons with intellectual disabilities. Most of these organizations were schools for learners with intellectual disabilities. Not all respondents specified a disability when they selected the category ‘Other’. Those that did, most indicated Autism (5 organizations), and questions were asked why Autism was not included as a separate category. Individual organizations indicated “Behavioural problems”, “Learning disability”, and “Cerebral Palsy” as a separate type of disability.

The majority of organizations serviced a relatively small number of people, with 83 organizations and schools (76% of respondents) serving less than 500 individuals with disability. Eight organizations indicated serving between 500 and 100 individuals, and eleven organizations serving between 1000 and 10 000 individuals with disabilities. Only

four organizations serviced more than 10 000 individuals; three were national disability organizations, and one was an organization which provided services for a number of schools and organizations working with disabled people.

6.3.2 Risk for HIV/AIDS: Awareness

In this section, organizations were asked questions pertaining to the level of awareness that exists about risk for HIV – the level of awareness of the respondents themselves, as well as their perception of the level of awareness of disabled people themselves.

6.3.2.1 Are Disabled People at Risk for HIV/AIDS?

The first question asked was:

Do you think that disabled people might be at risk for HIV/AIDS?

The overwhelming majority (105 respondents, or 95.5%) answered ‘yes’ to this question, with the remaining indicating that they did not know. Only one respondent answered ‘No’. However, this respondent explained that disabled people “are not exceptional as HIV affects all parts of the population”, reflecting an awareness that there is a risk, but not wanting to make a distinction of “disabled people” as a unique group of people. Three respondents were unsure, and one respondent did not answer this question.

Practically all respondents elaborated further on their answer, by giving reasons as to why they felt that disabled people might be at risk. Responses generally fitted into four themes or constructions about risk for HIV/AIDS, namely increased vulnerability; sexually active; lack of knowledge; and “equal” risk.

Disabled people are vulnerable

The vulnerability of disabled people in terms of risk for HIV was the most frequently mentioned. Respondents referred to disabled people as being vulnerable to sexual abuse.

A typical response is:

Our children, especially the severely disabled children sometimes get used by people in the community and they don't know how to defend themselves, or don't even know that it's wrong what they are doing to them. So, yes, they are very much at risk.

Another respondent wrote:

Patients are not able to consent to sexual intercourse. There is a high incident of sexual abuse and rape that occurs when they go home for holidays.

The above respondent's response suggests the institution as a place of safety, as this person feels that abuse occurs "when they go home". Other respondents referred to learners being abused by their family or members in the community. There was no mention of institutional abuse, although the following respondent talks about the vulnerability to sexual abuse as a result of intimate health care needs:

People who are dependant on caregivers for dressing and personal hygiene functions are at risk because of the continuous physical contact, changing of catheters, giving suppositories, changing dressings in the case of pressure sores open wounds. Caregivers and disabled person is at risk.

A few respondents also spoke of the sexual vulnerability of disabled people as a result of what the respondents suggest to be their marginalized identity. One respondent wrote,

Disabled persons are sexually active. They are living in Homes / Institutions and they are familiar with the other residents and the thought of them being HIV positive does not occur to them. Some disabled persons are very lonely and will easily get involved in a relationship when someone is affectionate towards them.

They accept the other party with no hesitation or considering the fact that they might be HIV positive and therefore no precautions are taken.

The above respondent does not refer to sexual abuse, but is drawing on constructions of disabled people as marginalized and stigmatized, and as a result might find themselves partaking in risky sexual behaviour in order to find intimacy. The respondent also refers to disabled people being sexually active as a risk factor, a point stated by a number of respondents.

Disabled people are sexually active

Many respondents talked about disabled people being at risk because they are sexually active. Two slightly different constructions were made in terms of sexual activity. In the first instance, many referred to disabled people as *also* being sexually active. This draws on the social myths that prevail of disabled people being asexual. Some typical responses were:

They are also involved in relationships which may lead to sexual activity and are part of the community.

We people with disabilities are like any other people – we make love with our loved ones! We might be at risk for HIV/AIDS

One respondent suggested that the myth of asexuality in itself might result in a person with disability putting themselves at risk in order to disprove this myth:

There is almost a culture that a person with a disability need to show that he or she can be sexually active or can have children. Despite this, most disabled people lead a normal life and is therefore sexually active.

A second type of construction revolved around the actual sexual behaviour of disabled people, where particularly persons with intellectual disabilities were seen as sexually impulsive. As one respondent wrote:

Die gestremde leerling het 'n baie hoër libido as normale leerders, veral wanneer hulle intellektuele vermoëns ingekort is

[Translation: the disabled learner has a much higher libido than normal learners, especially when their intellectual capacity is lower]

This was only mentioned in a few instances, but such responses draw on social constructions around disabled people as being sexually impulsive, or having an increased sexual appetite.

Disabled people lack knowledge

Another frequently mentioned explanation for disabled people being at risk, is that persons with disabilities lack knowledge about HIV transmission and prevention, due to having less access to information. For example, one respondent wrote:

Ignorance, lack of education and awareness. Some disabled people are in remote, rural areas and HIV/AIDS education is strongly needed due to myths, etc.

In some cases where respondents wrote about lack of information, respondents stressed Deaf persons in particular as having limited access to information. For example, one respondent wrote:

Among Deaf low literacy levels and poor reading ability limits access to information.

Another type of answer referred to learners' limited capacity to understand information, particularly in the case of severe intellectual disability:

Our school's learners are severely mentally handicapped, so understanding of HIV is very difficult for them.

Disabled people are at equal risk

A fourth type of response centred on the stressing of *everyone* being at risk, and a distancing from constructing disabled people as different to non-disabled people. Typical responses in these cases were:

Disabled people are as much at risk as anyone else depending on the disability and severity thereof they can be at risk of contracting HIV in all the usual ways.

People with disability are just as much at risk of contracting HIV/AIDS than non-disabled persons.

This stance is taken in responses to other questions on the survey questionnaire, which will be picked up below.

6.3.2.2 Are Disabled People at Greater Risk for HIV than Non-disabled People?

The question followed on the above question, with asking the respondent:

Do you think that disabled people are at greater risk for HIV/AIDS than non-disabled people?

Again, the majority (90 respondents, or 82%) answered 'yes' to this question, with a further nine respondents being unsure, and eleven answering 'no'. Those that answered no either explained that they felt that disabled people were at equal risk or at less risk because they were less sexually active than non-disabled people.

As with the first question above, practically all respondents elaborated further on their answer, by giving reasons as to why they felt that disabled people might be at risk. Responses generally fitted into similar themes or constructions about risk for HIV/AIDS, namely increased vulnerability; lack of knowledge; a limited capacity to understand; and engagement in risky sexual activity.

Increased vulnerability

Respondents frequently stated that disabled people are at greater risk for HIV infection because they are more vulnerable to abuse, particularly sexual abuse. Many respondents spoke of disabled people defenceless and vulnerable to sexual abuse. Typical comments were:

People like to abuse them specially the young ones because they are unable to run away and to protect themselves

They are soft targets for abuse. They have not got the intellectual capacity to know that they are endangered by sexual encounters. And if physically disabled, they may not have the strength to fight off a perpetrator. They may also be emotionally more vulnerable

A few respondents also spoke of what they felt to be disabled people's vulnerability to give in to sexual advances due to their stigmatized identity and what they felt to be a need for acceptance. One respondent wrote:

They are often seen as soft targets and are not physically strong to defend themselves. They also often see the sexual advances of partners as acceptance and therefore tend to give in easier to their advances.

Similarly, another respondent explains:

A lot of our children do lack self-esteem because they often do compare themselves with their peers who are not disabled, and I think that the girls are quite vulnerable in that they often equate physical love, with emotional love, and because of their deafness they don't always understand the different nuances of friendship. What to a hearing child would just be a friendship with a boy, they often would see as a love relationship and it's very difficult for them to distinguish between love and friendship. The little ones from the primary school are at risk from the abuse side, because they are deaf they can't express themselves; they have major language delays. They really are at risk from that point as well. They are easy targets because adults know that they won't be able to explain what happened.

The above respondent also referred to Deaf children's vulnerability to abuse, because of being perceived as unable to report on the incidence of abuse.

One respondent commented on the myth that prevails that disabled people are not sexually active, and therefore their perceived virginity puts them at risk. This person stated that

Because of the myth that if you sleep with a virgin, will be cured of AIDS, and people think that disabled people are not sexual

This person is referring to a myth that has existed in South Africa that should an HIV-positive man have sex with a virgin; he will be cured – what is known as “virgin-cleansing”. This is highlighted as relevant for persons with disabilities by Groce and Trasi (2004), who found reported incidents of HIV-positive individuals raping persons with disabilities, in the belief that to do so would rid them of the infection. This stems from the myth that disabled people are asexual, and therefore virgins.

Lack of knowledge

Respondents also explained disabled people's increased risk to HIV infection as a result of a lack of knowledge, due to a limited access to information on HIV. For example, one respondent wrote:

They don't access the campaigns, and are also not easy to be reached, because most of them are still deprived integration with community

Another respondent wrote about how HIV education campaigns are in a language or format that is not accessible to disabled people:

Education regarding HIV/AIDS are not always done in a language that disabled persons can understand. The media that are used to sensitize people about this issue are mostly not available to disabled persons (deaf-blind, multi-disabled, persons who are disabled who did not receive any formal training in alternative communication).

As with the above respondent, some comments made highlighted Deaf people as particularly excluded from general HIV campaigns.

A limited capacity to understand

Related to the issue of lack of knowledge, some respondents, particularly from organizations working with persons with intellectual disability, wrote about the limited capacity to understand HIV-related information as putting disabled people at risk. For example, one respondent wrote:

The other issue is their intellectual capabilities to understand the risks of HIV/AIDS.

Related to this, was a person's capacity to consent to sex, particularly persons with severe intellectual disability, thus making them vulnerable to sexual abuse.

Risky sexual activity

Some respondents gave explanations that related to the issue of sexual abuse and vulnerability. In this case, respondents wrote about the fact that disabled people are sexually active, but that, because of their stigmatized status, might be vulnerable to engaging with risky sexual behaviour. For example, one respondent wrote:

They try to compensate for their disability by using their sexuality more often, thus leading to reckless sexual behaviour; not understand the consequences of this.

Another person wrote about how sex might be used as a form of currency for poor disabled people:

Poverty, leading [to] having unnecessary sexual engagement for survival; and lack of information regarding the HIV/AIDS

These comments are slightly different to those commenting on disabled people's vulnerability to abuse. In these cases sex seems consensual but, because of disabled people's marginalized position in society, they are vulnerable to enter into risky sexual activities.

6.3.2.3 Do Disabled People feel they are at Risk for HIV?

The survey then asked the following question:

Do disabled people themselves feel they are at risk for HIV/AIDS?

Only 55 respondents (50%) answered 'yes' to this question, with 20 (18%) being unsure, and 34 (31%) saying 'no'. One respondent did not answer this question. Of those who said 'no', most wrote that they felt that disabled people are not aware of their risks, either because of lack of knowledge, or a limited intellectual capacity to understand. For example, one respondent explained:

At school we tell them all the things that can happen to them but it doesn't sink in. They will come to you and this person did this to me and we will say "but we told you, you must not do these things!" It is difficult to show the children how a person looks if they have HIV because it's not like it's an arm that's off or something physical. It is difficult for them to understand.

Three respondents observed that while the disabled people they worked with might be receiving information on HIV prevention, they nevertheless engaged in risk behaviour.

Respondents who answered 'yes' were provided with a list of factors that they were invited to select as reasons why disabled people feel they are at risk. The responses to these are shown on Table 6.4.

Table 6.4: Reasons why Disabled People feel they are at Risk

		Frequency	Percent	Valid Percent ⁵
Valid	Sexually Active	53	48.2	84.1
	Rape/Sexual Abuse	55	50.0	87.3
	Drugs	24	21.8	38.1
	Medical Procedures	19	17.3	30.2
	Lack of information on HIV/AIDS	37	33.6	58.7
	Don't have access to prevention programs	24	21.8	38.1
	Families will not let them participate in programs	27	24.5	42.0
	Police will not prosecute if the victim has a disability	19	17.3	30.2
	They live in an institution	17	15.5	27.0
	Prevention programs not in a language that can be understood	24	21.8	38.1
	Other	10	9.1	15.9
	Total	63	57.3	100.0
Missing	99	47	42.7	
Total		110	100.0	

Respondents could select more than one, thus the individual response percentages do not add up to 100%. The responses given are problematic to analyse, as in some cases,

respondents who had answered ‘no’ or ‘do not know’ also selected from the list of factors as to why disabled people feel they are at risk. This suggests that respondents first answered that they felt that disabled people did not feel themselves to be at risk, and then proceeded to indicate reasons why the respondents (rather than disabled people) consider being risk factors. Dr Groce, who conducted the World Bank Global Survey on HIV/AIDS and Disability, indicated in a personal communication that there were instances in the global survey where respondents answered ‘do not know’ to the first part of the section, and then selected factors in the second part of the question. They understood this to mean, that although the respondent did not know how disabled people themselves felt, they reflected issues of concern for the community. Only eleven out of 34 respondents who answered ‘no’ also answered the second part of the question. Practically all the respondents who answered ‘do not know’ also answered the second part of this question. The responses will thus be interpreted in the same way as was done in the Global HIV/AIDS and Disability Survey. As can be seen from Table 6.4 the issues that were most often raised as a concern for disabled people was sexual activity and rape. This corresponds to the qualitative answers given above with regards disabled people’s vulnerability and potential to engage in risky sexual activity. Medical procedures and institutionalization were less frequently listed as issues. Where respondents indicated ‘other’ reasons, their explanations tended to expand on factors already listed, for example vulnerability to sexual abuse, or access to HIV information and prevention programmes (for example, the absence of sign language interpretation for Deaf people; lack of transport to get to venues). There were 47 respondents who did not give answers to this question, and so this was recorded as missing data. The results from Table 6.4 correspond to comments made in the previous questions, with vulnerability to sexual abuse and risky sexual behaviour, and lack of access to information identified as particular issues for disabled people.

6.3.2.4 Type of Help Disabled People have asked for

Responses to the question of what type of help disabled people have asked for, is shown

⁵ The “Valid Percentage” refers to the proportion of respondents who had given a certain answer, calculated from the number who had actually provided answers to the question

on Table 6.5. Of the 89 respondents who answered this question, most indicated that disabled people have asked for education about AIDS.

Table 6.5 Type of Help Disabled People have asked for

		Frequency	Percent	Valid Percent
Valid	AIDS Education	64	58.2	71.9
	HIV testing	23	20.9	25.8
	Counselling	38	34.5	42.7
	Condoms	32	29.1	36.0
	Other	10	9.1	11.2
Total		89	80.9	100.0
Missing	99	21	19.1	
Total		110	100.0	

Most of the respondents who selected ‘other’, explained that disabled people tended not to ask for help. As one respondent wrote:

They seldom ask – they fret about the possibilities

There was also a suggestion made that asking for help is difficult:

Deaf people do not speak openly about HIV/AIDS and even those who know their status as positive just deny it.

The above respondent refers to the silence that exists around HIV, with many people not willing to disclose their status.

6.3.2.5 Knowledge of HIV/AIDS Prevalence

Respondents were asked whether they had any information on how many disabled people in their area had died of AIDS and were living with HIV or AIDS. Responses here reflect the silence that exists around HIV and AIDS, with 100 respondents (91%) stating that they had no information about disabled people who had died of AIDS, and 85 respondents (77%) stating they had no information of how many disabled people are

living with HIV or AIDS.

Those who indicated having some knowledge of disabled people who had died of AIDS actually stated that it was either parents or family members of learners, or staff at the organization that had died of AIDS, rather than disabled people themselves. Only four organizations had actual numbers of disabled people who had died of AIDS: two organizations knew of one learner, one organization knew of eight learners, and the fourth knew of 13 learners.

Those respondents who indicated having information on how many disabled people are living with HIV or AIDS, only ten organizations were specific giving numbers ranging from 1 to 16 people. One respondent said they had a prevalence rate of 5% who had tested positive. Other respondents were less specific, and referred to friends or staff members who were HIV positive. One respondent stated that it is difficult to know what the prevalence of HIV infection is, as HIV is not a notifiable disease, again referring to the silence that exists around HIV.

One respondent felt that this lack of knowledge about prevalence is problematic for them as staff:

That's a big problem for me because this is something that is contagious and if I don't know who has AIDS, how can I protect myself?

This silence is also reflected in the community responses to people who were living with HIV or had died of AIDS. Table 6.6 shows responses from the survey questionnaire, and show that 31% of the total sample stated that HIV/AIDS is not discussed, and 48% stating that it is often said that persons have died from something else.

Table 6.6: Community Response to Disabled People Living with HIV or Died from AIDS

		Frequency	Percent	Valid Percent
Valid	HIV/AIDS is not discussed	34	30.9	39.5
	it is said they died from something else	53	48.2	61.6
	Stigma/Prejudice	27	24.5	31.4
	Other	19	17.3	22.1
Total		86	78.2	100.0
Missing	99	24	21.8	
Total		110	100.0	

Some of the qualitative responses which were given under the category ‘other’ expanded on this prevalence of silence that exists around HIV and AIDS. For example, one respondent wrote:

If infected with HIV/AIDS, the families take control of the infected person by hiding them at home, because they are also afraid of being outcast by the community due to the misconceptions and stigma towards HIV/AIDS.

Six respondents indicated that the community responded openly or positively to a person living with HIV or having died of AIDS. For example, one school teacher stated:

There was somebody who the kids at this school actually know who had died from HIV and they were not at all discriminatory, in the fact that they were quite sympathetic, and that I found quite incredible. I think a few years ago if I had mentioned it, they would have asked “Oh, was he gay?” Or whatever, whereas now it’s, “Oh, that’s awful; that could happen to me”. So it’s a breakthrough.

More however, speak of the stigma that is involved. For example one respondent speaks of the double stigma it causes for disabled people:

People don’t believe that disabled can be infected. Some believe that God has punished them twice.

The remaining respondents stated that they there have not been any known HIV positive people, suggesting that it has not been an issue that their community has had to deal with or respond to.

6.3.3 Teaching Disabled People about HIV/AIDS through Disability Organizations

In this section, organizations were asked questions pertaining to the extent in which education on HIV and relevant topics associated with HIV are provided to people with disabilities, either by the organizations themselves, or other disability organizations.

6.3.3.1 The Organization’s Level of Involvement in Teaching Disabled People about HIV/AIDS

Respondents were asked whether their organization was involved in teaching disabled people about HIV and other relevant topics. Ninety-eight organizations (89%) responded that they were involved in teaching disabled people about HIV and related topics, with 12 organizations (11%) not being involved in teaching (5 were schools and 9 were organizations). Details of what topics are taught are shown in Table 6.7. This table shows response rates based on all surveys completed, thus while out of the 98 organizations that indicated that they were involved in teaching, 96 of these taught about HIV/AIDS (this is 87% of all organizations that responded to the survey).

Table 6.7: Organizations’ Involvement in Teaching Disabled People about -

	Frequency	Percent	Valid Percent
Valid HIV/AIDS	96	87.3	87.3
Safe Sex	85	77.3	77.3
Sexually transmitted diseases	83	75.5	75.5
Drug Usage	75	68.2	68.2
Other topics relevant to HIV/AIDS?	36	32.7	32.7
Total	110	100.0	100.0

Other topics mentioned tended to expand on the other categories, and included teaching disabled people about HIV testing and treatment; using condoms; abstinence; life skills; health and hygiene; healthy sexual relationship skills; and sexual abuse.

Details and descriptions of some of the HIV education programmes

Respondents were invited to provide details of the HIV programmes that are taught in their school/organization. Answers given tended to be brief and in point-form, giving limited details of the range and types of education programme that are available. All schools, however, indicated that HIV education is taught as part of the school's core curriculum, in a subject called "Life Orientation". From some of the descriptions given, this subject is taught up to once a week, and includes topics such as HIV, safe sex, drug abuse, sexual relationships, healthy lifestyle, and so on. It is difficult to assess the quantity and quality of this education in the various schools, and answers here ranged from reporting quite basic and insufficient education, to more intensive education sessions. For example, some respondents merely indicated that it is "part of the curriculum", giving no further details. Some respondents stated how the education that is given was basic. For example, one respondent wrote:

Very elementary: do not touch blood; your body belongs to you; do not walk with strangers

A few other respondents gave more detail about some of the topics that are taught:

1) HIV/AIDS is discussed – e.g. What is HIV/AIDS? How am I at risk? Living with HIV/AIDS. How can it be transmitted? (2) Sexually transmitted diseases: What is it? How can I prevent it? (3) Drug usage: Prevention programs. Various addictions. How do I get help? (4) TB: local clinic explains to the children what is TB, how do we cure it, etc.

Well it's part of the lesson plan. The department of education is very much pushing the HIV/AIDS thing, so we had a chap come at the end of last year to check on what we were doing. So say in mathematics we will use statistics of how many people have died of AIDS, or how many households are headed by children because of it. We use it across the curriculum. Right from grade R level. We've got a full life skills program run by the department on AIDS awareness.

Another respondent states:

We do it actually once a week; it's included in the syllabus. It differs in the time fare for each educator, but we do it once a week with the learners... Mine is on a Monday. I spend a Monday just on HIV/AIDS. We have the booklets we got from the department and the box with the dolls and whatever. We follow a program. I also use the HIV counsellor book. The first quarter I did "What is HIV" again because children with disabilities tend to forget things, so we went back to the basics; what is it; how can we get it? We even did the definitions, so they could know the abbreviations.

A few teachers spoke of the challenges they have in educating learners with disabilities about safe sex and HIV:

I do lifeskills groups with our senior learners. Show them videos and we do role plays. It is an extreme challenge attempting to teach an abstract thought to a concrete thinker.

We do a life skills course and we have books and visual material, but sometimes the books are not appropriate. They can't all read and the pictures are very explicit, so you can't focus on what you want to do with them because now they are all laughing because they see the private parts, so the focus is all off. We separate the girls from the boys. As soon as they reach twelve/thirteen you can't put them together anymore.

At other schools, education tended to occur on an informal level, with HIV being taught or discussed when it became necessary.

We have students here from Ireland who started a program here and started talking to the young girls. The children seem very interested, like the one started crying like mad, so it may be that she has been sexually abused or she lost

somebody through it (HIV/AIDS). We don't always know what the child is feeling. So it is actually... there is a bit of education. [...] There is no real program; it just comes up when it comes up.

Teachers were given training on HIV as to give information to learners. Medical nurse talks to learners about safe sex, drug usage when necessary or when someone is referred to her.

Other forms of HIV education programs reported on tend to take the shape of workshops, or occasional education drives, given to staff as well as disabled people. For example, one respondent wrote:

We offer talks and have guest speakers from the Dept as well as from other organizations – these are for staff, parents and children. We have a school HIV/AIDS policy and portfolio. Staff attend workshops and seminars and disseminate to the staff.

HIV/AIDS awareness through informational sessions to people with epilepsy and other related disabilities who are in residential facilities, protective workshops, income-generating projects and support groups.

Four organizations reported on a dedicated HIV education and prevention programme that had been developed. Two were organizations that cater for Deaf and hearing disabilities. One was an organization for physical disabilities, and the fourth was a regional organization for intellectual disabilities. One other organization was in the process of developing an HIV programme.

For example, one organization for physical disability, describes their HIV education programme:

We have a Trainers on Wheels programme, where disabled persons, their family & friends in the community are trained in HIV/AIDS related matters, prevention, pre- & post- testing, correct eating habits, behavioural changes. There is a strong focus on prevention, testing, the importance of knowing your status, the window period & also the future of life as an infected person, diet to build the immune system, behavioural changes.

An organization for intellectual disability provided details of an education programme that had been developed by them, and was being implemented at various schools. They describe their programme as:

[We] Have recently developed a sexuality HIV/AIDS programme called Step-by-Step for young adults with intellectual disability. The manual is in English and DVD which is used in conjunction is in English, Afrikaans and Xhosa. [We] run a self-advocate group that meets once a quarter. Author of programme above has worked frequently with this group around relationship, abuse, consent and a little bit on HIV/AIDS. Presently there's an HIV trainer (met through using him to train staff on HIV/AIDS from ATICC⁶). This superb trainer up until recently only worked with "normal people". He is trilingual (English, Afrikaans, Xhosa) and obtained funding to train him in our Step-by-Step programme. Running two groups with the author of our programme at a school for learners with special education needs (ID). School-leavers group and middle group. Each group will/is being run for 10 weeks.

The respondent enclosed a copy of their programme manual when returning their completed questionnaire.

⁶ ATICC refers to the AIDS Training, Information and Counselling Centre, an organization which, among other things, provides training for health care professionals, and has offices in various parts of the country

One respondent cautioned on the efficacy of HIV education programmes. This respondent wrote:

(1) 50% + of pupils are cared for by a guardian (mostly grandparent) or in a children's home. (2) Pupils' desperation with no apprenticeship system available to them has made them desperate - Any education on these issues without understanding 1 and 2 will fail

This respondent suggests that other issues (in this case poverty and unemployment) are perhaps more pressing and of greater concern than HIV/AIDS. Thus any efforts to address HIV, without addressing an issue like unemployment and poverty will be fruitless. This type of comment was expressed during the case study interviews, and will be discussed further in Chapter 7.

Reasons why no HIV/AIDS programmes have been set up

Respondents were then asked to indicate some of the reasons why their organizations were not involved in teaching disabled people about HIV. Although only 12 organizations indicated that they were not involved in teaching disabled people about topics relevant to HIV, 33 organizations ended up answering this question, as shown in table 6.8.

Table 6.8: Reasons why Organization has not set up an HIV/AIDS Programme

		Frequency	Percent	Valid Percent
Valid	Not the type of thing our organization does	8	7.3	24.2
	other organizations are better able to handle it	10	9.1	30.3
	Not a significant problem for population served	9	8.2	27.3
	worry about making disabled people more stigmatized	2	1.8	6.1
	Lack of resources / money	13	11.8	39.4
	Other reasons	10	9.1	30.3
Total		33	30.0	100.0
Missing	99	77	70.0	
Total		110	100.0	

This question asks why an HIV/AIDS education programme has not been set up, rather than whether the organization is involved in teaching around HIV. Thus, many schools, for example, while they may do some HIV education within the standard curriculum, do not have a dedicated HIV education programme. The majority of people did not respond to this question, but of those that did indicated, lack of resources and funds was the most frequently listed reason. Another reason which was most frequently listed was the feeling that other types of organizations are better equipped to provide HIV/AIDS programmes, most typically mentioned was health care clinics and HIV/AIDS organizations. Other reasons referred to included lack of expertise; no time available; an HIV program is not regarded as a priority; and that such a programme would not fall within the learner's intellectual capacity to understand.

6.3.3.2 Other Disability Organizations Involved in Teaching Disabled People about HIV/AIDS

The survey questionnaire asked respondents to indicate whether there were other disability organizations in the area that were trying to reach disabled people with HIV/AIDS prevention information. Fifteen organizations did not answer this question. Fifty-two organizations (47%) indicated that there were, and the remainder stated that there weren't any (22%) or that they did not know of any (17%). Some respondents named specific organizations that were involved. These organizations were either:

- Disability Organizations: for example, Cheshire Home for the Disabled; various Deaf associations and societies; Deaf Federation of South Africa (DEAFSA); Association of Persons with Physical disabilities (APD); Cape Mental Health Society; Western Cape Forum for Intellectual Disabilities; other LSEN schools; Cerebral Palsy Association; and Disabled People South Africa (DPSA).
- Government Departments: Department of Health; Department of Education; and the Department of Social Development.
- HIV/AIDS Organizations: Treatment Action Campaign (TAC); LoveLife⁷; ATICC

⁷ LoveLife is the national HIV prevention programme which is directed at South Africa's youth, and was launched in September 1999 (more information can be accessed from <http://www.lovelife.org.za>).

- Local health care facilities
- Other NGOs: for example Hospice; Workshops Unlimited

As can be seen from these answers, there seems to have been a misinterpretation of the question, in that respondents were asked to indicate whether there were any *disability organizations* that were trying to teach people with disabilities about HIV/AIDS. However, answers included non-disability organizations.

Organizations were also asked whether they had asked for help from HIV/AIDS experts and others from the government or local voluntary agencies to reach people in the disabled community. Seventy-two organisations and schools (66%) said that they had, and 37 (34%) said they had not. Organizations or institutions that were most frequently mentioned were:

- The Department of Health (26%)
- The Department of Education (17%)
- Local health care clinics or hospitals (9%)
- Disability Organizations (6%), for example: DEAFSA; SLED⁸; APD
- Other organizations. For example, LoveLife; TAC; ATTIC; religious organizations;
- HIV-positive persons and people living with AIDS to come and talk with learners.

Sixty-two organizations (56%) indicated that the organizations they had approached for help were helpful, and 8 (7%) said they had not been helpful. The remaining respondents did not give an answer.

Those respondents that indicated that they were not helped in most cases were not responded to, or were told that they were not experienced in working with disability. Those that were helped gave some explanation of what it is they found to be helpful. In many cases educational workshops and lessons were provided for disabled people, in formats that were appropriate for the specific disability (for example, using sign language

⁸ SLED = Sign Language Education and Development

interpretation; using non-complex, visual material for intellectual disabilities). Three organizations found it particularly effective to have an HIV-positive person (from Hospice) come and speak to the learners about their experiences. These respondents felt that the presence of an HIV-positive person made the issue more real for the learners. In some cases help was given to the staff and teachers themselves, where they attended training and education workshops on HIV. Personnel at organizations was also given information, pamphlets, videos and other material to use in teaching learners or disabled people they served about HIV.

6.3.4 Teaching Disabled People about HIV/AIDS through Non-Disability Organizations

In this section, organizations were asked questions pertaining to the extent in which education on HIV and relevant topics associated with HIV are provided to people with disabilities by non-disability organizations, and to what extent disabled people are included or excluded from general HIV prevention campaigns.

Responses to various questions indicated that fewer disabled people are reached by general HIV prevention messages than non-disabled people perhaps are. Table 6.9 shows that of the 85 respondents who answered this question only slightly more than half reported that there are non-disability organizations teaching disabled people about HIV/AIDS.

Table 6.9: Extent to which Non-Disability Organizations have taught on various HIV/AIDS topics

		Frequency	Percent	Valid Percent
Valid	HIV/AIDS	59	53.6	69.4
	Safe Sex	51	46.4	60.0
	Sexually Transmitted Diseases	48	43.6	56.5
	Drug Usage	44	40.0	51.8
	Other topics relevant to HIV/AIDS	10	9.1	11.8
Total		85	77.3	100.0
Missing	99	25	22.7	
Total		110	100.0	

Less than half of the respondents reported that non-disability organizations are teaching disabled people about other issues relevant to HIV/AIDS. Similarly, when respondents were asked to assess the extent to which disabled people are reached by HIV prevention messages meant for the general population, more than half indicated that disabled people are only partly reached by HIV prevention messages (Table 6.10).

Table 6.10: Disabled People reached by General HIV Prevention Messages

		Frequency	Percent	Valid Percent
Valid	No	35	31.8	35.7
	Few	10	9.1	10.2
	Some	19	17.3	19.4
	Most	23	20.9	23.5
	All	4	3.6	4.1
	Do Not Know	7	6.4	7.1
	Total	98	89.1	100.0
Missing	99	12	11.0	
Total		110	100.0	

This issue was explored further when respondents were asked to evaluate the amount and accuracy of the information received by disabled people. Sixty-four respondents (58% of total sample) felt that the amount of information reaching disability community was less than that reaching the general population, and only 34 respondents (31% of total population) felt that the amount of information reached by the disability community was equal to that reached by the general population. A minority (4%) felt that the disability community was getting more information on HIV. This was the case for all types of disability, with respondents stating that less information was reached.

With regards the accuracy of the information, sixty-one respondents felt that the information reached by the disability community was as accurate as that reaching the general population (55.5% of total sample). Fewer felt that the information was less accurate (28 respondents, or 25.5%). This was the case with all types of disabilities. Thus, while most respondents felt that the disability community was getting less information concerning HIV than what was reaching the general population; most felt that this information was as accurate. A few schools felt that their learners were receiving more

accurate information as a result of the school's education efforts. For example one respondent stated:

I would say they get more accurate, because you still have some out in the community giving those myths like taking a shower or things like that (that's the one thing popping into my mind right now), or sleeping with a virgin and then you're not HIV positive.

This person speaks of the many myths that prevail in South Africa about preventing HIV transmission, the virgin-cleansing myth being one that has been around for many years. This person also refers to the myth of showering after sex as a way to prevent HIV transmission. This was prominent at the time, due to comments reportedly made by Mr Jacob Zuma, who was previously the Deputy-President of South Africa. Mr Zuma had been accused of rape and the case was brought to trial in 2006. During the trial, it was reported that Mr Zuma had had unprotected sex with the accuser, an HIV-positive woman. Mr Zuma was the director of the National AIDS Committee, so when questioned about his risk-taking behaviour, Mr Zuma was reported to have responded that he felt he had reduced his risk for HIV infection as he had taken a shower immediately after having sex without a condom (Green & Gordin, 2006; MacGregor, 2006).

Another respondent wrote:

I think sometimes it's a lot more accurate. I think we can explain it a bit better because it's a school environment. They might come with an article and ask what is happening and we can explain it in a bit more detail.

One particular respondent, from an organization for persons with physical disabilities and intellectual disabilities, was uncomfortable with these questions, and wrote:

There is no basis for a distinction between disability and able-bodied HIV/AIDS

This response was perhaps given in misunderstanding the question, but it also echoes some of the comments made in section 6.3.1 above, where some respondents stressed the equality of disabled people towards HIV risk, and distancing from constructions of disabled people as a distinct population group at risk for HIV.

Reasons for why respondents felt that disabled people might not be reached by most of the HIV prevention messages reaching the general population are shown in table 6.11.

Table 6.11: Reasons why large HIV/AIDS Campaigns have been Inaccessible to Disabled People

		Frequency	Percent	Valid Percent
Valid	Because they were Radio Programs	28	25.5	29.5
	Because they were Television Programs	26	23.6	27.4
	Because they were Billboards	18	16.4	18.9
	Because they were other written materials	42	38.2	44.2
	Because they were complex materials inappropriate for intellectually disabled	65	59.1	68.4
	Training/Education session locations not accessible by wheelchair	20	18.2	21.1
	Training/Education sessions in which no sign language or captioning was available for those who are deaf	32	29.1	33.7
	Other ways	12	10.9	12.5
	Total	96	87.3	100.0
Missing	99	14	12.7	
Total		110	100.0	

The high number of respondents stating that information is too complex for persons with intellectual disability is consistent with the fact that the disability type that is most represented in this survey is intellectual disability (as shown in Table 6.3). Other factors are specific to some other types of disability - for example, information given in radio and television programs would be inaccessible to persons with hearing disabilities, and information on billboards would be inaccessible to persons with visual disabilities.

Some of the answers given by respondents with regards “other ways” in which disabled people were excluded from general HIV/AIDS campaigns, tended to expand on some of

those already listed. For example, stating that information given on television was not subtitled for Deaf persons. Some other comments made were that general HIV campaigns did not specifically target disabled people. One respondent also stated that:

Deaf persons have a reversed idea of positive and negative

This alludes to the confusion that some people have with the concept “HIV-*positive*” referring to something that is negative (i.e. it means that you are infected with HIV).

Respondents were asked whether there have been attempts by non-disability organizations to put HIV/AIDS prevention messages into more accessible formats. Only 33 organisations (30% of the total sample) said ‘yes’, with the same number saying ‘no’. The remainder were not sure, or did not answer. The various formats that were mentioned were: Educational cartoons and picture material for learners with intellectual disability; Videos and written materials for Deaf learners; Educational plays; Audio tape and material in Braille for Blind learners. Reflections on how well these alternative formats and programmes worked, were varied. In some cases, respondents indicated that these formats had only recently been developed and were about to be used. A few respondents felt that the picture materials had worked well with learners with intellectual disabilities as they were less complex and made it easier for learners to understand concepts. Three respondents were not positive about education programmes, attributing the failure to broader issues. For example one respondent wrote:

They have had little success because of the “culture” of hopelessness. I reiterate the desperate need for a proper and government funded apprenticeship system so as to provide hope for our youth. Each government department seems to work with blinkers on. Is there nobody in power who is capable of seeing the whole picture?

This response came from a school for learners with various disabilities. When respondents were invited to make any additional comments at the end of the survey

questionnaire, this respondent wrote, with what seems to be a sense of anger:

The sense of hopelessness in our poorer communities, aggravated by being mentally challenged, without any state help after school to help provide training and eventually a qualification is the Achilles heel of all our efforts so far. Until this is recognized and remedial action taken, ordinary South Africans have no choice but to continue their miserable life of hell.

The respondent alludes to the marginalized positioning in society of disabled people, and the sense of hopelessness that learners have with regards their future, which overrides all other concerns.

6.3.5 Help and Support for Disabled People with HIV/AIDS

In this section, organizations were asked questions pertaining to the extent in which disabled people can access support and health care for HIV and AIDS.

6.3.5.1 Access to HIV Testing

Of the 108 respondents who answered a question on whether disabled people known to the organization were able to be tested for HIV, 52 (47%) said ‘yes’. Forty-eight indicated that they did not know (44%) and the remainder said ‘no’ (7%). Respondents indicated reasons why some disabled people might have had difficulties in getting tested (Table 6.12)

Table 6.12: Reasons for disabled people having difficulties in getting tested

		Frequency	Percent	Valid Percent
Valid	inaccessible clinics	10	9.1	15.2
	there's no one willing to treat them	4	3.6	6.1
	no sign language translation	12	10.9	18.2
	other difficulties	18	16.4	27.3
	Total	66	60.0	100.0
Missing	99	44	40.0	
Total		110	100.0	

One respondent stated how it wasn't so much that disabled people could not access HIV testing, but rather did not want to. This respondent wrote:

That's a problem here [...] people are afraid, so they don't even ask. It's a no-go zone.

Other difficulties mentioned tended to focus on negative attitudes from those testing, and challenges faced by those doing the testing, as well as negative attitudes and anxieties towards testing on the part of disabled people,.

Attitudes of and challenges faced by those testing

Some respondents spoke of the negative attitudes towards disabled people that some health care staff holds. In particular was mentioned the assumption held by health care staff that disabled people are not sexually active, and thus do not need to be tested. As one respondent wrote:

People believe that they shouldn't be sexually active hence there is no need for them to be tested

This attitude also may drive disabled people away from being tested, for example another respondent wrote:

Adolescents with visual impairments tend to distrust health professionals and don't want to go for testing because of the negative attitude of health professionals towards their sexual needs

Another issues that was mentioned, was difficulties around getting informed consent for HIV testing, particularly from learners with intellectual disabilities. One respondent wrote:

Difficulty getting informed consent from patients. We call parents in to discuss

consent, if they have guardians/parents. It is a moral/ethical dilemma for us; we feel that we need to know if the status is positive to protect staff and other residents

This respondent's comment also speaks of anxiety about not knowing learners' status. This person refers to a danger in not knowing; that staff and residents can protect themselves if they knew who is HIV-positive.

Closely related, are the concerns and fears of disabled people themselves towards HIV testing.

Negative attitudes and anxieties of disabled people

Some respondents indicated that in a few cases disabled people do not go for testing because of ignorance or denial. Other respondents indicated that disabled people they work with might be afraid of going for a test. For example, one respondent wrote:

They don't want to know their status believing that if they test positive, they will have problem with the outcome.

For some, there is distrust about the confidentiality of the test results. This seemed to be a particular issue for Deaf persons, where there seems to have been some experience reported of nurses not keeping test results confidential. The extent of the problem around confidentiality as well as communication of test results with Deaf persons is explained by the following respondent, who lists various issues in point form:

(1) not understanding test results; (2) Discuss with hearing family, friends about test results and treatment because of no SASL interpreter services available; (3) No counselling; (4) no clarity on prescription of medication and side effects; (5) Can't communicate to doctor on side affects; (6) sometimes poor assistance and accessibility at police stations in cases of rape.

These concerns on the part of disabled people about the confidentiality of test results are related to the pervasive stigma that continues to exist in South Africa about HIV/AIDS. However, when respondents were asked in an open-ended question whether they knew of any disabled people who were reluctant to be tested or receive care for HIV, out of fear of word 'getting around', more respondents (55) answered 'no' (50%) than 'yes' (28%). The remainder did not know, or did not answer. However, it was mainly those persons that answered 'yes' that explained their answers, and wrote about the problems of stigma. Some wrote about the fear about HIV stigma. For example, one respondent wrote:

The whole issue of stigmatization and myth surrounding people living and infected by HIV/AIDS make people with disabilities reluctant to go for counselling and treatment because they are afraid of the kind of treatment or attitudes they will get from their families and general public. The process of accessing treatment for HIV/AIDS is very long and costly. They are also very afraid of disclosing to everyone along the process.

A few also wrote about the stigma associated with disability, and how this keeps disabled people away from getting tested. Some comments made were:

Parent sometimes hide the disabled people or children, because they feel embarrassed to be seen with disabled people. Some parents lock them in houses, and not even seek advice from the relevant people

Another person writes about persons with visual disabilities:

A major problem is that people with visual impairment experience so much rejection that they don't want to come forward and be humiliated again. People expect that they are asexual (myth/stigma). Because of this perception they fear rejection by others

For a disabled person with HIV, there is a double stigma associated with the disability and with HIV. One respondent states:

Some families cannot bear a second stigma because being disabled enough is a stigma to other people. Having HIV/AIDS is worse

The respondents stress on HIV/AIDS being “worse” points to the seriousness of HIV stigma that exists.

6.3.5.2 Access to Health Care: HIV Diagnosis and Treatment

While there seemed to be some exclusion of disabled people in getting tested for HIV, fewer respondents indicated that disabled people had difficulties accessing health care because of their disability. Only 11 respondents (10% of total sample) indicated that they knew disabled people who were unable to access health care because of their disability. Some of the reasons given were lack of sign language interpretation for Deaf person, negative attitudes of health care staff towards disability, and problems around giving consent (in the case of severe intellectual disabilities). In contrast, 94 (85%) respondents indicated that they didn't know of any disabled people unable to access health care.

With regards to HIV diagnosis and treatment, respondents were asked two open-ended questions. The first question was:

Sometimes people who are disabled are diagnosed with HIV/AIDS much later than non-disabled people, either because they do not recognize the symptoms, no one tells them about the symptoms, no AIDS clinic welcomes disabled people, or they are afraid and do not know much about HIV/AIDS. Have people you know had any experiences with this?

There were fourteen respondents who did not answer this question. Twenty-two (20%) said ‘yes’, and 74 (67%) said they did not know of any disabled people to whom this might have happened. Some of the answers given by those who said ‘yes’ pick up on some of the issues already mentioned, such as:

- Reluctance to come forward because of stigma associated with disability or HIV:

It is a taboo to be disabled and then comes the HIV/AIDS subject, it becomes even more for the disabled people and the perception of people who need to help people with disabilities with regards to HIV/AIDS symptoms

- Ignorance and denial about HIV:

Some are just ignorant (they don't believe that HIV/AIDS exists), especially in very rural areas – there is no proper flow of information in so much that HIV/AIDS is seen as a myth. The result therefore is fatal. People die without information.

Another respondent wrote:

Because of their intellectual disability they might not even be in a position to understand the message concerning risks in relation to HIV/AIDS. The other aspect is ignorance and denial to those who understand HIV/AIDS perfectly. Even if they see and recognize the symptoms they will blame witchcraft and something else / misconception that goes with HIV/AIDS

- Issues around confidentiality:

This was mentioned as an issue for the Deaf in particular:

A few cases where Deaf people were informed on their death bed about their HIV/AIDS status. Ignorance plays a role. Inaccessible health care services. The confidentiality is a problem in spite of the interpreter ethics. Please bear in mind that professional interpreting started a few years ago. Often family members act as interpreters which is dangerous. Abused Deaf women also plays a role – too scared to come forward and again the matter of interpreting services.

- Access to clinics and health care facilities:

People with disabilities often find it very hard to stand in long queues to be helped at hospitals or clinics because they mostly need assistance going to the toilet or just getting around in the facility. Therefore they are not keen on going to the clinics/hospitals and ignore symptoms of illness. Sometimes they are told to come back the following day. Public transport is not suitable for physical disabled and it is very difficult for the disabled to obtain transport which is suitable for them. This is also very expensive. They tend not to go back. People with disabilities tend to get tired easily, pending on the disability, waiting to be seen by medical personnel, but as no attention is paid to the special needs of disabled people, they often leave before they are seen

For persons with visual impairments, they may be reliant on others to take them to health care facilities, which also impacts on confidentiality:

Adolescents with visual impairments firstly experience problems, because their privacy is compromised. Cannot go alone to clinics – need somebody to take them.

One respondent suggested that parents of children with disabilities may be reluctant to access health care, in order to hide sexual abuse:

Family prefers to ignore it because person with disability was abused by family member

One person in particular was uncomfortable about this question, saying:

No. Your assumptions are questionable

This came from the person who was uncomfortable about the distinction made between

disabled and able-bodied people. This person's response may come from a position of not thinking about ways in which disabled people may be discriminated against or excluded from health care, but it again reflects the discomfort about the use of 'disabled people' as a separate category.

With regards to HIV treatment, the second open-ended question asked was:

Sometimes people who are disabled do not get as good medical care as people who are not disabled. This is particularly true when people who are disabled need expensive drugs, or extra care or hospitalization. Have you ever seen this happen when someone with a disability is diagnosed with HIV/AIDS?

There were 20 respondents who did not answer this question. Fourteen (13%) said 'yes', and 76 (69%) said they did not know of this happening to any disabled person diagnosed with HIV/AIDS. Some of the answers given by those who said 'yes' refer to broader issues of poverty and unemployment in South Africa, and problems of adequate health care in South Africa, rather than this being an issue to do with disabled people per se. As one person wrote:

It is surely the way with people who have medical aids; they get taken care of properly and get the best of medication if diagnosed HIV+. It is the poorest of the poor that does not get good care or does not even have the financial means to get to the clinic to collect ARV treatment.

Another person wrote:

In the RSA we no longer have a system for the proper medical care of those with less money. Unemployment, because they cannot afford tertiary education, remains a disease.

Access to treatment in public health care is also limited by the demands placed on limited

resources. As one person states:

We send them for ARVs the moment the CD4 count is less than 200, but the waiting list for ARV clinic is 2 months.

In other responses, people did write about some of the issues related to disabilities. One person wrote how disabled people may already feel hopeless about their future health, and thus not seek treatment:

Some believe if they die its better because they are already suffering with disability and if they are HIV/AIDS affected it makes it worse, and it scares them to look for expensive drugs. This is compounded by that they are poor they can not afford to buy for themselves.

Another respondent indicated that this was not only a view that may be held by disabled people, but by the health care staff as well:

Expensive care/treatment is often not available – particularly to those who have other major disorders/complicating conditions and whose quality of life is seen to be not optimal anyway.

Another respondent also spoke about poverty, but elaborated on the positioning of disabled people in a poor family. This person felt that there was no discrimination with regards health care, but goes on to write:

BUT, the problem is: (1) who takes care of the medication? (2) buying of expensive drugs. Caregivers do not dedicate themselves in buying these drugs, they abuse the money on their own and other siblings interests.

This person raises the possibility that family members, who have control over finances, and in particular the disability grant received by the disabled family member, might make

use of the money in ways that discriminates against the health needs of the disabled person.

Two people wrote about particular issues for specific disabilities. In the first case, one respondent wrote about the problems associated with interpreting treatment instructions to Deaf persons:

I can only comment with regard to Deaf people. It is important that instructions of taking medication must be clearly understood, i.e. “every 6 hours not interpreted as 06h00 and 18h00”. Doctors must explain to Deaf people the normal and dangerous side effects. Deaf people must understand what is wrong with them, why, how to protect themselves and the treatment – this hardly happened. At this stage, it is recommended that certain clinics and hospitals be identified and provide them with SASL interpreter services.

Another respondent writes about problems that persons with psychiatric disabilities may face:

Sometimes mental health service users find it difficult accessing general medical services as they are only seen as psychiatric patients. This obviously affects the help they will receive in the case of HIV.

As with the first open-ended question discussed above, one person was uncomfortable with this question and wrote:

No. Again your assumptions lack substance.

As with the previous question, this person’s response may be as a result of not thinking through ways in which disabled people may be discriminated against or excluded from health care, as well as reflecting a discomfort in differentiating between disabled and able-bodied people.

6.3.5.3 Access to Help from Police or Legal Services

Final questions on the survey asked about the extent to which disabled people with HIV and disability organizations have attempted to seek help from the legal system, and whether they were helped. A minority of respondents indicated that they knew of disabled people who had tried to get help from police or legal system (9%) or that their organization had asked the police or legal system for help (16%). In the majority of cases respondents indicated that they were helped. Only two organizations felt they were not helped. One of these stated that they were turned away because their learners were “mentally handicapped”.

6.3.6 Additional Qualitative Comments or Observations Made

The survey questionnaire had a space allowing respondents to make additional comments or observations should they wish to. Forty-two organizations or schools took this opportunity to say more.

Disabled people are excluded

Many of the additional comments provided, expressed gratitude for the attention given by the survey study on the issue of HIV and disability, which respondents found to be an important issue that needs to be addressed. This echoed observations that disabled people have been largely overlooked with regards HIV/AIDS. One person commented on this, stating how disabled people are not represented in HIV campaigns:

We think it will be better that people with disabilities are involved in all spheres of life where HIV/AIDS program are done, ads and posters, so that people will know that the disabled community is also affected and infected by HIV/AIDS pandemic. If you look at all adverts, it's the youth mostly targeted and what about the disabled community. To us it gives the impression that people living with disabilities will always be behind in everything until its late or they are all infected by the deadly disease.

One person commented on how disabled people in rural areas are particularly excluded from HIV prevention campaigns:

I can see there is a trend towards more information, particularly in the schools about AIDS, and that's a good thing. The children are being made aware of it. I think in the rural areas there is not enough information going around. I don't think they give out information so easily. But luckily because the children are deaf they end up in hospital, so in a way their deafness is an advantage because they get access to medical health care and then they discover that they are HIV-positive, so in a way that's a good thing. But we are getting in more children who are HIV-positive.

Many also gave their recommendations on what should be done. For example, some general comments about how non-disabled people should think about and treat disabled people:

there should be more awareness on HIV/AIDS to people with disability, where we can find them, on pension points because they are difficult to get when you want them. The ways of giving information to people must be understandable to people in their language and clear visuals. People must learn to treat people with disability as normal as possible, so they won't abuse them. The government must also change the process of getting HIV/AIDS treatment, because people get it late and end up dead, not getting helped and lost every cent they have. People that works on HIV/AIDS must learn and understands the ethics about the work especially Confidentiality and privacy and their attitude must change especial to people with disability

HIV/AIDS affects everyone, irrespective of your status, whether disabled or not. People living with disabilities are normal like any other person, so, when dealing with HIV/AIDS, programmes or anything, let people with disabilities be treated

like any other person. HIV/AIDS, like any other sickness cannot see me as an abled or non-abled body – it affects us the same

Others gave suggestions on what health care clinics can do to assist persons with disabilities get information on HIV/AIDS:

Hospitals and clinics should employ deaf to assist for deaf patients about HIV/AIDS counselling. Many deaf prefer deaf AIDS counsellor because it will be easy for them to communicate using sign language. They feel comfortable. They never comfort discussing with hearing people and not trust them too.

Disabled people should not have to wait so long for a grant because by the time they finally get it, they are already dead. There is no special place they can go, we can go to the hospital but then everyone can see “oh she is going for AIDS”. We need privacy.

Disabled people are at risk

Other comments added to responses already made in the questionnaire, elaborating on issues, particularly stressing the vulnerability of disabled people for being sexually abused and raped. For example:

Children with behavioural problems come from dysfunctional families. They are often neglected, physically and emotionally, and many of them are sexually active from a very young age. At this centre we have several HIV/AIDS programmes and the learners are protected from abuse while in our care. When they go back to their communities for school holidays they often are not able to make the right choices. The reason may be that they do not get the support from their families and/or that they have not yet internalized a sound system of values and norms. In my experience, knowledge alone is not enough to bring about a change in lifestyle.

Other respondent raised concerns about other related issues, such as unsafe sexual behaviour:

As the multi-disciplinary team working in the school and hostel, we are especially worried about the hostel situation and young children experimenting with sex play. We continuously have to guide these children and warn about moral and medical implications. Our children often come from families where they are exposed to inappropriate sexual practices (i.e. Many sex partners, prostitution, rape, incest).

The recycling of sexual relationships within a minute community and in some instances sexual starvation can lead to irresponsible risky behaviours. Family pressures to have kids can also lead to risky practices in the quest to prove fertility. Attitudes of healthcare workers in some instances can deter VCT as focus is on disability rather than on what the person needs.

Lack of resources for organizations and staff

A few respondents commented on the lack of training for their own staff about HIV, as well as the lack of appropriate resources:

We try our best to adapt the programs ourselves, but there is really not a program for the disabled people. We get training, but it is six weeks and that's it; no follow-ups. So it is difficult to get into the community and train other people because my knowledge is so limited. We could do with continually updated reports that are forwarded to the disabled community.

Well we had a problem with the curriculum. The one we do have now is on a much simpler level but I would say those pamphlets are still too much reading for them and most of our learners can't read; they need pictures. They need something like a play; even the older kids enjoy a grade 1 play. That is also a way of getting through to them.

Education not always effective

Some comments related to how education does not seem to change behaviours. For example, one person commented:

many learners seem to convey that they “know all about AIDS” – all seem to know how HIV/AIDS is contracted, but take a chance with unsafe sex. Have they become over exposed that at times seem almost blasé!?! The myth that the HIV+ person will be thin and appear ill seems a difficult one to dispense. Increasingly, learners’ family members are affected/infected by HIV/AIDS – this they understand but the implications and medical regime are difficult for them to process as conceptualizing an immune system, CD4 counts, etc., is problematic. The chronic illness of a patient is very traumatic for our learners as they are more reliant on their caregivers than learners in a mainstream school. The lifestyle changes needed to prevent HIV spread are known by the learners – however the integration of same info into their daily living remains problematic

HIV is not a big issue

Some respondents commented that while they recognize the importance of HIV education, they stressed that HIV had not really been an issue of concern at that stage. For example, comments such as:

[Name] is a small school (22 learners) who come from protected homes and we feel that they are at this stage not at risk

As a school with learning disabled children it is our aim to educate them in the best way possible to become aware of HIV and AIDS and any relating issues. To date we have not experienced any exposure, that we know of, to HIV and AIDS at our school. Some of the community are reluctant to become involved in our education programme, but we persist as we realize the importance of this.

Another respondent writes:

To the best of my knowledge, none of the children/students/ young adults at this school is HIV positive. They certainly are at risk, some more so than others. At this stage, it is not notifiable, so we would not know before symptoms appear. This has not happened to date. We do have an awareness programme, but as with all sex education in those who are intellectually disabled, it is difficult to know how successful one's input has been.

In many of these comments, the respondents report on the stigmatization of persons with disabilities, as people comment on how disabled people are not treated like “normal”, are excluded, and need to “prove” their sexuality. Respondents also comment on the stigma of persons with HIV, with comments made about associating the presence of someone at a clinic with AIDS, and associating thinness with HIV.

6.4 Conclusions

This chapter reported on the results of the survey. Both quantitative data and qualitative comments were reported on. The results indicate a high level of concern about the risk for HIV infection for persons with disabilities, with the majority of respondents feeling that disabled persons are at increased risk for HIV infection, because they are vulnerable to sexual abuse, engage in unsafe sex behaviours, and lack knowledge about HIV prevention. Overall, the survey suggests that organizations and school working with disabilities (at least those who responded to the survey), are providing HIV prevention education to the disabled persons they work with. However, most respondents felt that persons with disabilities are excluded from general HIV prevention campaigns, and thus receive less information about HIV prevention, and that in some cases the information received was less accurate. With these results in mind then, the next chapter reports on the results of the case studies, which focus on staffs' narratives about working with topics such as sex, sexuality and HIV, and explores some of the anxieties and emotional experiences involved in this work.

CHAPTER SEVEN

CASE STUDIES

7.1 Introduction

The previous chapter reported on the survey results. In this chapter I write the results of the case study analysis. I will write about the three organizations separately. In each case study I, begin with a reminder of the sources of data (described more fully in chapter five). Because the case studies make use of qualitative data, I use participants' quotes, sometimes lengthy quotes, to explore the reported experiences in each organization. After each quote I have indicated which participant is speaking by providing the research number allocated to him or her.

7.2 Case Study 1: A Support Organization for Institutions Working with People with Intellectual Disabilities.

Horizons⁹ is an organization, that is regionally based, that provides support services to a number of organizations and schools working with persons with intellectual disabilities. This organization had in the past few years developed a sexuality and HIV education programme for adolescents and young adults with intellectual disabilities. The programme was designed with a manual which could be purchased by organizations for use for staff to run the programme at the schools and organizations. The organization also provides training for facilitators of this programme, and recently started a supervision group for facilitators from various schools. Although this organization does not work directly with disabled people, they were selected as a case study because of having developed an HIV education programme.

7.2.1 Sources of Data

As the organization provides a supportive service to a variety of schools and organizations, data were collected from interviews with various parties at different

⁹ A pseudonym has been used to ensure anonymity of the organization.

organizations. Thus although it is not a case study of a single organization, the participants were associated by working together on the sexuality and HIV education programme. Data was collected from:

1. A series of individual interviews with key figures:

- The coordinator of the organization, who had been working there for just over 7 years at the time of the interview;
- The developer of the Sexuality and HIV education programme and principal facilitator and trainer of the programme, who had working contractually with the organization for approximately 5 years at the time of the interview;
- An HIV counsellor who had recently joined the organization as a co-supervisor of the teacher supervision group.
- A senior staff member at an affiliated organization for persons with intellectual disabilities, who had run this education programme at her organization, with groups of young adults. She had been working at that organization for 13 years at the time of the interview

2. One focus group interview, with a group of three teachers from two different affiliated schools, who were facilitating the program at their respective schools, and were part of the supervision group.

3. My own experience of being a participant co-facilitator of a sexuality and HIV education programme with a group of 8 male adolescents and young adults with intellectual disabilities.

Of the seven individuals interviewed for this case study, two were male and five were female.

7.2.2 Overall Impressions of the Education Program

Although the intention of the study was not to make an evaluation of the education program, all participants provided some impressions of the program. All participants felt positively about the education program that was developed and was being used. They felt it was an effective way of teaching children and adolescents with intellectual disabilities

about issues of sex education, sexuality and relationships, and HIV and other sexually transmitted diseases. They felt that it provided a method for providing necessary education that was not being met in the general curriculum. For example one participant stated:

It is part of the national curriculum: life orientation. But special schools, because all the resources, everything for mainstream is impossible to do with learners with intellectual disabilities. You see learners in the senior phase, being stuck with books of the grade one, grade two level, which is basically colouring in pictures and it's all quite meaningless anyway unless you manage to take it off the page. So the premise of the work that [we] have been doing is, that sexuality is about who we are and it's about relationships. (Participant 1B)

This person's impression of the 'Life Orientation' subject in the national curriculum provides an additional impression of the varying quality of this education offered at schools (see discussion in chapter 6).

Participants also felt that it was a program that was appropriate for the disabled individuals that they worked with, although one participant expressed the difficulties of making such education accessible for persons with severe intellectual disabilities:

And then of course the degree of disability does obviously make an impact as well – how much you can learn. That would be the downside of this program – it's that it's geared, but I mean what can you say. I don't think it's easy to teach someone who is severely disabled, intellectually disabled. How do you ever teach them about their rights, their "yes" feelings, their "no" feelings? (Participant 1D)

The above person refers to severe disability, but other participants commented on the challenge of communicating a complex message to all learners with intellectual disabilities. This will be discussed further below.

My own experience of the program is that it was a comprehensive program that taught about a variety of related aspects: social and sexual relationships, positive and negative sexual experience, body parts and bodily fluids, sexual intercourse, sexually transmitted diseases and HIV, safe sex and condoms. The program used a variety of materials to aid education, for example, puppets, pictures, clay models, role-play, and group games.

All the participants in this study had direct (and in one case indirect, but knowledgeable) experience of facilitating this education program. Despite the overall positive sentiments about the program, and about being a facilitator, their interview narratives revealed a number of struggles with teaching persons with intellectual disabilities about sex, sexuality and HIV.

7.2.3 “People don’t want to go down that road”: Perceptions of Resistance by Others to Raising Sexuality Issues

Although a sexuality and HIV programme has been developed and is being used at various schools, there was some indication from the interview participants that there was, and still is, some resistance from affiliated organizations in using this program at their schools. This was largely discussed by the director of the organization, who recalled some schools who were reluctant to take part in implementing this program. For example, she says:

Organizations which have a huge problem with sexuality, we haven’t seen. And I find that very tragic that they couldn’t be bothered but I don’t think it’s a resistance issue I just think people don’t want to go down that road and then decide they couldn’t be bothered or are too scared to embark on stuff. (Participant 1D)

She went on to talk about a particular example:

There’s a huge organization dealing with intellectual disability that I work a lot with and they have always been incredibly supportive of [our] work. They will

bend over backwards to support me and to help me and we decided we would run a pilot program at their facility [...] I contacted the director, who will do anything for me. She said “[name] please, I can’t go there I’m too scared of management” (Participant 1D)

When I asked her to elaborate, she went on to say:

Because they would freak out that they are now teaching people to become sexually active. And this particular organization – I opened to ... - I think it was about five years ago. They did a bit of work around sex, the next minute rumours were spreading that they were teaching all their residents how to have sex and that they must now all have sex. And she said “what!” And I think just for her – I respect her because she gives me so much support, she actually just thought at this stage, “I actually can’t go there now. I just can’t face having extra hassles”. (Participant 1D)

Other participants recalled the resistance raised by school staff in earlier years, when the idea of sexuality education was raised. One person recalls:

I can remember must have been about 6 to 7 years ago that the [name of organization] came to a group home meeting and it was the first time this thing of sexuality was talked about and I can distinctly remember the response from some of the sort of house mothers or staff were like very shocked (Participant 1A)

Another recalls the conflicting opinions among staff at the school in which this person works:

When we first draw up our sexuality policy we had the input of - first it was just the management and then we gave it through to all the other staff members and asked for input and then we got a lot of input and some of them – you know – a

total no-no, actually not suppose to sit next to each other in front of TV almost
(Participant 1E1)

The participants are referring to comments made by others; comments which seem to suggest the perception held by others that teaching intellectually disabled persons about sex and sexuality is potentially dangerous, as it is akin to giving them permission to have sex, and will thus encourage sexually expression (Craft, 1987).

Participants also talked more generally about anxieties of parents and staff that they had become aware of. These were more general comments of what the participants viewed as some of the difficulties people have in doing this work. For example, one participant talks about the challenge for some of talking about subjects of sex. Many of the participants also referred to general perceptions with regards the sexuality of persons with disabilities, that they are either asexual, or “oversexed”. For examples, comments like:

I think there's a huge fear of destroying the innocence of the intellectual disabled. That whole method that they're either over sexed or that they are so utterly innocent. People who are always children, forever children and you can't even begin to tell them because you think they won't understand. (Participant 1B)

You know for a long time, and it still lives to a certain degree in South Africa, there was this thing that people with disabilities are not sexual you know and the parents would often discourage relationships so in the context of this organization basically you never talked about sexuality of course there were people that were in a sexual relationship but they would probably go behind the dairy or in the bush or something like that (Participant 1A)

These are perceptions which have been documented in the literature (for example Craft, 1987; Heyman & Huckle, 1995; see further chapter 3). Participant 1A provided an explanation consistent with psychoanalytic thinking for why she feels parents have this anxiety:

There's already issues around sexuality for people with disabilities, you know, from the first moment of conception, even carried in the parents. It was that moment of conception to do with sexuality that created this person with disabilities. So they carry a lot of stuff and in more, sort of, sophisticated families, put it that way, it's quite an intense and heavy thing. And I think that's why often in families they don't talk about sexuality because in the parents you could say is this kind of guilt, that if they haven't resolved the fact I think it's very hard for people to have a child that's disabled. It's a personal thing, you know, the father either interprets it as it's his seed his semen or the mother interprets it as my womb. So it's deeply personal, deeply subconscious. I think it can then be projected because generally parents often they just cannot imagine their child being sexual and I think it's all sort of complicated (Participant 1A)

This participant is not a parent of a child with disability, so is not talking from personal experience, but rather from her impressions from working closely with families over many years. The above comments relate to parent's reported anxieties about the link to disabled people's sexuality and reproduction (Martorella & Portugues, 1998)

In the above quotes, participants are talking about other staff and parents, rather than their own feelings and anxieties. While it is very likely that the organization and facilitators have confronted this resistance and anxiety in other staff and parents, this may also allow the participants to project their own anxieties into others; so that the resistance is seen as coming only from others and not themselves. Using the psychoanalytic concept of splitting, the participants initially position themselves as 'good' (those who are concerned and are doing this work), and others as 'bad' (who are opposed). I say "initially" because later in their interviews some of the participants' own anxieties about similar themes of sex education as potentially "dangerous", and disabled sexuality as inappropriate emerged. Some of the participants were more conscious of this than others.

7.2.4 Challenges in Getting the Message Across

Many participants talked about the challenge they had in educating persons with intellectual disabilities about quiet complex topics associated with sex, sexuality and HIV. The challenge here was about finding ways to make the educational material understandable – how to explain complex, abstract concepts. One participant states:

it's always trying to think concretely. How can we show something that's an abstract concept that we take for granted (participant 1B)

This was particularly challenging for a participant who had only recently began working with persons with intellectual disabilities. This participant commented a few times on the challenge of getting the message across. For example, the participant said:

when I had to be involved with a specific group of people, intellectually disabled people, it was quite a challenge for me. And struggling a bit to be able to understand and taking things for granted, saying things, a lot of words, not knowing that words get confused with words and concepts. Rather to demonstrate things so that they can understand it. And I think that was my, taking for granted, thinking that I was talking to mainstream people but meanwhile this specific group of people do not understand me. That was my difficulty. (Participant 1C)

However, this participant later mentioned having a sibling with disability, and that part of the frustration is having had the experience of the sibling being misunderstood by others.

At home I think I have communicated and been aware and quite frustrated when people don't understand my brother because it's quite personal you know. And I think through that, those experiences I was – I had my own sort of gut feeling and also...ja, my own feelings, and also how we should communicate with people and be quite aware how they are people with feelings to. They get hurt. I think my past experience also was always sitting there (Participant 1C)

Part of the frustration and anxiety then is to not hurt the feelings of those with disabilities, as the participant's sibling was hurt by being often misunderstood. As Roberts (1994) argues, human service care workers are drawn to the helping professions with a need to make reparation for harm. Anxiety occurs about their own potential to harm and damage. Being misunderstood, and more importantly not understanding the intellectually disabled person has the potential to hurt feelings, and thus harm.

Teaching about sexual intercourse was also difficult as it raised uncomfortable feelings in the facilitator, due to the need for graphic description, which may feel inappropriate at times. For example, one participant said:

Another difficult area to teach about is that actual sexual act. How to you teach about the actual sexual act? In the old, the organization I worked with, we had beautiful puppets made. Four-foot puppets and the man, he could have an erection, it lifted up and you could put a condom on him and he could have sex with the women. So you could put together, I mean it's incredibly skilled puppetry, you couldn't leave those in a school easily for teachers. And it was also incredible how the transference from the puppeteer into the person, we all now sort of felt like we were in the relationship, we could all start feelings of heavy breathing internally, it became dangerously crossing the line somewhere, which is difficult. So now I've made lots of these little cut out characters. And I got them clothed in underwear and naked. Now it is possible to show sexual positions with that or maybe a little bit of sexual touching without, but again it does feel crossing the line somewhere and I don't know whether that's just my personal embarrassment (participant 1B)

Another participant also comments on this:

the intimate sex section it is more difficult. But last week now, we had split the groups - she took the men and I took the ladies. But then, the soon as you sort of started, and you see how they really listen to me, and how they really, you know,

in their way, they attend and ask questions and it becomes more easier. But it is not easy. And I also think it is the way how you personally have grown up and how you have lived your life and that kind of thing – you know what’s it about, but it’s not that easy to explain it to somebody (participant 1E1)

While the participants were more conscious of these difficulties, their interview narrative also revealed a further, less conscious, tension with regards educating on matters of sex and sexuality – a tension between the need for education, from a human rights perspective, and the need to control sexual expression from more personal views and attitudes.

7.2.5 Tensions between a ‘Human Rights’ Discourse and a Discourse of Control

Although all participants were involved in providing dedicated education around issues of sex, sexuality and sexually transmitted diseases, and it is work that they are not “opposed” to doing, their interview narratives revealed considerable ambivalence about providing sexuality education. From the interview narratives, there emerged a sense of a tension between a ‘human rights’ discourse which supported sexuality education and the recognition of the sexual rights of persons with intellectual disabilities, and a discourse of needing to control or restrain sexual expression. On the one hand there was a recognised need to allow persons with disabilities to lead fully sexual lives, but there was also a more implicit need to control the sexual expression of persons with disabilities. This was revealed in two interrelated ways. Firstly, significant tension existed between ‘human rights’ and constructions around morality and what is regarded as moral sexual behaviour. Related to this was a discourse of allowing disabled people the right to have sexual relationships, while simultaneously describing the sexual expression of intellectually disabled persons as inappropriate, problematic, and even dangerous, and thus needing to be controlled.

“It’s the whole morality question”

For some, the tension existed in that providing sex education in effect gave sanction for intellectually disabled persons to engage in sexual relationships, which was problematic

for organizations that had a Christian ethic. This was an area of personal struggle for the facilitators, who themselves had a Christian moral ethic. This was spoken about most in the focus group interview. For example two participants said:

Participant 1E3: In similar centres like ours, you do get centres still that, where they absolutely – I mean, it’s just like sex is a no-no and I mean in our environment, it is not that sex is a no-no. But what we say to them is, what we try to teach them is that when you have sex with somebody you need to at least be in a partnership of at least a kind – not like a one day, two day setup situation. So the first thing you need to be in a good relationship before you can think of sex. That is what we are trying to teach them. Then the second thing is, we are trying to teach them about privacy. Now I ask you with tears in my eyes where on our grounds are you private? Cause I mean we are in the middle of mid-town. Right around us are houses. So even if I am behind the building I am right in the window of the neighbour next door. So unless you have specific rules that they can use or you say alright you can go into each others rooms, which are not allowed, where are they private? So actually you say; “no sex”.

Another participant adds to this, by saying:

Participant 1E1: And if you have, like we said we will call it private lounges, if we have that and is being used for that, then you have to pass our board management who hold consistent clearance. And you have the morality thing again – the church – is it no right for a church organization to have a place available where people can go and have sex?

Although the participants speak generally about organizations being concerned with questions of morality, this was also personal concerns, indicated at times by the use of the pronoun “we”. The above comments also show the facilitators anxiety about needing to promote a certain type of sexual relationship – long-term partnership. This arises out of fear that what may happen instead is that sexuality education would promote uninhibited

sexual behaviour. This is made more explicit in the following discussion about the provision of condoms:

Participant 1E2: Just one question, Does the centres provide condoms for this kind of ... because I know at our organisation, after I given them AIDS/HIV training, I put the condoms there and I, even female condoms and all the stuff. I teach them about all the stuff. I've encountered that some of the centres don't even make it visible; there is the condoms you can take it.

Participant 1E3: Ja, ja. We don't have it available as such. I do have some in my drawer, you know. But that's part of the morality ... And also your people all go home at night; ours stay there. So that makes it a bit different.

Participant 1E2: Maybe in the hostels there need to be a centre, maybe a suggestion just, look here on this table there is the box of condoms, in a basket or what – and ... if you go past there you can take one condom or two condoms. Of course we all now ... rules but at lease it is available.

Participant 1E1: It is part of the whole morality question. And I think this is between staff also. If you now make it available like that, do you give the okay that you can have sex left, right and centre, you know?

The above participants draw on discourses of intellectually disabled as sexually uninhibited, positioning themselves as the good, moral person. The participants, although involved in providing sexuality education, struggle with their anxiety of opening up 'Pandora's box' as regards the sexual behaviours of persons with disabilities. If they provide sex education, then *they* will "have sex left, right and centre". These anxieties about sexual abandon are projected onto the people with intellectual disability who come to be seen as threatening their sexual morality. The way to manage this then is by attempting to control the sexual behaviours of persons with disability, by making the availability of condoms difficult, and promoting particular types of relationship. The

participants spoke further about, while providing sex education, needing to prevent and control certain types of sexual behaviours and certain types of sexual experiences. This will be picked up again a little later.

Two other areas that raised difficulties for some of the participants was the question of allowing pre-marital sex and the question of homosexuality. Both were unacceptable to some because of their Christian faith.

“Pre-marital sex is still out in terms of my personal belief”

For two participants, there was a struggle with “allowing” pre-marital sex for persons with intellectual disabilities. This was against their own personal religious beliefs, and made them uncomfortable in terms of providing sex education and so giving sanction for sexual relationships, which would generally occur outside of marriage. The participants were conscious of their own anxiety with this, and it did not prevent them from providing sex education, but they were aware of the difficulties this raised for them. For example, one participant states:

A lot of them or a couple of them are church-based and that – there’s this huge debatable issue around pre-marital sex. So basically you don’t want people to be sexually active and so we try and shut it down. And yet there’s one facility which I am hugely impressed with. I don’t agree with all the things – their whole style of work, but they have really tried to look at alternatives around sexuality. They have certainly as an organization debated it. And for me – I have huge respect for them. Yes they are struggling and saying if you need to be married before you can have sex. The reality is that the majority of these people never get married. And so it’s a very – for me as a Christian person myself - hugely difficult issue.

(Participant 1D)

Although this person speaks primarily about the beliefs of organizations, she also refers to her own difficulty with this, most clearly in the last sentence. But also previously she says “you don’t want people to be sexually active and so we try and shut it down”. She

seemed to be reporting on a particular discourse about preventing sexual relationships, but she locates herself within this discourse by the use of the pronoun *we*. A little later this participant states more directly:

Pre-marital sex is still out in terms of my personal belief. And I will never be faced with having a child with intellectual disability because I do know that marriage and intellectual disability are not easy options. And yet to deny someone the opportunity not to have sex, I mean there are many single people who don't ever have sex. (Participant 1D)

Another participant also comments on this difficulty:

A lot of tension also comes with different, how can we say, morality levels, or what people think about what is sin and what is not sin and whether it is now a sexual relationship before marriage. But can they marry? How easy is it for them to marry? Can they be in a longstanding relationship? What is a longstanding relationship in their sense? Some of them don't even really have a time concept. You know all they – even amongst staff, there is tension because we are struggling, we are still - with our sexuality policy – every time we discuss it, we stumble along. How can you separate your personal values and your personal religious beliefs from how you look at it professionally and human rights? And can I prescribe for another person what his morality should be like? And then the other tension is that we are a church organisation ... how do you get by with that. .. a lot of tension. (Participant 1E1)

The above participant speaks of her own difficulty with allowing pre-marital sex. Although in many ways she speaks in general terms, she also speaks from personal experience, when she revealed a little later in the interview that she is a mother of a child with disability.

Providing sex education, then, and “allowing” for the possibility of pre-marital sex, becomes a threat to the self. The two participants, rather than unconsciously splitting this threat away from themselves onto others (as would be the case in what in Klein terms a paranoid-schizoid position), they have a more ambivalent experience of it, accepting their own feelings about it and the threatening aspects of this. They experience this from the depressive position, where they are able to tolerate their own ‘positive’ and ‘negative’ experience of this.

One participant described how the beliefs of organizations made sex education difficult for her, and she raised this very tension in providing sex education:

I suppose in sense there are a lot of people with intellectual disabilities that relationships sometimes aren't on offer for them, so you're stuck with this contradiction that you needing to teach about sexuality, HIV and Aids and relationships and yet, perhaps for some, relationships aren't encourage and others relationships is actually forbidden. And then some would perhaps have relationships but fairly supervised (Participant 1B)

So while this participant wants to provide sexuality education, she is aware of how this may be a “contradiction” for some, who are prevented from having sexual relationships.

“Homosexuality – this is also a huge issue”

As with pre-marital sex, another area of tension was the inclusion of homosexuality in the sexuality education programme. Freedom of sexual orientation is a protected right in South Africa's constitution, and for this reason homosexuality was included in the sex education programme – not as a separate topic, but rather in portraying both heterosexual and homosexual relationships and sexual encounters (both consensual and non-consensual). However, the inclusion of homosexuality was a source of anxiety for some of the participants, who spoke of it being against their religious and moral beliefs. One participant, for example, said;

For me it's also an issue of homosexuality. I don't know if my children are going to be gay one day. That is also a huge issue. Because it's all very well saying the church position of it: you can be gay but you can't practice it. If my child is gay I don't think I would say that to him. It's like, what am I going to do? What about marriage? I don't know, I just haven't had to face it you know. The realities are some people are gay. I don't know whether you [*the interviewer*] are, I don't know. But for me it's such a hugely difficult issue. It's very nice to dictate to the world what to do: don't have an abortion. What if I have a severely disabled child, I knew I was carrying a child that was disabled. I don't know what I would do?
(Participant 1D)

The above participant's comments are interesting. She begins to talk about the issue, for her, of homosexuality, and immediately starts asking herself what she would do if she had a gay child. She ends off however, talking about the choice of abortion, of she should know she should have a severely disabled child. This could be interpreted as homosexuality, as well as disability itself, being so 'monstrous' as warranting the possibility of aborting. She stresses both homosexuality and disability itself as unwanted, echoing Sinason's (2001) argument that no parent longs for a disabled child. The 'monstrous' aspects of homosexuality, and disability, are such a threat to herself, that she imagines that it may only be possible to manage that by eliminating the threat altogether.

The above participant also wonders as to my own (the interviewer's) sexual orientation. I am a gay man (I did not state this at the interview, however), and this particular part of the interview became rather uncomfortable, for both of us. During my participation in the sexuality education programme, some anxiety arose in me with regards my own sexual orientation. During the first few sessions, the students participating in the programme, starting asking me whether I was married, had a girlfriend and so on. I was aware of anxiety about making my sexual orientation known. Part of the anxiety was based on the perceived moral issue around homosexuality with the organizations I was working with. The construction of homosexuality as immoral was drawn on by some of the students themselves, when during one of the sessions, a homosexual relationship was depicted as a

choice. The response from some of the students was that this was “disgusting”. In order my own sense of anxiety about the threat to self, I chose to silence the topic of homosexuality. I regard my own response as understandable; I was just trying to maintain my privacy. But this raised a thought for me about what it would be like for a homosexual disabled youth participating in this education programme? This highlighted for me the tension that existed for the participants about the ‘need’ to promote a human rights approach to providing sexuality education, and the need to promote particular sets of moral norms, and so it seemed to me that sexuality education may be used to silence some aspects of sexual human experience, and promote other aspects. I will return to this argument a little later.

In other studies, the inclusion of homosexuality in HIV prevention education with intellectually disabled learners has been met with some controversy and opposition (for example Newens & McEwan, 1995). The inclusion of “accurate and valued images of homosexuality” (Cambridge, 1998, p. 70) in HIV prevention education for intellectually disabled people is a challenge. For the writer of the education programme, the inclusion of homosexual relations was a source of difficulty as she struggled to think about ways to include homosexuality, without offending others:

areas that can be difficult in terms of this work, and I think one of the most important areas, especially in terms of HIV is same sex relationships. How is that raised in your group? And I think that is a area that there can be a lot of resistance from teachers. But also do you choose to put same sex relationships on a equal? Do you present them equally with heterosexual relationships - it could be this or it could be this? Do you leave it very general to say two people and if the penis goes inside the other person? Because I do that sometimes; “the penis goes inside the anus or the bottom of the man”. So you leave it to be more ambiguous, where otherwise it could be either a man or a woman. But I haven’t actually ever in the character work developed a same sex relationship. With the character work we’ve developed a relationship between a man and a women from meeting right through

to deciding to have a sexual relationship. But I haven't done that same sex, that's probably my resistance

She does not speak about her own moral values around homosexuality, but rather the struggle that she has in including homosexuality in a way that will not be interpreted as offensive. Her comments show her awareness at her own silences around this.

“We weren't saying that you can't have a sexual relationship, but if you are going to this is the healthy way”

When talking about risk factors for HIV infection, some participants described the sexual behaviour of persons with disabilities as potentially promiscuous and uninhibited. While most stressed that such behaviour was no different to non-disabled persons, some of the ways in which these comments were made tended to stress the promiscuous behaviour of intellectually disabled persons in particular. For example, one participant commented:

lots of people are never sexual in their lives and I have to say that in our sector in the world, people with intellectual disability, I have seen people, oh oh my goodness, are, I mean would sleep with anyone and everyone. It's like they are just people like normal people. Those who are very active and those who are absolutely non-active (Participant 1D)

The person above comments on promiscuity, and although qualifying her comment in the second last sentence by referring to disabled people being just like “normal” people in this respect. The stress placed on disabled people's behaviour (“oh my goodness”) suggests the notion of uninhibited sexual expression. One facilitator spoke of her awareness of her own anxiety about what she perceives to be the consequence of providing sex education, that it will give disabled people sanction to try things out, it will release the disinhibition, in a way. She states:

I still feel, and I think it's important to listen to this, I still feel anxious at times when doing work on masturbation. I mean I have very explicit pictures or

introducing condoms in a packet. I mean I still have feelings of anxiety. Is this going to be okay? I always fear, is someone going to go off and prove the, the fear that I think is around sexuality education, that that means that they are going to go off and act out what we have been teaching them (participant 1B)

This experience or perception of the sexual behaviour of intellectually disabled persons led to a tension on the one hand to provide sex education and allow for the rights for sexual relationships, but at the same time controlling the expression of this. This is evident in comments made by one participant:

We weren't saying that you can't have a sexual relationship, but if you are going to this is the healthy way. They suddenly kind of found themselves in a free adult space and out of that could make educated choices as well (participant 1A)

We support relationships, long term relationships, but I'm not encouraging people (snaps fingers) to go from boyfriend or girlfriend like that. (Participant 1A)

Promiscuity is, of course, a risk factor for HIV infection, and part of the general HIV prevention campaigns involve the promotion of one, faithful sexual partnership. However, the issue here seems to lie in the question of choice. The above two comments show that while recognizing the need to provide a "free adult space" in which choices can be made; attempts are made to restrict "choices" to acceptable "healthy", "long-term" relationships.

This anxiety also became evident to me during one of the education sessions that I participated in. At one point one of the students was talking about seeing a movie on television, where a man was in bed with two women; what I interpreted as a scene depicting a sexual threesome. I became aware of an anxiety in me to try and stress this as "unhealthy" form of relationship to the student. Of course, there is some basis to this, in that it can be considered unsafe sexual behaviour, and, if it occurs within a relationship, could create emotional difficulties for the primary couple. However, after the session I

reflected more on my anxiety and what that was about. I started to think that it was not just a question of it being truthfully ‘unhealthy’. If the three people had used condoms, it would be safe sex. And there are many cultures in which polygamy (not necessarily threesome sex) is acceptable. My anxiety, I felt, mostly around needing to “shut down” this possible sexual behaviour for the student. To enter into a discussion around it, may ‘awaken’ in fantasy the student’s desire to have such an experience. It was easier then to depict this as ‘bad’ and something that he should never do. I was drawing on discourses that sex education will promote sexual behaviours in persons with disabilities, as with participant 1B earlier when talking about masturbation.

Some participants described how residences are segregated for males and females, and that part of the ‘work task’ is to be “very, very aware” that there is no sexual contact. At the same time, condoms are made available at some residences. So while promoting safe sex, sexual contact itself is controlled.

Other participants also spoke of the segregation of the sexes in residences in an effort to prevent sexual contact. This time, the construction of sexual contact was as being potentially abusive. One participant states:

See we are the one hostel. Sixty-seven in one hostel. I mean you can’t have a male walking in the corridors where a lot of other girls are there and they go in their pyjamas to the bathroom and things like that, you know? You can’t allow that. Because then you have no control over abuse. Because then any male can go in there and abuse the ladies, especially lower functioning ladies (Participant 1E1)

The need to protect persons in their care against abuse is a necessity, of course. However, part of the interview narratives draw on the constructions of the sexuality of disabled people as deviant and potentially dangerous, accompanied by a need to control behaviour. The organizations, which have disabled youth in their care, are called upon to protect their population from harm, and abuse is a reality that needs to be prevented. In some

instances, however, the potential for abuse raised an anxiety in facilitators in trying to teach females to say 'no' to sex.

the main thing for me is still the fact that they are allowed to say "no". Girls are allowed to say "no". That is so, so important. (Participant 1E2)

Another person also spoke of the potential emotional danger that relationships may bring, in the form of stress for the disabled person:

I'm quite open around sexuality. I see that one thing I am a bit - although it happens I've done it myself (*inaudible*) - you leave somebody for somebody else. It's a classic scenario in life. But it's very hard for people with disabilities; to leave the one who's leaving and the one the new relationship. I think there's a tremendous amount of work around that [...] people can move on faster if they don't ponder too much go too deeply into the whole thing, but there's got to be, you've got to be constantly aware of where people are at. Because something like that can actually, I think you know, it's quite easy for people with an intellectual disability, which is so different to psychiatric, there's a lot of - and I've seen it a lot - of unworked through, build up over time in a person with an intellectual disability. They just suddenly turn psychiatric and then they end up intellectual dual diagnosis (participant 1A)

The above participant speaks of the need to protect disabled people from the potential emotional damage that relationships may bring, when relationships end. This draws on constructions of disabled people as innocent and needing protection from some of the more difficult realities of life.

7.2.6 Discussion: Using Sex Education to Promote Particular Behaviours

Through my own experience of participating in the education program, and in examining some of the more ambivalent narratives in the interviews, I was left with an overarching

sense of a tension existing between providing sex education and promoting human rights, and the need to control the sexual expression of persons with disabilities.

Interestingly, many of the difficulties expressed by participants were around communication – how to communicate complex, abstract constructs to persons with intellectual disabilities - a ‘task’ which my impression is the sexuality education programme has attempted to achieve very well. My study was not an evaluation of the education programme, but my impression of it was that it was a comprehensive, creative, well-designed program that covered a variety of important areas. However it seemed to me that there was a difference in how sexuality education was used to convey a certain “message”. It is interesting then that an anxiety existed about how to communicate and get the message across – the question is: what is *the message*?

The narratives reveal a conscious ambivalence in some participants and a more unconscious conflict in others about needing to promote a certain kind of sexuality. It is not just about providing sex education and education about HIV, but it is about the need to ‘control’ the sexuality of disabled people in a way that is “moral” and “healthy”. It seems to me then that there is a potential to teach sex as being ‘bad’ by emphasising sexual abuse and disease as the consequences (and only consequences) of sexual relationships. This is not to say that this is what participants *are* doing. No observations were made of how facilitators did the education. The program that I did participate in had a facilitator who was very experienced and conscious of her own anxieties. But here I was aware of areas in which I silenced some sexuality issues, thus promoting a particular message. The narratives expressed some constructions of the sexuality of intellectually disabled persons as potentially deviant, inappropriate and even dangerous – sexuality behaviours that needed to be controlled. One way of doing this is to construct sex itself as ‘bad’. This is suggested in one participant’s comment, when talking about educating her own disabled child and other children about sex:

I’ve got a child with intellectual disability as well, so every time I think how I as parent feel; how I would have or could have put this to good use many years ago,

if only I had it this way. And now for all those parents who can't talk to their children and don't know how to talk to their children and never have spoken to their children about their sexuality, I just need to do it. I need to do it because they need it. They need it as people. They need to know. *They need to know that they can be empowered to say no* that they can be – that sexuality is actually very nice and very beautiful. The fact that I am a woman and you are a man and the two of us are totally different but we can be in a *friendship* and we can be in a *nice friendship and that sex is not, not the issue*, or should not be the issue in a relationship – as it was mentioned - it is just the cherry on the top in the long run. *It may really not come to that point, and never have to come to that point* because a relationship, as such, can be nice and beautiful and lekker¹⁰ and all of that *without having actual sex*. And then of course the dangers; what sex these days look like. (Participant 1E1 – emphasis added)

Although on the one hand, the above person talks about sexuality as being potentially “beautiful”, her anxiety sits mostly with *needing* to promote abstinence; that a relationship is possible, and perhaps even better, *without having actual sex*, because sex is dangerous these days. This very clearly demonstrates the anxiety that is raised by confronting sexuality in persons with disability; it confronts us with notions of damage and vulnerability (Marks, 1999a; Sinason, 2001). Sexuality education then can be used as a means to prevent sexual expression in persons with disability. This is complicated by the real danger of HIV. The prevention of sexual expression in persons with disabilities has a long history, and there may be a difficulty in using disease as a reason to avoid sex. This may play into the stigmatized experience of persons with disabilities, as one participant explains so eloquently:

This whole thing around sexuality and condoms is also creating a kind of - there's something wrong with my fluids, cause I also have to use a condom. Or there's something wrong with her body, that I always have to have something between us, you know. And that's like another thing on people [...] It is a stigma, I think.

¹⁰ This is a colloquial Afrikaans term meaning “nice”

It's a fact because historically condoms were there to stop babies from happening. But now basically are there because you get sick; either I'm sick or you're sick, therefore - and I don't know if you're sick or not, kind of thing. So I think it's also creating a strange, you know, subconscious. And I think that's just generally in all people, you know. And they sometimes, I think, don't want to use a condom because they want to defy that thing. I mean that's my theory on why a young person just doesn't want to use a condom. Because we are all sort of anarchists on some level and we're being dictated to by something; either it's LoveLife boards or its this virus that nobody can even see, and I think - I don't know how to, I mean, I'm thinking about, I'm not sure yet, how to communicate those kinds of things to people with special needs. But it is a weird thing a condom, you know. When you think about sexuality and, I don't know, semen and all of these things, its like 'life'. And now you always have to stop 'life'. You always have to stop it, and you have to wrap it up. I mean even in the book tie a knot in it, wrap it in toilet paper, and throw it in the dirtbin, you know. There's something very "mmm" about it. Or, and I think that's what's also going to be a challenge with people that's not disabled, to, I don't know, free that spirit which I think is making people a bit depressed. And then with people with special needs, I don't know, maybe it's enough to just think about it. I'm not sure (participant 1A)

The above person reflects on the experience that condoms create for persons in general – a stigmatizing effect about one's self and bodily fluids. That the self is so dangerous now that 'life' needs to be stopped. This echoes historical thoughts about the sexuality of persons with disabilities, and the need in the past, and still today, to prevent births. Sterilization was commonly used as a way to 'stop life' and also 'control' the sexuality of persons with disabilities. Sexuality education today, in the context of HIV and an awareness of the prevalence of sexual abuse, may be used to similarly 'control' and prevent the sexual expression of persons with intellectual disabilities.

7.3 Case Study 2: A School for the Blind

Hillcrest School¹¹ is a school for children and adolescents with visual impairments, including partially-sighted and blind students. The school is located in one of the less-privileged suburbs in Cape Town, and has African¹² and coloured learners, many from under-privileged backgrounds. In recent years youth with other disabilities have also been enrolled in the school. While the vast majority of learners have visual impairments, there is a small minority of learners with physical disabilities (resulting from Cerebral Palsy), and learners with intellectual disabilities, who do not necessarily have visual impairments. According to some of the teachers who participated in the interviews, the school has learners aged four to twenty-one, with the majority of students being fourteen and older.

According to the completed survey questionnaire, the school does not have a dedicated HIV prevention program, but sexuality and HIV education is included in the curriculum under the subject “Life Orientation”. The school has made materials available in Braille for the students. Other occasional HIV awareness events are conducted in addition to the life orientation classes. The responses from the survey indicated that learners with visual disabilities were understood to be at increased risk for HIV infection. The respondent felt that persons with visual disabilities received less information concerning HIV than non-disabled persons, but that the information that was received was as accurate as that received by the general population.

7.3.1 Sources of Data

To summarize the sources of data (discussed with more detail in chapter 5), data was collected through individual interviews with different key members of staff, as well as a focus group interview with some of the school’s teachers. Specifically, data was collected from:

¹¹ The name used here is a pseudonym

¹² See footnote 1 in Chapter 2 on the use of racial categories under apartheid South Africa. These racial categories continue to be used today in South Africa as a means of describing people. I make use of them

1. A series of individual interviews with key figures:

- Two of the deputy-principals of the school. They were interviewed separately. Both had been working at the school for between 11 and 12 years.
- The school's only nurse, who had been working at the school health care centre for three years at the time of the interview.
- The only school psychologist, who had been working at the school for approximately eight years.

2. One focus group interview, with a group of three teachers, who taught various subjects at the school, but who all have at some point done some education around sexuality and HIV. All three teachers had also worked in the hostels at some point. One of the teachers was himself blind. The teachers had been working at the school between 16 and 25 years.

Of the seven individuals interviewed for this case study, two were female and five were male.

7.3.2 Unseen Dangers: “Are there Persons with HIV around?”

In all the interviews, participants stressed blind learners being exposed to spilt, possible contaminated blood (which they could not see) as being the primary risk factor. A typical comment to this effect was:

touching contaminated blood and not knowing; not realizing maybe there is blood on something and touching it. That's one of the dangers I would say for the blind (participant 2A)

The participants' narrative contained considerable anxiety with regards not knowing who was HIV-positive or not, and the potential danger of learners being exposed to contaminated blood. Their discourses were that of the HIV-positive person being unidentifiable, and in this sense the anxiety was around the “unknown” danger of who

here, as they are referred to in the data. In some instances the term 'black' is used to refer to 'African' learners.

was infected and who wasn't. This may mirror the blind learners' possible anxiety about "unseen" dangers. One participant commented:

It is difficult if, you know, the confidentiality clause around people with HIV. What do you do? Do you tell people who is the HIV positive child? Because people want to know who's – because they know whenever we approach them and say, people please be aware, treat every person as a person with HIV, because that is our approach. Because we want you to protect yourself against infection so and so .But then they continually go around – who is the person, are there persons with HIV around? (Participant 2B)

'Not knowing' causes significant unconscious anxiety for individuals who may be left feeling vulnerable by an environment that cannot be controlled. Going around trying to find out who is HIV positive or not (as mentioned by the person above) is an attempt to control that anxiety. Some of the participants stressed that the school's policy was to treat all learners as if HIV-positive, and so using universal precaution. This did not seem satisfactory though, as anxiety about not knowing was evident.

Although most participants were concerned about the learners risk to touching and being exposed to contaminated blood, there was some anxiety in the interview narratives about their own risk of exposure to contaminated blood. One of the teachers in the focus group stated:

I just wanted to say something regarding the confidentiality issue. I mean, if I look at the situation now at the hostel. I know myself, and my wife knows about the youngsters in the hostels. But it's not easy, you know, to tell even. Lets say I'm not at the hostel for that particular time and this particular child, you know, gets hurt or bleeds and I haven't tell anyone of the supervisors, and by that time they have just out of ignorance, just touched the child and helped the child, and later on found out, "but listen here, something is wrong here". In that way, I would say, I'm also a bit – how can I call it – advocating the fact that you should

actually inform the colleagues. They trust them, right? And even I would trust their integrity; they are going to handle that child in the same way as they is going to handle all the others (Participant 2E2)

The other teachers in the group agreed to what this participant said. ‘Knowing’ would allow supervisors (and teachers) to protect themselves against infection. Despite comments made that the HIV-positive child would not be treated any different, the suggestion that ‘not knowing’ and using universal precaution as being unsatisfactory and not safe enough, suggests otherwise. This is also suggested in another part of the focus group interview, where comparisons were drawn between HIV and leprosy:

Participant 2E1: I had one situation in class where one of the learners had a seizure, actually. I was busy teaching this – how to handle a person with [*inaudible*] - and I made the mistake by going to the boy without proper care, and I took the boy down to the clinic and I came back and I asked them [*the other learners*] “what mistakes did I do?” The problem is here it was a class full of totally blind learners, and I was late in class and they started – but no, maybe this boy, this learner has a disease. But what if, and then want to help, and then it’s a problem because - not being informed who is and who is not. No. But that is a very dangerous thing because now it’s like, it’s like – what was the old - the Bible that had -

Participant 2E3: Leprosy?

Participant 2E2: Leprosy?

Participant 2E1: - and that is a thing that a person should avoid.

The risk for HIV infection through exposure to contaminated blood is not considered to be significantly high (see for example, Havens and the Committee on Pediatric AIDS, 2003; Tokars et al., 1993). Tokars and colleagues (1993) calculated the risk for HIV infection after being exposed to contaminated blood to be 0.36%. There is then a minor risk for a person, with an open wound or cut, to be infected with HIV through touching contaminated blood. However, some of the participants seemed very concerned about the

potential risk from exposure to blood. The source of this anxiety, aside from the anxiety that ‘unknown’ raises for many of us (as it increases a sense of vulnerability), may stem from the risky sexual behaviours that are known about and seen. The participants spoke about some of these sexual behaviours, and the interview narratives contained an expression of these behaviours being ‘out of control’, that the teachers and staff could not do anything about that – exposure to blood then, and knowing who was HIV-positive or not, was the area that could be controlled.

7.3.3 “You can’t stop it”: Sex and Pregnancies, Despite Safe Sex Education

Most participants had some sort of comments in their interview narratives relating to the prevalence of (unsafe) sexual practices, despite efforts to teach about HIV and safe sex. This was something that teachers felt they had no control over. Some typical comments were:

Well if a child still goes and has sex, what can we do? At least we have a program where we try to inform them on a regular basis (Participant 2B)

I only make sure that they are informed. What they do at the end of the day, it is out of my hands (Participant 2A)

We try our utmost to prevent such things but the kids do go home. So it’s not a matter of that we have them for twenty-four hours and we can see and look after them for twenty-four hours. They do go home and they can pregnant and can get infected over a weekend (Participant 2B)

Most of the participants openly talked about their learners engaging in sex. One participant however, was less direct in talking about this as happening at the school, framing the prevalence of sex in broad, general terms. For example, he says:

It creates an opportunity. I mean, people might differ. I mean, at the end of the day you can say, well if there is sufficient supervision then it won’t happen. But I

mean, this school yard is massive. I mean, I suppose it create easily opportunities for sexual encounters. I mean, you have a lot of places, you know. And then, I mean, the hostels has a – and this is only a view it is not supported by hard evidence – but I know hostels have a particular history of especially sodomy. In that particular context. I mean, that has been a characteristic of hostels or dormitory type of resident. Because if you look at our hostels, most of them are dormitories. And if you look at the range of children from severally blind and profound and mentally handicapped; small children, you know, being in the presences of bigger children. And although the incidences of that is not very high but the – it has – it becomes a concern (participant 2D)

He speaks of same-sex encounters (which most other participants do not comment on), but it is done within a kind of hypothetical speech. His comments allude (quite strongly) to what happens at *this* school, but in an effort to protect himself, he stresses that this is “not supported by hard evidence”, and that it might be possible, because that is a particular “characteristic” of hostels and dormitories. When I asked him directly whether this had occurred at the school, he said:

There has been incidences , but usually we try to pick it up as early as possible and once we see that guys or children are engaging in same sex type of relationships then we send the offenders home (participant 2D)

Another participant recalled the embarrassment he felt when he walked in on two learners who were having sex in the hostel. He recalled:

I just got a hunch from one of the prefects that a boy took one of the girls into the hostel. And I just went to the hostel, and when I got there the door was locked. And I got my keys and I opened. When I opened the room he thought it was his roommate. I walked in and they both were totally blind and they were busy. I just got into the room turned my back and said to him, “listen Boet [*brother*], I’m in the room, you get to finish with what you’re busy with” [*laughs*]. I reported the

incident to the principal and what he did after that, I don't know. But, I mean, you should have seen my face and my reactions at that time! It was very, very difficult. I don't want to be in such a situation again because it wasn't – it wasn't nice and it was embarrassing. (Participant 2E2)

From what some of the participants said in their interviews, the prevalence of pregnancies seems to be a fairly recent phenomena. For example, one participant reflects back:

for many years at this school we were really proud in saying okay we don't have any pregnancies and then all of a sudden I think it was that specific year when I started the HIV program, two of the kids in the program became pregnant. The one actually died but she didn't die of any sexually linked diseases. But she eventually died and for me it was a question of was the program effective, why did you still go and get pregnant? So I said it was at their own decision. It was her own decision to go and have unprotected sex irrespective to what we do in the programme (Participant 2B)

This person referred to a learner who had died in the past. Only one other participant mentioned this incident. Having learners become pregnant is difficult for any school, but this particular incident seemed to have been particularly traumatic for the school, as there was much conflict within the school at the time on how to deal with this issue. This may have been particularly stressful for one staff member who became very involved with the case. She described the incident with some detail. She described how two years previously, during the change of the school nurse, the learner did not receive her contraceptive injection, and fell pregnant. As she did not menstruate, everyone assumed she was still on the contraceptive injection, and so her pregnancy was only discovered after six months. The staff member goes on to describe what happened:

When somebody really picked it up she was quite far and she was six months pregnant already. Then we had the problem she was medically not very well, she was high risk [...] the area where she comes from in the Northern Cape is quite

desert – there's no hospitals nearby where they know – the ambulance, they phone the ambulance they comes four, five six hours later, you know. And we knew that was the situation so much that we didn't want her to go back home, we wanted her to have the baby here. And then the majority, quite a few of the teachers – not say the teachers – more of the seniors, that were informed about the situation (not that I think everybody was informed of the situation eventually), felt keen that okay fine let her stay on in the hostel as long as possible, being high risk for medical reasons as well. There was quite a few that was still very cattish and wanted her out, away from the school and didn't support the whole – we actually eventually then tried to place her outside the school, until the child is born. She herself had some issues; she didn't want to stay with this one and didn't want to stay with that one, you know; people who was really willing to take her. And the school was even prepared to support her financially as well [...] the people she wanted to stay with, we knew wasn't in any real situation to really care for her the way she should be cared for, and if anything should happen she would be exactly in the same bad situation almost than she would have been at home. And because of this fighting and thing going on, eventually we just got tired and said, "Well now you have to decide; you want to go home, then you go home. We've done everything. These are the option we put to you. These are the things you didn't want to have done" and... - opted to go back home and she herself knew the risks, you know, that if she needs help. Or we told her she is high risk and that means she might have to have a caesarean, and you can die if you don't get that help in time. She eventually decided she's going to go home. We spoke to the parents. We spoke to the mother – not so much to the mother but the granny self – and we spoke to the sister, her older sister who informed then the mother. She insisted eventually she's going to go home [...] the person at the – it's actually a family member of hers – that I contacted, he was kind enough to get her in Kimberley and take her home and then I explained to him the whole situation; that he must explain to the mother that these are the dangers. I also contacted the social services that work with them in the area. I faxed the letter with all the information, all the dangers. Besides all that, she went into labour. She couldn't give birth. The

ambulance came five, six hours later. Eventually she didn't make it. They got her to the hospital, but she died a few hours later. She had the child and, you know, those were the things we were trying to prevent. And I think quite a few of the teachers that was so insensitive actually felt very bad when this had happened, because these were the things we warned them about and these were the reasons why we said the child must stay (Participant 2A)

The details in this story reveal numerous conflicts amongst various parties, as each had opinions about how the situation should be handled. The death of the girl then appeared to have caused considerable guilt among the staff, who were at odds about how best the girl should be helped. This participant lays the blame firmly on others, including the girl, who did not agree with what she felt was the correct procedure for handling the situation. This may have left the participant with feelings of anger, as well as guilt for not having been able to "save" the girl. This is reflected in her interview narrative where she at various stages talks with much anxiety about her attempts to tell others "the facts", particularly individuals from other "cultures". This will be picked up on below.

The various extracts above describe the prevalence of sex and pregnancies among the learners. Participants attempted to find an explanation for this prevalence. Some participants felt that the youth of today had a different moral ethic to them in their day. Comments to this effect were:

You see, the issue with older guys, is that sex, according to them, you can only exercise sex within marriage. And that's the issue that are going around. Now these days sex is totally something different. (Participant 2E1)

The thing that's really creeping me is this recreational sex. In our days you had your partner, and you stayed true to your partner but these days it's - I've got an urge and I have to... (Participant 2E2)

And you can't stop it [*responding to the comment about recreation sex made above*]; you can stop it but then you need somebody around twenty-four hours a day [...]. So they have no respect for themselves – you understand (Participant 2E1)

With these explanations, the participants defended themselves against notions of immorality, by positioning themselves as the older, moral, self-respectful individuals, and the learners as the immoral, disrespectful youth. In this sense they positioned themselves as 'good' and the learners as 'bad', as they had "recreational sex" despite the teachers' efforts to educate them.

A more prominent discourse that was used to explain risky sexual behaviour was that of different "culture", where learners from other "cultures" were positioned as ignorant, irresponsible, and at risk because "they" did not follow the advice of Western thought.

7.3.4 "Where Culture also come in and isn't doing what Medicine is Saying"

One participant in particular (participant 2A discussed above in relation to the death of a pregnant girl), referred to "the issue of culture" many times during her interview. However, most of the other participants also commented on "culture" being an issue that they felt works against HIV prevention. The participants, all of whom were coloured, seemed to use the term "culture" as a proxy for race, referring to African students. Ballard (2003) notes how 'culture' is generally used, particularly by white South Africans, to refer to race. In one or two of the participants' comments, it was clearly suggested that "culture" referred to African (or black) individuals:

And that was also a culture issue because she is also a black girl. (Participant 2C)

Because there's a lot of black students and the cultural ... that kids didn't know any of it ... because that is the culture (Participant 2C)

A major thing for many of our kids is a cultural issue. And this is sometimes difficult because I might be from a Western culture and my approach will be Western. But those who believe in the traditional values, sometimes I have to convince people that certain other people do have rights whether they are from black culture or not, they do have rights (Participant 2B).

The person above talks of a clash between “Western” culture and “black” culture. His last comments that they “have rights” alludes to the possibility of racism and discrimination. The potential for ideas about difference in “culture” to be embedded with racism is reflected in the following statement, where the participant states how one needs to be “careful” what one says with regards “culture”, as it might come across as offensive:

I thinking touching on culture, as I said, because you have to be so careful how you approach it and how you say, put it, you know [...] because they can become very offended, or they can feel that you are against their culture. So you have to be so careful when you touch when you – and I can assure you that’s never been anytime Xhosa-speaking children, that culture didn’t come in when sex and HIV and sex education was considered it. It always creeps in. But I will always tell them the – try and be positive about both. And I won’t see culture as the negative. I will try and look for the good in it, in the cultural thing (Participant 2A)

Similarly another participant states:

Because you must know how to talk with them. Because they are very sensitive for anything. Because maybe they think you make a joke of them. So you must be very careful what you say in front of them. (Participant 2C)

Despite efforts to be politically correct, the narratives clearly portrayed “cultural” beliefs as negative, in relation to safe sex behaviours and moral behaviours. Individuals from other “cultures” then came to represent the ‘bad’ immoral notions of self, which were denied in the participants. In this way the self is protected as ‘good’, responsible and

moral, and others were represented as 'bad', irresponsible and immoral. This forms the basis for a psychoanalytic understanding of racism, where split off aspects of uncontrolled sexuality and aggression are projected onto black others (Clarke, 2000; Kovel, 1995). In South Africa, race is strongly linked with representations of HIV and AIDS, where HIV is associated with being a black disease, and it is African sexuality that is thought of as the cause for HIV infection (Cameron, 2005; Rohleder, 2007).

Some of the projections of black individuals as 'bad' are reflected in some of the participants comments. For example:

And so black issues became very important and we have to address some of the black issues because many of the guys they feel they have the right to hit their girls and we cannot as people of the school intervene and say, "no that's not the way you do it, that's not the way how you do it". So there was always a clash with cultural issues. And what is expected of us here at school. So, that is one of the main difficult things (Participant 2B)

Participants framed the issue of "culture" as problematic for HIV education. They described unsafe sexual practices, that they attributed to being a cultural belief, rather than unsafe practices. For example, the practice of not using a condom during sex, was attributed to a "cultural" issue:

Okay the black kids don't want condoms. Like, the man don't want to, the black man don't want to have sex, they want it flesh to flesh (Participant 2C)

Some of the explanations for why sex occurs at hostels, are also attributed to culture. For example, one participant spoke of African males requiring to have sex with a female as part of their initiation into manhood:

The other issue that we got at the hostels, I don't know whether it is a cultural thing, but especially with our black learners when they come back from the

initiation rite¹³ – I don't know if it is a cultural thing, but they would then assume that if they come back after their initiation and they see some of the, especially some of the girls at the hostels, then they would go for this youngster. They are a man now, and they can go now for any, especially a black youngster. I've spoken to a couple of them who's gone now and according to them if they come from the bush they can, you know, have sex with any young girl. According to them it is cultural (Participant 2E2)

“Culture” also became an issue with regards the use of contraceptive, particularly the injection. The reason given is that the injection prevents menstruation, and this was seen as unhealthy in African culture. For example, one participant states:

The challenges are the cultural things. For example, if I found out that a girl is sexually active, I would advise her on certain things to do. I would warn her about certain things [...] we would end up putting them on the injection, which is contraception because it's – we're not always sure if they remember to take the tablet – so we put them either on the month or three month contraceptive injection. What happens there is that when they are on the three months contraceptive injection, they don't menstruate and they will come back and say they don't want to take it because what happens to all the dirty blood in their bodies? Culturally it says no your body must get rid of it and you are going to get sick now because of, you know, all those clashes. And eventually who ever gave them the wrong idea? You have to struggle to tell them the truth; the right thing and to convince them that it's not like this, it's like that. (Participant 2A)

The above participant speaks about cultural beliefs as clashing with (her) medical beliefs, which are assigned as “the truth”. Similarly she says at another point of the interview:

¹³ This participant refers to the initiation rites for men practiced among the African cultures in South Africa. For example in the Xhosa tradition (relevant to the Western Cape, where many Xhosa live), boys are initiated into manhood through a traditional rite of passage. Part of the initiation requires males to live

where culture also come in and isn't doing what medicine is saying, you know; what we know should be done (Participant 2A)

Much of her anxiety when speaking about “culture” was that individuals from other cultures (African learners) will not agree with what she states as the right thing to do. This anxiety can be better understood, when we consider the experience of the death of a past learner, which the participant described in some detail above. In her description, the participant detailed all the things she tried to do to “save” the girl. This experience may have left her anxious and fearful that a similar danger and loss might reoccur. The anxiety to tell the “facts” and the “truth” is an attempt to ward off such unpredictable dangers. This is shown in accounts she gave of more recent cases. For example:

We've had a few cases there as well where the child doesn't have the capability or the capacity to understand what is happening. Like the one child was – how far – already six months pregnant and she didn't know what was going on in her life and according to... happened. When we first found out, we called the mother in and she told us what happened. And we sent her to have a termination of pregnancy, because she said the child was raped. And then there was also cultural issues coming in there because the uncle said “no, it is not right”. It is against the culture to have the child terminate – the pregnancy terminated. The mother had gone in the meantime on her own to some hospital and where they gave – or when it happened – when the child was raped at the time. According to the mother they had taken her to some hospital where they did the necessary test and the medication was given. But I believe there was a follow-up which the mother never went or tablets that had to be given again and it wasn't given and the pregnancy went on. And I don't know if it is ignorance in the mother's side or - after the long school holidays we realized that the child is still pregnant, and we sent her to doctors and stuff. We called the mother in and said, “well what now? You are going to sit with a child. Your daughter is in this condition; she won't be

separately from society for a period of time, and during this time the males are ritually circumcised. After the initiation, the 'boys' return to society as 'men'.

able to look after the child. You are struggling. You are basically living on the care-dependency¹⁴. How are you going to survive to look after another mouth? And the child was raped. What you gonna to do?” And that was the issues where the uncles came in and said “no, it shouldn’t be done”. And then we said “it isn’t the uncle that is going to struggle with the child; you are going to struggle with the child. And your own daughter will never ever have the capacity to look after the child. What you going to do?” And then we wrote a few letters to certain organizations trying to terminate the pregnancy still and the mother gave her consent eventually when she realized what’s happening. (Participant 2A)

The narrative in the above extract is one of an anxiety about trying to prevent imagined dangers and problems. It is an anxiety about an unknown future; unpredictable events. In an effort to protect her own self from this anxiety about unknown dangers, she projects the “unknown” on to the child and parents, who are then seen as “ignorant”. In this way the participant remains the one who “knows” and so is outside of potential guilt if something happens – the guilty party would be the others who were “ignorant” or did not listen to the “truth”.

In light of these comments about “culture” and a clash between different opinions and points of view, I wondered whether such a “culture clash” existed among members of staff. When I did ask this directly, the participant said that there were none. However, at some points in the various interviews there did emerge some disagreements among staff about various issues.

7.3.5. Staff Disagreements

One example is the disagreements over the most appropriate procedure for helping the girl who was pregnant some years back, and subsequently died. Another source of disagreements was the introduction of condoms at school some years back, with some

¹⁴ In South Africa, persons with disabilities may qualify for a state grant. Adults with disabilities who are considered unable to economically sustain themselves receive a ‘disability grant’. Children, who may require special care and extra attention, guardians receive a ‘care-dependency grant’ (Swartz & Schneider, 2006)

members of staff advocating that condoms, should be made available, and others (a previous principal being identified in particular) being against this.

When I got here there was quite a dilemma and a need was felt at the time (I don't really know why), to promote certain things like HIV and the use of condoms. The principal at that time was – because I was quite upset when I found out that condoms weren't freely available to them, so I actually implemented it, and said, you know, “see that there is condoms available. Why can't they use it? And why isn't it freely available?” And the principal at that time wasn't very keen on this. I just ignored him and I just went ahead [...] he felt that giving the children condoms we actually tell them to have sex; we're promoting sex (Participant 2A)

Another participant comments:

Before it was a big issue rather to have anatomical instruments like vaginas and penis and condoms because at one stage the principal at this school was completely against condoms. He felt at that stage we must rather approach the governing body to ask them whether it is okay, because he has a issue with it. [...] Having condoms available is like promoting sex amongst youngsters. But all the people in my department, which is the support services, were always of the opinion – especially me and the professional nurses and my colleague, is that we have a duty in that we are professionals in the health sector basically and we are supposed to provide people with what is their rights if they want to engage into sex. Although we, for example, will promote abstinence we must have condoms available for them if anybody wants to get into sex because it's their own decision, they decide whether they like to be active or not. (Participant 2B)

Some of the teachers spoke of their own discomfort about the availability of condoms, and how they have had to change their attitudes about it over time:

Participant 2E2: in previous years – I am here now for almost twelve years [...] if I go on, you know, what do you call it, ‘klopjag’ (*raid*) through the hostel, just looking for dangerous things, then I would normally, years back, I will take the condoms, right. And even destroy it, right. Because that was my upbringing, you know, it’s just something not -

Participant 2E1: it’s taboo

Participant 2E2: Yes, it’s taboo. Now a day’s, if I see it, I’ll tell them: “you put it back in your cupboard, but please, don’t just let it lie open so that everybody can see it. Leave it in your cupboard, but almost, like, hide it behind some of your clothes”. So that is what I will tell them.

The presence of condoms still causes some anxiety for this teacher, who includes condoms in the list of “dangerous things” to look for in the hostel, and it being something that needs to be hidden.

There was some difference of opinion, even, in the participants’ account of staff disagreements, with some participants talking about disagreement, and one participant in particular, de-emphasising the existence of disagreement:

There is general consensus within school management and teachers that the issue of HIV and AIDS should be addressed. So there were not serious energy; no serious objectives were noted of being against it. I mean, they might have murmured but I don’t know of anyone that had objections to such an initiative. (Participant 2D)

Further tensions between staff are also suggested by the school psychologist, who spoke about the teachers’ resistance to educate around safe sex, leaving her feeling the need to “do everything”. For example, she states:

A lot of teachers avoid the whole issue. A lot of them would just not touch on anything

She adds a little later:

They tell you straight out ‘no’, and because they know there’s other people that can do it also, so they will just avoid it

She explains further:

They refused to give certain parts of the life orientation, or teach it. They would want me to do certain parts, and they would only do the one’s they feel comfortable with. Which resulted in me doing the bulk of the life orientation and they would do the ...not even a third – less than a third. So I put the option to them and said “well it can’t go on like this. This is one subject. I don’t see the sense in breaking it up, and I’m doing the bulk of the work. I would rather do everything”

Her concern about this was that the “right” information was not getting through. There was a doubt then about the depth of the message that was being put across to learners.

7.3.6. Discussion: Getting the Message across to Prevent Unseen Dangers

After conducting the various interviews at Hillcrest School, I was left with some sense of confusion as to what I had learnt from the participants’ narratives. I felt there was some inconsistencies between some participants’ accounts, with, for example, participant 2A revealing many challenges and difficulties experienced at the school with sexual behaviours and pregnancies, and participant 2D de-emphasising any difficulties, maintaining a more generalized discourse. I was also left somewhat confused about who provides the sex education, with the psychologist saying that she does it, and the teachers saying that they do it. In reflecting on these countertransference feelings I felt that they might tell me something about the organisation itself around an anxiety about getting a message across to prevent unknown (and unseen) dangers. With the presence of differing points of view and different voices, there may be some confusion around what the “correct” information and procedure might be.

Interestingly, many of the participants began their interviews to talk about blood as the primary risk factor, specifically blind children's inability to see whether they are touching blood or not. Embedded in this with the participants' own anxiety about which learners are HIV-positive and which are not. The fact of not knowing was a source of anxiety, as it threatened the sense of safety that the participants had

Related to this was the discourse around unsafe sexual behaviours – promiscuity, not using condoms, and pregnancies. The school, it seems, had experienced much difficulty with this, and had experienced a traumatic incident where one of the learners had died from birth complications. There appears to have been significant conflict about the management of that event, which is perhaps still felt at the time of the interviews. Much of the discourse was a discourse of othering and laying blame onto others who come from a different “culture”. Despite efforts to educate the “truth”, participants seem to feel helpless in their ability to do anything about it – “you can't stop it” one person said. In this discourse, what comes through is a defence against guilt, perhaps stemming from the death of the learner some years back. Blame is projected out onto cultural others, who are then seen as “ignorant” and irresponsible in their sexual behaviour. In a similar way, Gibson and Swartz (2001) reported on how staff at a school for physical disabilities, ‘othered’ the black students, racially different to themselves, referring to them as “difficult” and “uneducated”.

Part of the narrative about “culture” is that the African children will not listen to “truth”. What the “true” message is, is also a concern for some, as some tensions are evident between members of staff about what should be provided or not (condoms being the things that was mentioned). However, there is also indication of a conflict in the content of sexuality education, as alluded to be the psychologist mostly, who was worried that teachers were not giving the information across. The teachers here became the recipients of guilt, and were thus positioned as the ones to blame.

7.4 Case Study 3: A School for Children with Cerebral Palsy

Pinewood School¹⁵ is a special education school for children and adolescents with physical disabilities, as a result of Cerebral Palsy. The school has in the last 3 or 4 years also begun to include children with other disabilities, particularly intellectual disability, so classes now contain children with varying disabilities. The school has approximately between 320 and 350 students, ranging in age from 4 to 21 years. The school is located in a lower class suburb in Cape Town, and the majority of learners come from the more disadvantaged areas of Cape Town.

As with other schools, sexuality and HIV education is taught within the subject 'Life Orientation', which is part of the national curriculum. According to the completed survey, learners with physical disabilities were thought to be at equal risk for HIV infection as persons without disability. The respondent felt that "both groups are equally at risk". The respondent also felt that persons with physical disabilities received an equal amount of information concerning HIV than non-disabled persons, and that the information that was received was as accurate as that received by the general population.

7.4.1 Sources of Data

As discussed in chapter 5, the school was approached, and the interviews conducted, while there was a nationwide strike of teachers and public health workers, as a result of grievances over pay. As a result of this, initial meetings had to be rescheduled, and the time available to conduct interviews needed to be used as efficiently as possible. As a result interviews were slightly shorter in duration than for the other case studies, and slightly fewer interviews were conducted. For this case study, data were collected through the following individual and group interviews:

- Two individual interviews: one with the school's nursing sister who had been with the school for 27 years, and one with the school nurse, who had been with the school for approximately 5 years.
- A group interview with two child minders at the school's hostel. One had been working at the school 14 years. The other child minder has been working at the

¹⁵ Pinewood School is a pseudonym

hostel for just under a year, but had previously been working in the school's kitchens for 19 years.

- A group interview with three teachers at the school, who had been working there for between 13, 21 and 23 years.

All seven of the individuals interviewed for this case study were female.

7.4.2 Challenges to Providing HIV Education

The interview narratives included some discussion about HIV education. Some of the participants' comments regarding sexuality education and education around HIV seemed to suggest that it was not very intensive. One of the nurses also stated how she only periodically gives education around HIV related issues, when teachers ask:

Only when a teacher approaches me to say look I have a problem in the class and I feel as a teacher uncomfortable to talk to the children about it. Will you come and talk to the children? And that happens once in a blue moon. (Participant 3A)

One teacher states:

I haven't really used the workbook ... but I will talk to the people. If something happens then I will speak to them (Participant 3D3)

The above participant refers to a workbook used for the Life Orientation subject. One participant commented that workbooks are not always available. She stated how she had been waiting for workbooks to be delivered for the past two years.

Part of the problem for teachers, is trying to teach a class with varying disabilities, with children who have various degrees of cognitive ability. As one teacher states:

I find it very frustrating especially if you have gone out of your way to – because you’ve got different levels in your class – try and at least reach some of them, and it is a total loss (Participant 3D1)

In addition, the participants’ interview narratives contained a variety of factors that they felt hampered effective HIV prevention education.

“They just don’t get it”

Teachers, who were involved in educating on issues of HIV in the Life Orientation subject, commented on how it seemed that the learners were not incorporating what information is given, and learning from it:

The learners that we have, especially in the high school, they are very much aware of their own sexuality, but they do not see the danger. That is the problem. They don’t see it like “HIV will affect me; I mustn’t have sex with someone”. They don’t see it like that. (Participant 3D2)

I do speak about it and it seems if they don’t get it, you know. They just don’t get it (Participant 3D3)

One teacher commented that the learners seemed to be “bored with it, but yet it didn’t hit home so that it can sink in”. She felt that it perhaps was due to their barriers for learning that made it difficult for learners to incorporate the information given.

“You feel embarrassed”

Some of the participants also spoke of the discomfort and embarrassment felt around talking about sex. For example, the teachers commented on this, when referring to an HIV training course that they attended over one weekend. One participant described the course as “shocking”. When I asked her to elaborate on what she meant, the teachers said:

Participant 3D1: it was an eye-opener

Participant 3D2: Yes, it's just that we are living in a very innocent kind of lifestyle [...] sexuality and terminology and everything is handled at all levels, so that to expose them to the, shall I say, the street language, the medical language, whatever. All the terminology. And each context gets handled, so that you can handle, you know, you come open use – you've read it all or you've seen it all, type of thing. Pictures and everything is provided

Participant 3D1: I think it would've been better if it was over a week. But you had all this real ... information in a day and a half

Participant 3D2: day and a half. I mean, it's things I've never heard

Interviewer: Graphic?

Participant 3D1: Graphic. Very graphic. I've never seen terminology, I've – sexual things. I've never. But it's out there, and you're supposed to know it. You're supposed to know it to guide them, but they know more than you!

This embarrassment and discomfort seemed to deter teachers from actually providing the education:

I actually find it very challenging to get through to them. We don't have the same, I want to say, background, because when you start off with something, you will find them looking at one another and laughing and having this - because they are used to totally different wording of a thing or totally different situation. So I will just do it incidentally [...] if someone brings it up. I don't make a formal lesson of it, because then you get derailed totally, because it's a joke and it's a laughing (Participant 3D2)

However, it was not only the teachers who expressed discomfort, the nurses and child-minders did too:

When you talk to any of these learners, when you introduce them to sex, they immediately start laughing and giggling. It is not easy to educate them with regards to safe sex and things like that. If you something like that you have to go

into a class and work with a small group of children. Then you can have more control of the group. The bigger the group, the more difficult it is to get your message across then, because they will sit and make jokes and make fun of what you are talking about. [...]That in itself is difficult for me because if I talk to people; I'm a very serious person and I find that I lose it when people laugh and I try to talk to them about something that is serious to me. (Participant 3A)

Well you feel embarrassed. But I mean the child needs an answer and you've got to answer them, and you've got to – when you answer then, how you explain to them and that it doesn't offend them and that it doesn't offend yourself?
(Participant 3B2)

It seemed to me then, despite the responses made in the survey, that there was only some HIV prevention education provided in the school. Teachers and other staff found it a challenge to educate learners who did not seem interested, but also that it raised a lot of embarrassment for the participants, as the response from learners was to laugh at them and giggle. During the interviews, I was left feeling that HIV was not regarded as much of a priority in comparison to some other social problems, which the participants themselves also pointed out in one or two comments.

“HIV is not high on their agenda; Survival is high on their agenda”

Many of the children and adolescents at the school come from disadvantaged backgrounds, from areas of Cape Town where unemployment, poverty and gangsterism are rife. In the context of these pressing social problems, HIV was seen to be regarded as an issue that did not require a priority. This was commented on by teachers who reflected on what learners seemed to think:

Participant 3D2: The majority of our kids they've got to deal with violence and death every single day, so HIV is not high on their agenda. What's high on their agenda -

Participant 3D1: Survival is high on their agenda

At another point during the focus group interview, one of the participants said:

But on another level we'll find in, you know, with the education in general, especially amongst our communities, that they've got lots of poverty and social problems and all that, that their education is such easily ... - you know. Children come to school and they like doing their teacher a favour by doing, you know. There's like no goal in life. There's no aim. They just come because they must [...] it is not that they say, "we don't know about AIDS". Everything that we offer them is sort of – they have this apathy, you know. (Participant 3D2)

Although the teachers spoke about HIV not being a priority for the learners, it was also apparent that it was not so much a priority for the staff, who had many other difficulties to deal with:

Participant 3D3: for moderation it is so difficult to produce these things – HIV and AIDS. Although now I was shocked, I was terribly shocked when I did the course. But still a little bit on that level where the other workers are there [*indicates with her hand held higher up*] and HIV are here [*indicates with her hand held lower*], you know what I mean? It's not like -

Participant 3D1: - a priority in my life

Participant 3D3: - and I know, I know the dangers out there. I know, I know. But at the moment I think the teachers are so over worked with all this admin that even though ... – when I went to the workshop I was shocked but there are other things at the moment that are more important.

The participant speaks about the challenges of providing HIV prevention education, and about how it may not be a priority in the face of other problems. However, the question of HIV prevention as a priority was made more evident by the interview narratives as whole. Very soon into each interview, other issues than HIV prevention, became the immediate

focus of attention. The participant above (participant 3D3) comes across as quite tired and almost desperately resigned. She stresses “I know, I know”; she is aware of the importance, but feels resigned to be able to do much about it, in the presence of other pressing issues.

7.4.3 “We must be here to Protect the Children”: The Need to Protect against Vulnerability

In all interviews, but particularly an interview with one of the nurses, sexual abuse and rape was highlighted as a significant problem. One participant stated: “it is very serious and prevalent in our school”. One of the nurses used most of her interview to tell me about some of the incidents of sexual abuse and rape that she had learnt about. For example:

caught the father having anal sex with the child. And I’m talking about a seven year old child. This specific child was too scared to come and tell us this year about abuse that is happening at home because her mother said to her, “you don’t go tell them at school what is happening because then we are going to be put out of this room and do you want us to live on the pavement?” (Participant 3A)

She recalled how she was eased into this exposure to traumatic stories when she first started working at the school:

In the beginning it wasn’t easy and they didn’t just throw me in. [Name] dealt with most of the things. She always used to bring the children in here to the back and everything was like hush-hush. Until slowly she got me involved in, “this is what happened to this child”. (Participant 3A)

In light of the prevalence of sexual abuse and rape, the interviews contained a narrative of a need to protect the children against harm from the “outside”. One participant, a mother of a disabled child, described the “outside” world as “very, very cruel”, but seemed uncomfortable, perhaps because it is too personal, to state why she felt this. The

protection of children appeared to be seen as one of the primary tasks of the school. As one participant stressed:

We must be here to protect the children (Participant 3B1)

Participants made use of a discourse of disabled children as weak, naive and innocent, and as a result were vulnerable to be taken advantage of by others:

Our children are very meek and mild. (Participant 3A)

Look most of them can't really protect themselves in the outside world. Look here they are fully protected. If they go out here they might not be so fully protected like we are here. Understand? (Participant 3B2)

Our learners are very low functioning. That already is a risk for them because they are easily influenced. Our children are very gullible. Our children want to be accepted and people from the outside use that to get to our children because lots of our children they just want to be accepted and they just want to be loved and whoever makes a move on them, they will actually, I think lots of our learners they will actually go for it because of that wanting to be cared for and loved. (Participant 3A)

The above participants referred to a disabled person's need for acceptance. This was also commented on by many of the other participants, for example:

[The physically disabled] are more, I think precocious than the other girls, can I say. Because they like to, I don't know if it is – they would just let go [...] because I think they want to be, shall I say – not part - they want to be accepted, like being wanted, being accepted in society as so-called normal. So they will, they have that [...] because sometimes when you ask these girls, "Now why did you go do that?" – "no, because he is more interested in that girl, because she is

prettier than me, and she's (maybe) walking better than me". So they will do that to sort of that to get that attention (Participant 3C)

More than this, the need to have a child, in order to prove "normality" was also mentioned:

Because you get the ex-learners, we get them outside. To them it is not important the fact that they achieved some educational certificate or whatever. First thing they will tell you: "Juffrou [*miss*], I've got a child". That's the major achievement in their life and apart from falling pregnant – the course - having unprotected sex so they will not worrying about the dangers of HIV. But it's about that achievement of, "I can show people I'm not a child; then I've made it in my community. I've made it in". (Participant 3D2)

This was also found by Becker and colleagues (1997), who suggested that the experience of low self-esteem in some disabled women, makes them appreciative of any sexual attention received, which may lead to promiscuity as women accept any man's sexual advances. This also puts women at risk for abuse.

Some participants felt that the school was able to provide protection, as there were more people looking out for the children with disabilities. Although this was a "challenging" task:

Very challenging, because you don't like these kind of thing to happen to any child. But, you know, I feel these children here are also more at an advantage because here is so many more people who can look out for them. In normal schools it is just the teacher and the parent. But here it is the nurses, it is the therapist, it's the teacher, it's their housemothers, the drivers. So there is quite a lot of people that will see, "hang on something is happening here". (Participant 3C)

However, the ability to protect the children was not so straightforward, as one participant let me know by relaying a difficult experience for her, of a learner who was raped:

About two years ago, we had one of our learners that was raped at gunpoint. At home while they were having a braai [*barbeque*]. The brother has some strange characters for friends and it happened at home and it was one of her brothers' and she came to tell us that they had a braai and they were drinking and she was drinking and one of her brother's friends raped her at gunpoint. But because, again of who, where this child comes from, and the threats that came afterwards, after we responded on this. We got welfare involved and somebody went out for a home visit. The threat that came back to us, was again that we mustn't get involved and this child is one of that big gang boss [describes who]. So we feared for our lives that they will come and shut us up personally here in this school. "We must leave it alone". That was the message from the mother. "We must just leave it alone". So it is difficult for us to protect our children. (Participant 3A)

Such powerlessness felt about the ability to do anything to protect was a source of tremendous anxiety for the participants.

[It is] difficult for the staff. And even though we have a psychologist on site at school, our learners is about three hundred learners. She hardly gets time to counsel the learners let alone counsel a staff member. She just told me recently, "You must know when to back off. You get too involved with these children and that's why they see you as a crutch. They hold on to you because they know that you are going to do something for them. So you must know when to retreat and when to draw back". And that's not easy. If you are a people's person it's not easy – easier said than done. A job for me is not just a job. A job is a job when the job is well done. When I know I've done everything in my power to get that child to that point where I feel the child is protected and safe. (Participant 3A)

For this above participant in particular, the inability to do anything about preventing abuse was a source of great anxiety for her. During the interview I sensed a tremendous amount of sadness, and became concerned about her own mental state, feeling that she was struggling to cope. I asked her how this was affecting her:

[It] is very trying. If you yourself should work in this situation. There will be very many days were you would go home and think about these children because your mind is so preoccupied wondering whether the child is okay? I sometimes give my cell number and tell them to sms me if they are okay or tell them to give me a call ... You have to get yourself some kind of outlet or you'll have to find someway of just cutting off. [...] Although you do sometimes find that I take it out at the people at home. My family, when things get to much at work, you are so stressed out and you can't talk to them or they don't know what you going through at work. You become agitated at home. And they feel that you are agitated for no apparent reason. (Participant 3A)

Her comments indicate her own traumatized response to having to witness the trauma of others – what is known as ‘secondary trauma’ (Gibson, Swartz & Sandenbergh, 2002), where care workers, working with people who have experienced trauma, may develop symptoms of post-traumatic stress disorder (PTSD) themselves over time.

The above participant spoke of her struggle coping with her witnessing of the trauma of abuse, and her helplessness in being able to do anything about. Other participants’ interview narratives also indicated a sense of helplessness and a struggle to cope with the emotional effects of working with children with disabilities.

7.4.4 “Not that you are scared, but you are so much more alert to think that anything can just go wrong”: Managing Anxiety about the Potential to Harm

As discussed in chapter four, Roberts (1994) argues human service staff are often drawn to the work from an unconscious need to make reparation for aggression and the potential

to harm. Attempts to make reparation for one's own aggressive tendencies, is made through attempts to 'repair' damage in others. When this is challenged, it is experienced as a threat to the self, and creates overwhelming anxiety.

In many of the participants' interview narratives, such anxiety about the potential to cause (further) damage is evident. For example, the child-minders expressed great concern that they were often required to manage the medication of the children, particularly over the weekend. Although they were given medication to administer, presumably with instructions, as any parent would do, they expressed tremendous anxiety about something going wrong, or rather they doing something wrong, which may cause harm to the child. For example they state

Participant 3B1: Over weekends there is no medical staff here whatsoever. When there is a need we must phone them. Sometimes we don't even get them at home or whatever. We use our own discretion.

Participant 3B2: So for the disabled child, we know it's special children, they need more care than the ordinary child and also on the other hand you need to be so careful because you need to protect the child and you need to protect yourself. Because if you don't protect the child, on the owning that anything happens to that child, you are the one responsible for that child. You see that's the other hand that we need to think of many a times, because you can't just give any child medication if you don't know. And here many times we have to use a mother's instinct to see what you can do.

Participant 3B1: Here if you get the ... cough syrup and we got to administer it to the child if we now see oh it's the flu and whatever. Even the children that's on – that get epileptic fits, I got to see that I make up their tablets for breakfast, lunch and supper. I don't work weekends, so I got to make those tablets up for them on weekends. I have already spoken about it and said, "but I am not medically inclined". As was said it's just as well as me giving your child medicine when the doctor gives a prescription. But to me it is still, that is not your child. It is somebody else's child. You can give your child what you want. Am I right?

I sensed a lot of anger while the participants spoke, so asked them if they felt angry about this at all, to which one responded:

There is lots of things one can get angry about. Because I mean I'm not medically inclined. I never studied to be a sister or a nurse. So that work is actually their work that I am doing here. So, but I got everything written which I did out of my own when I got here, I got a book and I told the sister now tell me which child gets what medication and that medication, how many milligrams that one must get, like the Epilim. Like 500 and 200 and whatever. And I wrote everything down in a book. Because I can just make a mistake and something happens to the child and then they will blame me. (Participant 3B1)

The other child-minder adds:

Not that you are scared, but you are so much more alert to think that anything can just go wrong. I think that is our main thing and concern if anything goes wrong. (Participant 3B2)

The child-minders here felt abandoned to their own discretion by the health staff, and angered by carrying the responsibility for the children, which they saw as the job of the health care staff. The child-minders expressed much grievance with regards their work, which I will come back to a little later.

It has been shown how the practice of task-orientated nursing functions as a defense against anxiety of working holistically with damage (Menzies, 1960; Van der Walt and Swartz, 1999; 2002). Interestingly, the nurses at Pinewood School commented on how nursing work at the school was different to the nursing work in other contexts, because it involved working closely and over time with the same individuals, rather than the task-orientated nursing they were used to previously:

I just thought, when I started with nursing. We do the school nursing, where you do the home visits to schools. But that was very different. That was community nursing where you are based at a clinic and you go out to various schools. Not being stationed at one school and see the same children every day and become so involved with the children [...] So you get to know that child so well. Where as the other type of school nurse, you don't know that child. You deal with that child like a once off type of thing. (Participant 3A)

As task-orientation is seen as a defense against the pain of working with closely with entire 'damaged' patient, it made sense then that working closely with the 'damaged' children was difficult. One nurse pointed out how there wasn't an ability to repair the damage and fix problems, as was the case in a general hospital, for example:

In the hospital I worked in the ICU. So it was quite something else. People come in sick and they leave. They get better. But here they stay the same (Participant 3C)

As shown above one of the nurses struggled to manage the emotional effects of working with the children at the school. The other nurse was more defended in her interview, and her comments seemed to suggest that she manages her anxiety through a process of depersonalization and detachment.

You can't let emotions get in the way, so to say. Well, I didn't do that. If you work with, in conjunction with other people I don't think there is time for you to get emotional (Participant 3C)

This is also suggested by how she describes the nature of the patients she works with:

I didn't expect to see saw many, as I said, different disabilities – it's arms; it's legs; it's face; it's everything. This one can't talk; that one can talk a little bit.

This one can't hear. So you needed to learn how to work with each one, because each one's got a different thing, you know (Participant 3C)

She describes part objects, similar to what Menzies (1960) found nurses talking about patients in her study. Thus patients are referred to as "arms", "legs", and "face", rather than as a whole object. In that way she minimizes her emotional experience of the patient as a whole.

In the case of abuse, it is procedure at the school, for cases to be referred to the psychologist and nurses, who would then follow it up with the appropriate authorities. There were instances, though, when teachers were approached by children with stories of abuse. For teachers, the opportunity to "pass on" children who had spoken of abuse to the psychologist or nurse, allowed them to protect themselves from the trauma of experiencing the witnessing the pain of the child. When I asked the teachers whether there have been learners who have approached them about experience of abuse, they said that there had been, but that "fortunately" they were required to refer the child to the psychologist. When I asked them why they felt this was "fortunate", they responded:

Participant 3D1: Fortunately, to me, because otherwise if it would have been a normal school, with no psychology and nursing, you would have to be the one to go to social worker. Ja, I do think so. So you can just, sort of -

Participant 3D2: Pass it on to the ... otherwise

Participant 3D1: pass it on... start the investigation ...

Interviewer: Yes. You are talking about the legal and that kind of

Participant 3D1: yes, yes

Interviewer: But emotionally, you know, to listen to those kind of stories, what is it like? Difficult I should imagine?

Participant 3D1: Well they

Participant 3D3: I – over all the years I've been trying not to get involved if it is that heavy stories. I would get involved if it's no food and no clothes. But if it's

court cases and things like that, I would just put the story into the psychologist's hands, and I would back of totally because -

Participant 3D1: And if they don't call you back, then you don't assume that you're needed

Participant 3D3: I don't

Participant 3D1: and basically it is also a survival mechanism

Some of the participants' comments reflected an unhappiness or dissatisfaction at work, which participants also spoke about more directly at other parts of the interviews.

7.4.5 “You just want to survive from day to day”: Dissatisfaction at Work

Perhaps not surprising, given that the interviews took place at a time of striking and grievance over pay, some of the focus of the interview was around job dissatisfaction, which was expressed in varying ways, depending on the participant's position within the school.

The teachers spoke about lack of resources, both within the school, and as a result of the poverty of the learners. This made teaching difficult, with much time spent trying to provide, with unsatisfactory pay:

So it's time for the curriculum, the departmental demands; you need to be a fairy-godmother because you must see to all the other barriers. You've got your primary caregiver and with all these kids with all their problems, it's a hell of a care giving task. It's from pencils they don't have to write with. You start your lesson and you look around and no one is writing. But it's a fact that if they don't have money to buy a bread, where will the mother get money to buy a pencil? An eraser? A ruler? So now, with your little salary, you must buy all this stuff and bring it with you to school (Participant 3D2)

The teachers also commented on how, with the inclusion of children with other disabilities to physical disabilities, the nature of teaching has changed. Some participants referred to the “difficult” children, who seemed to refer to children with intellectual

disabilities and children with “behavioural” problems. Teachers described how much of the time in the classroom was spent trying to maintain discipline and order:

I visited the school in 1982, and to me this was my little place under the sun. But it changed. It changed a lot, with this new government policies where we are now a school for learners with bad ... - we are more now like a sergeant. It's about just getting them into; I think half of your day is getting them into an educational atmosphere. And when you start to give them some work. Every period, I think a quarter of the period is getting them there. And in the mornings an hour to find out who had supper last night, who never had any soap to wash with, sent them off to the hostel to go and wash them (Participant 3D1)

The teachers tried to portray a difficult working environment, and one teacher concluded about her work:

You see ... you just want to survive from day-to-day (Participant 3D2)

She uses the word “survival” used by one of the other teachers to describe what the learners priorities are in the face of many social problems – to just survive.

One of the nurses was less direct about her job dissatisfaction. She was clearly struggling to manage her emotional experience of working with trauma. When talking about her job, she attempted to speak of it as a personal growth experience. She stressed a few times “it changed me a lot”. While she attempted to use this phrase to mean that she had grown as a person, I was left with a sense of the “change” being a negative one, rather than positive. This became evident, when once again she described how the job had “changed” her, but in the same breath said how she has received other job offers recently:

This kind of setup was very strange to me. I had never worked with children. I don't have patience with children. The job itself changed me a lot. I've grown to love the children that I work with. I've also had quite a few job offers. Even to go

and do – the latest one I got was last week to go and work at [name]. And they offered me almost double what I'm earning now, but it is so difficult to break away because if you think about the children; what type of sister are they going to get? Will [name of other nurse] cope? Things like that. So you just stay on for the children. It's difficult. I want to go but there is so much hope that is holding me back. (Participant 3A)

The child-minders voiced much anger at what they experienced as their marginalization at work, and being left to their own devices (as discussed above). Some of their dissatisfaction also was around their anxiety about their own health risk, in working closely with the bodies of the disabled children, and feeling that they had little material resources to protect themselves:

I think it is time that we should wake up here. Do you understand? What protection do we have here? The only thing that we have is gloves. And that the people only use when they do the bowel wash, (Participant 3B1)

We don't even get an injection like those ... we get nothing. So actually there is very little to protect ourselves. Sister goes home as soon as the school closes, sister is gone and we are put up with the rest, even over the weekend. (Participant 3B2)

The child-minders anxiety was that in being exposed to bodily fluids and blood, they themselves might be at risk for HIV, or other infections.

7.4.6: Discussion: HIV not as much a Priority as Survival is

It may be that these feelings and dissatisfaction in relation to their work was more present in the participants' minds (and in my mind) at the time of the interviews, because of the nationwide strikes over pay. However, the comments express major difficulties at work, as the participants struggle to cope with a variety of issues, mainly associated with

limited resources and poverty, and the trauma of abuse, that the priority at work (and for the focus of the interviews) was not HIV, but rather the other problems.

Aside from the job dissatisfaction, many of the participants were struggling with managing their anxiety about their potential to protect the children with disabilities from harm. Given that the prevalence of sexual abuse and rape is so high, and ultimately outside of the control of the staff at the school, this was a “self-assigned impossible task” (Roberts, 1994, p. 110). The result is that the anxiety is ever present as the care workers would not be able to protect the children from harm. This may result in feelings of inadequacy, frustration and anger, which are then split off and projected out onto others, who are then seen as to blame for their inability to do their work. For example, the child-minders who blame the nurses; the teachers who blame management.

It is this experience of helplessness and the emotional effects of working with traumatized and disabled children that overshadows everything else. The priority is attempting to cope with the emotional difficulties of the learners, and, by contagion (Moylan, 1994), the staff. In this context HIV is not as serious a priority as survival is.

CHAPTER EIGHT

DISCUSSION AND CONCLUSION

8.1 Introduction

In this final chapter, I draw on the findings of the survey and case studies, in the context of what has been learnt from the literature review, to make some concluding comments and recommendations. I begin by revisiting some of the key findings from the survey study and the case studies. I also look at some of the limitations of this research. I go on to discuss the usefulness of a combined quantitative and qualitative research approach. I look at two key issues that emerged from this study before ending off with recommendations for future research.

8.2 The National HIV/AIDS and Disability Survey

A major limitation of the survey is the poor overall response rate of 18%. Mail surveys in particular has been noted as being at particular risk for poor response rates, and a response rate of below 50% is considered unacceptable (Goodwin, 2003; Mangione, 1995). The response rate of 18% for this survey, therefore, makes it highly problematic to make generalizations of results. This is not altogether unusual, and low response rates have been reported for other postal surveys conducted in South Africa. For example a nationwide postal survey of HIV counselling services in South Africa, achieved a response rate of 21% (Richter, Durrheim, Griesel, Solomon, & van Rooyen, 1999). The Global Survey on HIV/AIDS and Disability, although using a snowball sampling methodology, also achieved low response rates at the time that some of the data was published (Groce, 2004).

However, the response rate of 57% for national disability organizations is more promising, although still to be used cautiously (Goodwin, 2003; Mangione, 1995). The fact that a majority, although small, of organizations representing various disability populations at a national level, make the results a representative one. In addition, as was

indicated in Table 6.3 in chapter six, survey responses were received from all types of disabilities surveyed.

It is difficult to understand for sure the reason for the low response. Despite numerous contacts made, both by email, post and telephone calls, the response remained poor throughout the course of the survey study. Only a few reasons could be gathered from organizations as to why they did not respond, and this centred around either the survey being regarded as inapplicable to them, or that the organizations had too much work to be able to dedicate time to completing the questionnaire (see chapter six). This does provide two possible reasons to consider more closely.

Firstly, the list compiled of organizations and schools working with persons with disabilities, was obtained from various sources. In many cases, no information was available, particularly for LSEN schools, on the nature of disability of the learners, or the age of the learners at the school. The only information available was the name and contact details of the school, and their inclusion on a list of LSEN schools. It may be that some organizations and schools were indeed not appropriate for the survey, as they may have considered their population to be non-disabled. For example, a school for children with learning difficulties (that is reading, writing and comprehension difficulties, but not necessarily intellectual disabilities) may be listed as an LSEN school, as it provides special, remedial education. This, however, was not always known from the list of schools. Aside from these possible cases, though, some organizations and schools responded that the survey does not apply to them, *despite* the fact that they did work with persons with intellectual disabilities. As reported in chapter six, one of the responses given by one of the organizations that did not reply was:

Our people are not supposed to have sex ... they are sterilized

Such a point of view indicates a possible denial about the nature of risk for persons with disabilities. The comment is interesting in numerous ways. At an obvious level, sterilization does not prevent sexual intercourse, but also, the inclusion of the word

“supposed” suggests the possibility that it might not be true that “their people” do not have sex. It also does not consider the possibility of rape. This issue also relates to the type of organizations and schools that did respond. It may be likely that only organizations that *were* aware of HIV as an issue, responded to the survey. There may then be a response bias from organizations and schools that are attentive to the issue of HIV/AIDS, and no response from organizations and schools who are not.

The second factor to consider is one of capacity. Given that South Africa is struggling to manage with numerous social problems, under conditions of scarce resources, many organizations, particularly at local/regional level are under-resourced and over-stretched. The significantly better response rate from national disability organizations, as compared to provincial and local organizations, may point to this. National disability organizations are likely to be better resourced, and able to attract funding from a variety of sources, both nationally and internationally. Smaller organizations are more likely to struggle financially. Many organizations and school then simply do not have the time, resource or staff to be able to dedicate time to completing a questionnaire, and going to the post office to post it. Lack of resources was also evident by the fact that many organizations and schools did not have email or fax, and so posting was the only means of contact with regards the survey. The problem of resource was also evident in case study three, where teachers commented on the amount of work they were required to do.

As suggested in texts on research methods, mail surveys tend to elicit poor response rates, as it is easier for people to avoid responding (Goodwin, 2003; Mangione, 1995). It may be then, that for surveying health and service organizations in national studies, postal surveys is not the best method. The opportunity to approach some organizations and schools in Cape Town in person, improved the response rate in the Western Cape Province. The response rate remained low, as many organizations and schools in the Western Cape, located outside of Cape Town, were not approached in person. The presence of the researcher may encourage respondents to complete the survey as it may give the study further importance. It is also, of course, more difficult to avoid responding. The problem here, however, comes back to the issue of capacity. Approaching 601

organizations and schools across South Africa in person, requires a tremendous amount of resources and time, which a study such as this one certainly did not have.

Despite the poor response, I do not feel that the results of the survey should be easily dismissed. As mentioned the majority of national disability organizations responded to the survey. These organizations represent, at a national level, various affiliated regional and local organizations and schools that were included in the distribution of the survey questionnaire. Therefore the results may describe a relatively representative picture of what is going on with regards HIV and persons with disabilities.

To recap, the survey results indicated:

- A high awareness of the risk for HIV of persons with disabilities, with 82% of respondents stating that they felt disabled people were at greater risk for HIV infection than non-disabled people.
- This greater risk was mostly attributed to disabled persons being more vulnerable to sexual abuse and rape, and lacking information about HIV and safe sex.
- Hardly any respondents knew of the prevalence of HIV/AIDS within the disabled population they work with.
- The majority (89%) of respondents to the survey indicated that they do provide HIV prevention education to the disabled people they work with.
- Most of the HIV prevention education occurred within the curriculum at LSEN schools (under the subject 'Life Orientation'). Only four organizations had indicated that they had developed a dedicated HIV prevention education program. The remainder appeared to provide education periodically.
- The majority of respondents felt that persons with disabilities were generally excluded from general HIV prevention campaigns: 58% felt that the amount of information reached by disabled people was less than that reached by the general population. The majority (87%) felt that HIV prevention campaigns were inaccessible to people with disabilities for one reason or another (for example materials being too complex for intellectually disabled).

- There was some evidence that persons with disabilities are unable to access adequate health care services and HIV testing.

8.3 The Case Studies

Despite the survey results indicating that organizations and schools are aware of the risk for HIV infection for persons with disabilities, and are providing HIV prevention education, the case studies demonstrate some significant difficulties and challenges in doing so. To summarize:

Case study one, an organization supporting services for intellectual disabilities, have developed a dedicated, comprehensive sexuality and HIV prevention programme. However the interview narratives revealed some anxiety associated with teaching sexuality to persons with intellectual disabilities, with a tension between a human rights approach to the sexuality of persons with disabilities, and a need to control and restrict sexual expression. The interview narratives contained some anxiety about sex education maybe awakening or encouraging some sexual behaviours that are perceived as unacceptable or immoral.

Case study two, a school for the blind, included HIV prevention education in their curriculum, in the 'Life Orientation' subject. Much of the discussion of risk centred on blood, and the dangers of touching spilt blood that cannot be seen. However, much of the interview narrative revolved about the anxiety of unforeseen and unknown dangers, stemming from the death, some years back, of a student during a complicated pregnancy. There was much guilt and blame as a result of this, which was projected onto "cultural" others, who became represented as irresponsible, unknowing and engaging in dangerous behaviours. Efforts were made to educate these cultural others about the "truth" in an effort to prevent these risky practices ascribed to their "culture".

Case study three, a school for children with physical disabilities as well as intellectual disabilities, also included HIV prevention education in their curriculum, under 'Life Orientation'. However there was some indication that this was not done as intensively as

perhaps required. Some of the participants' comments suggested that HIV education was done at an ad hoc basis, rather than in formal education sessions. This may have been as a result of the school needing to cope with other problems, which were seen as more significant and more of a priority than HIV prevention, namely sexual abuse and rape, poverty and lack of resources. Participants' interview narratives revealed a collection of staff members struggling to manage feelings of helplessness and powerlessness in the face of significant challenges and trauma. The word "survival" was used on more than one occasion, to describe what the priority for both staff and learners is.

8.4 Limitations of the Study

As discussed above, a serious limitation of the survey study is the poor overall response rate. However, with the majority of disabled peoples' organizations being represented, it does provide a good sense of what is being done about HIV/AIDS and people with disabilities. The generalizability of findings from the case studies is also limited by the small number of organizations and schools that were used. The constraints of resources in conducting this doctorate study, limited the number of organizations that could be used. In addition, out of convenience, only organizations and schools in the Western Cape were approached for the case studies, and so the experience of people working with disabled persons in other parts of the country, are not explored. However, the case studies provided an exploration of some of the anxieties and unconscious experience of working with topics such as HIV/AIDS and working with persons with disabilities. It attempted to reveal an emotional experience, supported also by some of the psychoanalytic literature, which could be applied to the experience of others working with similar issues.

Another major limitation of this study is the exclusion of the experience and perceptions of disabled persons themselves, apart from disabled people representing DPOs and other organizations in the survey study. Participation of persons with disabilities on any research involving disability is very important, and this absence in this study is acknowledged. However, as discussed in the introductory chapter, this study forms only a part of a much broader research study on HIV/AIDS and disability in South Africa, where interviews with persons with disabilities themselves are planned.

8.5 The Usefulness of a Combined Quantitative and Qualitative Research Approach

The study made use of a combination of quantitative and qualitative research methods, which as stated in chapter five, allows for triangulation of results.

The survey study provides larger amounts of data, and provides an overall sense of what is going on. This is much needed information in that until now we had no sense of what organizations working with disabilities are doing to address the HIV crisis with the people they work with.

The results of the survey portray a somewhat positive and ‘desirable’ picture about the provision of HIV prevention education at schools and organizations. This may, of course, be as a result of a response bias, in that only organizations that have provided some education about HIV were the ones to respond. It is probable that organizations that are not providing HIV education did not complete a survey, possibly as it was perceived as being “not applicable” to them, as per some of the reasons given by organizations and schools for non-response. However, the ‘desirable’ picture that the results do give, may not reveal some real difficulties and anxieties that staff have in addressing topics of sex, sexuality and HIV. These emerge in the case studies. The organizations and schools used as case studies indicated in the survey questionnaire that they were providing HIV education (to varying degrees). However, when staff were given an opportunity to talk about their work experience during a narrative interview, the staff difficulties and anxieties were revealed. In some cases, the interview narratives suggests that there is a reluctance to approach topics, such as at Pinewood School, where some staff members spoke about avoiding educating on issues of sex and sexuality.

Survey studies are not always able to capture fully the emotional experience of human service workers, nor are they designed to do so. The case studies, on the other hand, reveal an anxiety around needing to protect disabled persons’ vulnerability; protect against ‘unacceptable’ or ‘immoral’ sexual behaviour, sexual abuse and rape, and pregnancy. The narratives seemed to draw on disabled people as vulnerable and needing protection, as well as innocent and needing to protect their innocence (this will be

discussed further below). The use of psychoanalytic theory as a framework for understanding and analyzing some of the narrative interviews, also allows for the “truth” of what is being said (both in the interview as well as in the survey) to be challenged. As Hollway and Jefferson (2000) argue, many research traditions make the assumption that research participants are “telling it like it is” (p. 2), and tend to treat people’s accounts as unproblematic or transparent. They go on to suggest that in everyday life we are constantly questioning and interpreting and challenging the accounts of others, and not taking what they say at face value. Formalized research does not always do this. Using a psychoanalytic approach does offer one a method for questioning and interpreting the ‘surface’ of what is being said, possibly leading to a deeper, and more nuanced understanding of experience.

Psychoanalytic theory, as Hollway and Jefferson (2000) argues, allows us to have a greater understanding, and account for, differences and variations in how identities are socially constructed. The psychoanalytic concept of splitting allow us to understand how different constructions of disabled people as, for example, innocent versus deviant or over-sexed versus asexual, functions as a defence against anxiety. Constructing disabled people as deviant and over-sexed may function to locate these split of aspects of ourselves (psychoanalysis argues that we all have sexual urges that may be regarded as deviant or inappropriate and so are suppressed or denied) onto others in an effort to rid ourselves of the “bad” aspects of our human nature. Similarly constructing disabled people as innocent and asexual may function as an attempt to deny the ordinary sexuality of individuals that are often understood as “damaged”.

What the case study method also allowed for was some exploration of organizational dynamic, particularly as experienced in Pinewood School. Together with Swartz, I have argued about the need to take into account organizational dynamics in relation to the provision of HIV prevention services (Rohleder & Swartz, 2005), as it impacts on the staff’s ability to perform their task. Thus, we argue that studies into the efficacy of HIV voluntary counselling and testing must bear into consideration the context in which the service is provided.

8.6 HIV Prevention Education and Persons with Disabilities in South Africa

Topics such as sex, sexuality and sexually transmitted diseases tend to raise anxiety in most of us. These are topics that often make us uncomfortable or embarrassed. It is important to state that many of the issues and anxieties for educators around sex education are not specific to disabled people, but may reflect the issues and anxieties associated with raising these topics with any target group. However, what some of the literature, particularly the psychoanalytic literature, and the material from this study suggests, is that in sex education with disabled people, these issues and anxieties are intertwined with notions of damage and raising the possibility of causing harm. Disabled people may be constructed as deviant and even dangerous, and any encouragement of sexuality may lead to inappropriate and deviant sexual behaviour. Alternatively, disabled people may be constructed as innocent and vulnerable and needing to be protected from the “dangers” of sex.

A human rights approach to the care and educating of persons with disability would encourage sex education and the facilitation of positive sexual relationships. Unfortunately, I would say, there is a dilemma with regards sex education in the era of HIV/AIDS with persons with disabilities. On the one hand it is essential. HIV is the biggest health crisis in contemporary society, and in South Africa it is perhaps one of the biggest obstacles to development. Southern Africa stands at the epicentre of the HIV pandemic. To exclude disabled people from HIV prevention campaigns, and from acquiring the information required to know how to protect themselves, is a human rights issue. On the other hand, as the case study interviews have suggested, sex education in conjunction with HIV prevention education may be used predominantly as an opportunity to discourage sexuality. The discourse is one of demonizing sex; sex as bad and dangerous; sex as being associated with abuse, rape, disease and death. Historically, the sexuality of persons with disability has been the focus of a problem-focused discourse. Disabled people are often sterilized as they are regarded unfit for procreation. Sexual relationships, particularly among the intellectually disabled, are restricted as they are considered inappropriate, even dangerous. Thus, HIV once again provides a reason for restricting the sexual lives of persons with disabilities. What may be excluded is a

discourse which empowers the sexual lives of persons with disabilities. This echoes the argument made by Tepper (2000) who points out how social discourses about sexuality and disability emphasize deviance, asexuality, inappropriateness and abuse, and what is missing is a discourse of pleasure.

Interestingly, a similar argument was put forward in the early years of the HIV epidemic in South Africa, as regards black South Africans. Condoms were initially viewed with scepticism in light of the history of the apartheid government's attempts to find ways to reduce the black South African population (Crewe, 1992). HIV and the use of condoms was seen as another method for attempting to prevent pregnancies. Caldwell, Orubuloye and Caldwell (1992) have also argued that HIV was viewed with suspicion as a myth for many people in Sub-Saharan Africa, as it was viewed as a campaign by Westerners to restrict the pleasures and sexual moralities of people's sexual lives, attempting to "make Africans conform to Western norms" (p. 1171). In the early years of the epidemic in the United States, the gay population were similarly suspicious of the messages of safe sex (for example abstinence and the use of condoms), as being oppressive of their sexual human rights (Shilts, 1987).

HIV may also further be experienced as a source of stigma by people with disabilities, as their blood and bodily fluids are constructed as potentially infected, and therefore a risk to others. Their bodily fluids, like their disability becomes an 'abomination of the body' (Goffman, 1963). This was referred to by one of the participants in case study one, who said:

This whole thing around sexuality and condoms is also creating a kind of - there's something wrong with my fluids, cause I also have to use a condom. Or there's something wrong with her body, that I always have to have something between us, you know. And that's like another thing on people [...] It is a stigma, I think. It's a fact because historically condoms were there to stop babies from happening. But now basically are there because you get sick; either I'm sick or you're sick (Participant 1A)

Furthermore, there is a more complex dilemma in the tension between a human rights discourse versus the exerting of control over the sexuality of disabled people. The fact is that disabled people are a vulnerable group, as the abundant literature that reports high prevalence of sexual abuse suggests. This presents a dilemma for those placed in positions of looking after and being responsible for the safety and well-being of some persons with disabilities. From a human rights perspective, one would want to provide sex education in order to empower a healthy sexual life for persons with disabilities. At the same time, there is the reality of the dangers associated with sex – the sexual transmission of diseases and the possibility of sexual abuse and rape. There is, in many instances, a real need to protect persons with disabilities.

How, then, do we provide sex education that is positive and empowering, while at the same time raising the dangers associated with sex and discouraging sexual behaviours that may place one at risk. There is no easy solution to this dilemma. We do live in a time when we need to be concerned about HIV, and other sexually transmitted diseases. HIV prevention education is necessary. We also need to be concerned about sexual abuse and rape and provide education accordingly. However, we need to be careful not to demonize sex, and not empower persons with disability to be permitted to have fulfilling, healthy and pleasurable sexual lives.

8.7 Is HIV a Priority?

Although it is my belief that HIV is a health crisis that needs to be given priority, some respondents to the survey and some participants in case study 3 question whether HIV is, perhaps, a *necessary* priority in the face of other serious issues such as poverty and violence. HIV, because of its latency period, does not result in illness for a considerable length of time. Thus in countries in Africa, with histories of wars, famine and other epidemics, HIV is not experienced as an immediate concern (Caldwell et al., 1992). Lindegger and Wood (1995) have pointed out how it may be likely that in parts of South Africa, the threat of HIV/AIDS is not as immediate in the concerns of people as much as violence and hunger are.

The findings from case study three indicate that HIV may not be a priority in the face of sexual abuse and rape and poverty. These are the areas that are of immediate concern. Sexual abuse was highlighted in the survey and in all three case study organizations as a serious issue, with high reported prevalence of sexual abuse and rape. Sexual abuse, of course, places an individual at risk for HIV infection, but HIV prevention education, while raising awareness of this, would not prevent sexual abuse. The priority is to protect (as clearly shown in the case studies), which providing HIV prevention education cannot effectively do. This is a social issue that requires a much broader intervention. It is not my suggestion that the importance of HIV prevention education should be diminished; on the contrary, I think it vital. But for an organization and school, struggling to cope with limited resources, there is a need to prioritize.

It may be then, that some of the non-response to the survey may be as a result of this. Organizations may have perhaps not responded, because HIV is simply not seen as an immediate priority – “it is not relevant to us”, as much as other serious problems are.

8.8 Recommendations for Future Research

This study was an exploratory one in an area in which little is known in South Africa. There remains a lot that is not known, and warrants further investigation.

As mentioned, one crucial perspective that is missing in this study, is the voice and experience of persons with disabilities themselves. While we have gained a better understanding of some of the issues and anxieties facing service providers, we know little about how persons with disabilities experience and are affected by HIV. Research is needed exploring whether disabled people themselves are concerned about HIV/AIDS, and what are their concerns. A useful research approach would be in-depth interviews with persons with a variety of disabilities – intellectual, physical, sensory and medical. Such research may explore how disabled people have experienced the HIV epidemic, and whether they feel themselves to be at risk. This in fact is planned for in the context of the larger project of which this study forms a part.

There is a need for a prevalence study. As the survey and a review of the literature has shown, little is known about the prevalence of HIV infection among persons with disabilities. A prevalence study would provide a much needed indication of the severity of the issue, and which populations among the disabled are most affected. This presents considerable ethical problems that need to be considered. Chief amongst them is the issue of consent for HIV testing, and the provision of suitable pre- and post-test counseling, and the consequences for disabled people of knowing their status. Even if testing is to be done blindly, in other words, the testing of anonymous blood samples, consent remains an issue.

There is also a need to ascertain the level of knowledge about HIV/AIDS among persons with disabilities, to see to what extent information has been gained and incorporated. Related to this is the need to conduct evaluations of HIV prevention education programmes, to ascertain their efficacy in getting information across. The suitability of the 'Life Orientation' curriculum needs to be investigated to see how it has or has not been suitable adapted for specific audiences, for example material available in Braille for the blind.

A serious issue that has been highlighted in this study is that of sexual abuse and rape, which still remains largely silent. It is worrying to hear that staff are asked by parents in some instances to "back off" and "leave it alone". Incidents of sexual abuse and rape need to be named and made visible. South Africa has one of the highest rape prevalence in the world, and rape is a social issue that needs to be addressed broadly, and, indeed, much work is being done about it. However, the silence around rape with persons with disabilities needs to be challenged.

8.9 Concluding Comments

Nelson Mandela, in his closing speech at the International AIDS conference in Durban, South Africa in July 2000 said: "Let us not equivocate: a tragedy of unprecedented proportions is unfolding in Africa".

Southern Africa is at the epicentre of one of the biggest pandemics in history. Globally HIV/AIDS has been met with an enormous response through research, writing and dialogue. One of the most vulnerable populations in the world, persons with disabilities, most of whom are reported to live in the developing world, such as Southern Africa, has until recently been overlooked in relation to HIV/AIDS. Groce, together with the World Bank, has taken an important step in learning more about HIV/AIDS as it affects persons with disabilities. It is hoped, through conducting studies such as this one that we can begin to address some of this silence, and contribute in fighting the tragedy of HIV/AIDS in South Africa.

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ADDENDUM A: SURVEY QUESTIONNAIRE

NATIONAL SURVEY ON HIV/AIDS AND DISABILITY

(Please complete questionnaire, and post completed questionnaire together with the signed consent form.)

Background Information

1. Name of person filling out form <i>(This is to enable us to address future correspondence to the relevant person):</i>	
2. Position of person filling out form:	
3. Name of Organization:	
4. Mailing Address:	
5. E-mail:	
6. Phone number:	
7. Fax Number:	
8. Type of Organization: <i>(please mark with a tick or 'X')</i>	
Governmental Organization:	
National:	
Provincial:	
Municipal/City:	
Other:	
Non-Governmental Organization:	
International:	
National:	
Local/regional:	
Other:	

9. Are you an organization of disabled people (DPO) (an organization controlled by people with disabilities themselves)?	
Yes:	
No:	
10. Type of Services Provided: (<i>Tick or mark with an 'X' all relevant boxes</i>)	
Advocacy/Policy:	
Education:	
<i>Medical/Counseling:</i>	
Rehabilitation Services:	
Development/Economic:	
Legal:	
Other:	
11. Type of Disability Served: (<i>Tick or mark with an 'X'</i>)	
Physically Disabled:	
Blind/Low Vision:	
<i>Deaf/Hard of Hearing:</i>	
Intellectually Disabled:	
Mentally ill:	
Multiply Handicapped:	
Epilepsy:	
Chronic Disease:	
Hemophilia:	
All disability groups:	
Other:	
12. Number of individuals with disability/family served:	
1-100:	
101-500:	
<i>501-1,000:</i>	
1,001-10,000:	
Above 10,000:	

Part I: Risk for HIV/AIDS: Awareness

1. Do you think that disabled people might be at risk for HIV/AIDS?		
Do Not Know:	<input type="checkbox"/>	
No:	<input type="checkbox"/>	
If no, Why?		
Yes:	<input type="checkbox"/>	
If yes, Why?		
2. Do you think that disabled people are at greater risk for HIV/AIDS than non-disabled people?		
Do Not Know:	<input type="checkbox"/>	
No:	<input type="checkbox"/>	
If no, Why?		
Yes:	<input type="checkbox"/>	
If yes, Why?		
3. Do disabled people themselves feel they are at risk for HIV/AIDS?		
Do Not Know:	<input type="checkbox"/>	
No:	<input type="checkbox"/>	
If no, Why?		
Yes:	<input type="checkbox"/>	
If yes, Why? (Tick or mark with an 'X')		
Sexually active:		<input type="checkbox"/>
Rape/Sexual abuse:		<input type="checkbox"/>
Drugs:		<input type="checkbox"/>
Medical procedures:		<input type="checkbox"/>
Lack of information concerning HIV/AIDS:		<input type="checkbox"/>
Don't have access to prevention programs:		<input type="checkbox"/>
Families will not let them participate in programs:		<input type="checkbox"/>

Police will not prosecute if the victim has a disability:	
They live in an institution:	
Prevention programs are not in a language that can be understood:	
Other (Please explain):	
4. If the people you work with feel that they are at risk, what types of help have they asked for? (Tick or mark with an 'X')	
AIDS education:	
HIV testing:	
Counseling:	
Condoms:	
Other (please explain):	
5. Do you have any information on how many disabled people in your area -	
A.) have died from AIDS?	
No:	
Yes:	
If yes, please describe:	
B.) are living with HIV or AIDS?	
No:	
Yes:	
If yes, please describe:	
6. If there are individuals with disability in the community who have died from, or are infected with HIV/AIDS, how have others in the community responded? (Tick or mark with an 'X')	
HIV/AIDS is not discussed:	
It is said that they died from something else:	
Stigma/prejudice against those who are infected:	
Other (please explain):	

Part II: Teaching Disabled People about HIV/AIDS through Disability Organizations

7. A.) Is your organization involved in teaching disabled people about: <i>(Tick or mark with an 'X')</i>	
HIV/AIDS?	
Safe Sex?	
Sexually Transmitted Diseases?	
Drug Usage?	
Other topics relevant to HIV/AIDS? (please describe)	
B.) If your organization is involved in these activities, please describe the program/s in more detail here:	
C.) If your organization has not set up an HIV/AIDS program, what are the reasons? <i>(Tick or mark with an 'X')</i>	
It is not the type of thing your organization does:	
Other organizations are better able to handle it: If so, which organizations:	
You do not think it is a significant problem for the population you serve:	
You worry about making disabled people even more stigmatized:	
Lack of resources and/or money:	
Other (please explain):	

8. Are there any other disability organizations in your area that are reaching or trying to reach people with HIV/AIDS prevention information? Please describe:

9. Have you asked for help from HIV/AIDS experts and others from the Government, Department of Health or local voluntary agencies to reach people in the disability community?

No:

Yes:

If yes, what type of organization did you ask?

10. If you did ask for help from other groups or organizations, were they helpful?

No:

If no, what were the reasons they gave for not helping disabled people?

Yes:

If yes, what did they do for disabled people that you found to be helpful?

Part III Teaching Disabled People about HIV/AIDS through Non-Disability Organizations

11. Have there been efforts by non-disability groups to educate the population you serve about: (Tick or mark with an 'X')	
HIV/AIDS?	
Safe Sex?	
Sexually Transmitted Diseases?	
Drug Usage?	
Other topics relevant to HIV/AIDS? (please describe)	
12. A.) Have you ever seen any of the disabled people you serve reached by HIV prevention messages meant for the general population?	
No:	
Yes:	
> If yes, how many of the people in your community do you think were reached?	
Few:	
Some:	
Most:	
All:	
> If yes, what types of information were received?	
B.) Do you think the amount of information concerning HIV/AIDS that is reaching the disability community is:	
Less than that reaching the general population?	
Equal to that reaching the general population?	
More than that reaching the general population?	
C.) Do you think that the information concerning HIV/AIDS that is reaching the disability community is:	
Less accurate than that reaching the general population?	
Equal to that reaching the general population?	
More accurate than that reaching the general population?	

13. Have large HIV/AIDS campaigns (by non-disability organizations) been inaccessible to the people you serve because they were:	
Radio programs?	
Television programs?	
Billboards?	
Other written materials?	
Complex materials not appropriate for the intellectually disabled?	
Training/Education sessions in locations not accessible by wheelchair?	
Training/Education sessions in which no sign language or captioning was available for those who are deaf?	
Other ways (please explain):	
14. Has there been any attempts by non-disabled organizations to put HIV/AIDS prevention messages into a format that would be more accessible to your people?	
Do not know:	
No:	
Yes:	
> If yes, what kinds of formats?	
> If yes, how well do you think these programs have worked?	

Part IV Help and Support for Disabled people who are Infected with HIV/AIDS

15. Have disabled people you know been able to find out about their HIV status (been able to get tested for HIV)?	
Do not know:	
No:	
Yes:	
16. Do you know any disabled people who were not able to be tested for HIV, or had trouble getting tested because of:	
Inaccessible clinics:	
No one willing to treat them:	
No sign language translation:	
Other difficulties (please explain):	
17. Do you know any disabled people who could not access health care programs for people with HIV/AIDS or obtain treatment for HIV/AIDS because of their disability?	
No:	
Yes:	
If yes, please explain:	

18. Sometimes people who are disabled are diagnosed with HIV/AIDS much later than non-disabled people, either because they do not recognize the symptoms, no one tells them about the symptoms, no AIDS clinic welcomes disabled people, or they are afraid and do not know much about HIV/AIDS. Have people you know had any experience with this? (Please explain)

19. Sometimes people who are disabled do not get as good medical care as people who are not disabled. This is particularly true when people who are disabled need expensive drugs, or extra care or hospitalization. Have you ever seen this happen when someone with a disability is diagnosed with HIV/AIDS? (Please explain)

20. Because the disabled community is often small, there may be additional reluctance to come forward to ask for diagnosis and care. People are sometimes worried about word 'getting around.' Have you ever heard of this happening?

21. Sometimes disabled people with HIV/AIDS and disability advocacy groups need help from the law: either to get care and services, or to allow them a say in what services they want to use.

A). Have the disabled people with HIV/AIDS you work with ever tried to get help from the police or legal system?

Do not know:	
---------------------	--

No:	
------------	--

Yes:	
-------------	--

If yes, were they able to get assistance or were they turned away?

B). Has your organization ever tried to get help on HIV/AIDS issues from the police or legal system?

Do not know:	
---------------------	--

No:	
------------	--

Yes:	
-------------	--

If yes, were you able to get assistance or were you turned away?

Part V Additional Comments or Observations

A large, empty rectangular box with a black border, intended for providing additional comments or observations.

THANK YOU FOR YOUR TIME IN FILLING OUT THIS SURVEY

ADDENDUM B: SURVEY COVER LETTER AND CONSENT FORM



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner



NATIONAL SURVEY ON HIV/AIDS AND DISABILITY INFORMATION SHEET AND CONSENT FORM

Hello, my name is Poul Rohleder, I am a Doctoral student at the Department of Psychology at the University of Stellenbosch. Together with the Human Sciences Research Council, I am conducting a study on HIV/AIDS and persons with disabilities. We are approaching your organization with a survey questionnaire, as part of a National Survey on HIV/AIDS and disability. We are asking Disabled Persons Organizations and organizations working in the HIV field to answer a few questions on a survey questionnaire, which we hope will benefit persons with disabilities and their organizations.

The Human Sciences Research Council is a national research organization, and we are conducting research regarding how the HIV/AIDS epidemic is affecting individuals and groups with disabilities. Little is known about HIV/AIDS among people with disabilities, and we are thus carrying out this research to help gain much needed information to help organizations address this issue.

We send this survey with the request that you fill it out on behalf of the organization you work with. (If you think someone else in your organization would know more about these questions, we would appreciate it if you were to give it to them to fill out.) We are approaching all organizations working for and with disabled persons, and are asking that only one representative from each organization fill out this survey. We are interested in hearing both from organizations that are working on HIV/AIDS issues and from organizations that are not currently involved in HIV/AIDS issues. We are doing this as a national survey, and after combining all people's answers, we hope to learn more about how HIV/AIDS is affecting people with disabilities. This will help us make useful recommendations to the relevant authorities and organizations.

Please fill out the form in whatever language is easiest for you to write in. We will be looking for information about programs that provide HIV/AIDS education, interventions, and services to disabled people and communities. We would also welcome stories from disability advocates about attempts to get help for HIV/AIDS in one's community, examples about not being able to get help for one's community, and stories about

HIV/AIDS organizations who have tried to reach disabled people. Please note that there are no 'right' or 'wrong' answers to any of these questions. Also feel free to leave blank any questions for which you may not know the answer or which you may not feel comfortable answering. However, keep in mind we realize there is often little information available on this topic and so we are also interested in people's ideas, impressions, knowledge, practices and attitudes. Some questions thus ask for your personal views and opinions. Also, please note that we are not asking (and do not want) personal information or names of individuals who might have HIV/AIDS – we feel it is very important that we do not invade anyone's privacy.

Please understand that your organization's participation is voluntary and your organisation is not being forced to take part in this study. The choice of whether to participate or not, is your organization's alone. However, we would really appreciate it if you do share your thoughts with us. If your organization chooses not take part in answering these questions, you will not be affected in any way whatsoever. We will be making follow up contact with organizations to help remind them to return the filled survey.

The questionnaire asks for the name of the person filling out the form, and the name and contact details of organization. This information is for administrative purposes only, and to allow us to send you a copy of a final report of the study findings. Your name or that of your organization will not be recorded or linked to any published data. Only the researchers will have access to this information. The final published results will use descriptive statistics of overall answers to the various questions, based on all completed surveys. Therefore your own individual answers will remain confidential and there will be no negative consequences from the answers you give. The information will be compared for discrepancies among different groups of disabled persons. In the case of some disabilities there may be only one organization nationally. Every effort will be made to ensure confidentiality, but it may be that such an organization may be easily identifiable on the basis of the specific disability. This may be the case with your organization, so please take note of this limitation to confidentiality in deciding to complete the survey.

Once the study is completed, the results will be made available to the World Bank's Global Survey on HIV/AIDS and Disabilities, and may also be published in an accredited academic journal. We will also be compiling a research report detailing what the results are, with discussions and recommendations. This will be provided to each organization who participated in the study, and will be posted to the person who completed the questionnaire.

We may wish to approach a small number of organizations at a later stage in order to arrange some interviews so as to get an in-depth understanding of issues around HIV/AIDS and persons with disabilities. Not all organizations will be contacted for this purpose. Consent to conduct such interviews will be asked of the organization at the time. Participation in this survey in no way commits your organization for such later interviews.

Please return the completed survey by post or email to the HSRC (contact details below). In addition please fill in and sign the attached page requesting your signed consent, and attach to the completed survey.

Sincerest thanks,

Mr. Poul Rohleder, MA (Clinical Psychology)
Department of Psychology, University of Stellenbosch

Prof. Leslie Swartz, PhD
Human Sciences Research Council;
Department of Psychology, University of Stellenbosch

Ms Margie Schneider
Human Sciences Research Council

Please return completed survey to:

By Post:
Disability Studies
Child, Youth, Family and Social Development
Human Sciences Research Council
Private Bag X41
Pretoria 0001

By Email: disability@hsrc.ac.za

Should you wish to discuss an issue which may arise, you may contact:

Poul Rohleder
Cell: 084 619 3848
Email: disability@hsrc.ac.za



NATIONAL SURVEY ON HIV/AIDS AND DISABILITY

CONSENT

I hereby agree, on behalf of our organization, to participate in research regarding HIV/AIDS and Disability. I understand that I am participating freely and without being forced in any way to do so.

I understand that this is a research project whose purpose is not necessarily to benefit me personally or our organization.

I have received the telephone number of a person to contact should I need to speak about any issues which may arise.

I understand that this consent form will not be linked to the questionnaire, and that my answers will remain confidential. And in the case where our organization is easily identifiable, I have understood the limits to confidentiality detailed in the information letter.

I understand that if at all possible, feedback will be given to our organization on the results of the completed research.

.....
Name of participant

.....
Position in organization

.....
Name of Organization

.....
Signature of participant

Date:.....

ADDENDUM C: CASE STUDIES INTERVIEW CONSENT FORM

RESEARCH STUDY ON HIV AND DISABILITY INFORMATION SHEET AND CONSENT FORM

My name is Poul Rohleder, I am a Doctoral student at the Department of Psychology at the University of Stellenbosch. I am conducting a research study on HIV as it affects persons with disabilities. Part of my study involves a national survey of disability organizations and special education schools. This survey is being conducted in partnership with the Human Sciences Research Council.

A survey questionnaire gives useful, but limited information on some of the issues around HIV and persons with disabilities. So, in order to gain more indepth knowledge, a second part of my study involves doing in-depth case studies of selected organizations working with persons with disabilities.

_____ has given their permission for their school to be used as a case study, and I am approaching you as a staff member of that organization. I will be conducting individual interviews, which aims to explore some of the challenges of working with persons with disabilities, and issues around HIV (like health-risk, sex, sexuality and so on). There is little research and information about this, particularly in South Africa, so this is an exploratory study that will permit others to learn from your experience.

Your participation is voluntary, and before we start the interview, I ask that you here give your consent. In order for you to give your consent, you will need to know the following:

- 1. Duration of Interview:** The interviews will take approximately 1 hour
- 2. Language:** Interviews shall be conducted in English or Afrikaans. Should you prefer the interview to be conducted in another language, an interpreter may be needed.
- 3. Interview technique:** Although I will ask a few questions, the interview will be more like a conversation, where we explore some of the issues that you raise as the interview proceeds. The interview will be tape-recorded. This is so that I may be free to talk with you and not have to take notes all the time. The tape will be used for research purposes by myself or an assistant only and not be made available to others
- 4. How the information will be used:** What I have learnt from the interviews will be used to compile a short feedback report which will be made available to the organisation itself. This report will detail some of the general points that were learnt. In addition what is learnt from ALL the interviews and case studies will be used to publish much needed research results in academic journals, so that others may be informed.
- 5. Confidentiality:** The consent form below asks for some identifying details such as your name and the name of the organisation. This information is for administrative

purposes only, and information that you give will be used anonymously and confidentially.

Any reports and publications will use the information and words as spoken by you, but no names will be mentioned in the report. Therefore your own individual answers will remain confidential and anonymous. In the case of some disabilities there may be only one organization nationally. Every effort will be made to ensure confidentiality, but it may be that such an organization may be easily identifiable on the basis of the specific disability. This may be the case with your organization, so please take note of this limitation to confidentiality in deciding to take part.

If you would like to participate in this study, and agree to be interviewed on this topic please complete and sign the following form.

Name: _____.

Age: _____.

Home Language: _____.

Gender: please tick: female male

Do you or a member of your family have a disability? _____.

_____.

Name of organization you work for / are involved with: _____.

How long have you worked for / been involved with this organization? _____.

What is your position in the organization? _____.

CONSENT

1. Have you read and understood the information given above? Yes No

2. Are you prepared to be interviewed and for the interview to be tape-recorded, on the condition that what you will remain anonymous? Yes No

3. Are you comfortable in being interviewed in English? Yes No

signature: _____.

Date: _____.

THANK YOU!

ADDENDUM D: INTERVIEW SCHEDULE

RESEARCH STUDY ON HIV AND DISABILITY: INTERVIEW QUESTIONS

1. Tell me a bit about the work that you do here?

HIV AND DISABILITY:

1. Do you think HIV might be an issue for persons with disabilities? Why?
2. How has HIV affected or impacted on your organisation or school?

INTERVENTIONS:

1. Does your organization or school currently have any HIV intervention programme? Tell me about it.
2. What are some of the issues for your organization or school around HIV education and prevention?
3. Have you been involved in any HIV education or prevention programme here? What is it like for you?

RISK FOR HIV:

1. Do you think that disabled people might be at risk for HIV/AIDS? Why?
2. What are some of the HIV risks for persons with disabilities?
3. Are the disabled people you work with aware of HIV? What sorts of things do they know or not know about it?
4. Are the disabled people you work with sexually active do you think? What are your thoughts and feelings about this?
5. Are there incidents of sexual abuse do you think? What is that like to deal with?

TALKING ABOUT SEX:

1. Do the disabled people you work with come to you with any questions or problems related to HIV or sex? How do you deal with that?
2. What do you find most difficult or uncomfortable?
3. Are there any things that you feel is best not to talk about? Why?
4. What are some of the typical things you would talk about?
5. What are some of the difficulties or challenges around talking about sex?
6. What makes talking about such topics easier?

PARENTS:

1. What are some of the parents opinions or reactions about HIV and sex?
2. Do you agree or disagree with the parents about some things?

THE JOB:

1. Are you satisfied with how your organization or school deals with issues around HIV?
2. What makes your job difficult?
3. What makes your job easier?